PUBLIC INPUT
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Public Input 2018 Survey Findings: Families and Professionals Navigating Relationships to Support Deaf and Hard of Hearing Children's Development from Infancy to Early Adulthood

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Clerc Center Mission Statement

The Clerc Center, a federally funded national deaf education center, ensures that the diverse population of deaf and hard of hearing students (birth through age 21) in the nation are educated and empowered and have the linguistic competence to maximize their potential as productive and contributing members of society. This is accomplished through early access to and acquisition of language, excellence in teaching, family involvement, research, identification and implementation of best practices, collaboration, and information sharing among schools and programs across the nation.

For questions or feedback:

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Overview

The national public input survey disseminated in 2017 and 2018 asked respondents about barriers preventing deaf and hard of hearing children from realizing their academic, linguistic, and socio-emotional potential. "Family involvement and support" was identified as one of the barriers.

The Family Involvement and Support model (see above) is based on an interpretation of analyses of comments respondents wrote about the ways families are involved with their deaf and hard of hearing children. Family involvement and support is a complex, culturally defined, social engagement involving families and their deaf or hard of hearing children and the professionals who teach and/or provide services for them. Families as a group are diverse, such as those families who live in rural areas, who use a language other than English, who are members of ethnic or racial groups, and/or who have deaf or hard of hearing children with disabilities or who are lower achieving academically; within each group, there is also diversity. Decision making and actions by parents and professionals, independently and jointly, determine how they involve and support deaf and hard of hearing children from birth through adolescence. The ways those parents and professionals are involved are also influenced by beliefs they hold, shaped in some part by societal beliefs and by the laws and systems that determine the type, availability, and accessibility of resources for families of deaf and hard of hearing children and the professionals who work with them.

The Family Involvement and Support model has nine components:

1. Societal Beliefs
2. Laws
3. Systems
4. Families
5. Systems Specific to Deaf and Hard of Hearing Children
6. Family-Professional Connections
7. Decision Making and Action
8. Deaf and Hard of Hearing Children
9. Overall Development and Transition to Adulthood

Each model component is represented by a color and includes an explanation. The specific layer in stripes entails these four components:

1. Families

2. Systems Specific to Deaf and Hard of Hearing Children
3. Family-Professional Connections
4. Decision Making and Action

Each of these components is explained separately below, including descriptions of the relationships among the components. The striped layer demonstrates the dynamic interrelationships among the four components in complex and social contexts influenced by societal beliefs, laws, and systems. These components have an impact on deaf and hard of hearing children's language, literacy, learning, and well-being. Over time, these impacts contribute to their transition to adulthood.

Societal Beliefs

Societal Beliefs, represented as the outer, dark blue layer, refers to misconceptions the U.S. society holds about deaf and hard of hearing people based on attitudes and lack of knowledge and understanding about those individuals (including those who are deafblind, deafdisabled, POC). Parents may be unaware of how these societal attitudes shape their expectations and decisions about: 1) follow-up and early intervention, 2) the importance of learning and/or using language with their deaf or hard of hearing children as early and consistently as possible, and 3) strategies to meet their children's needs. Significant, ongoing public education about deaf and hard of hearing children and their needs is needed to change attitudes and beliefs held by the public and increase families' awareness about the importance of early hearing detection and intervention (EHDI). Increased awareness could potentially encourage more families to seek EHDI services early in their home state.

Examples of responses related to Societal Beliefs:

> *"... In general, society has a lack of understanding about the needs of D/HH people. When the parents have a lack of understanding, they are unable to advocate appropriate needs for the child. Because language development is crucial in the very early ages of hearing loss, many times the learning curve for families takes longer, leaving the child at a disadvantage ...."*

> *"The hearing still consider deaf people novelties. Due to this lack of understanding, unless the child's parents are deaf, there are no expectations, little to no family involvement and support. The child is thus deprived of any meaningful communication early in life. They are parked in front of the TV and given no chance for a future—unless the child is incredibly resilient and able to*

make up for all the loss … If the public insists on continuing to see them as interesting and novelties, our deaf will never be able to overcome the stigma to go on to meaningful employment and lives …."

"… Some families jump right in and are great in supporting their child and others are reluctant and do not understand the significant impact they have on their child's development. Sometimes I think the advertising autism has done in educating the general population on the importance of early identification and intervention is something that needs to happen for hearing loss as well …."

Laws

Laws, the next layer, in medium blue, refers to legislation impacting state and federal systems that provide services for families with deaf or hard of hearing children. Availability and types of services impact these families' knowledge of and decision making about them. Families eligible for, seeking, and/or receiving services are also influenced by the type and quality of services provided by federal and state entities. For example, language policies can determine the types of intervention services (e.g., language services) for parents with deaf or hard of hearing children. Legislation also dictates how and what services (e.g., educational services) are made available as a result of funding allocated to these services.

Examples of responses related to Laws:

"… If there was valid policy and legislation, there would be fewer CI [cochlear implant] *"fixes" and much more meaningful intervention. CIs do not work as advertised … yet. Families do not understand the complications involved. All they know is that their child is all better. I have seen 2 that functioned as promised out of a school full of kids. All of this ends up in a vicious circle that very few seem to be able to extricate themselves from …."*

"… I chose policy and legislation because it is a constant battle to get the needs met of my child. Money is always the driving force behind the school district. That is deep-seated with the government …."

Systems

Systems, represented by the layer in bright blue, refers to the state and federal systems (e.g., Medicare, foster care, EHDI) that determine availability and provision of funding,

services, and/or resources for people in accordance with laws. Respondents described systemic barriers, such as EHDI system gaps, limited Medicaid funding for families living in poverty, and system navigation challenges with medical insurance and government assistance that may prevent families from getting services they need for themselves and for their deaf or hard of hearing children.

Examples of responses related to Systems:

> *"There is no system to make sure infants that fail the newborn screening are rescreened unless the parent is willing to follow through. Infants in foster care frequently don't get rescreened, and the hearing* [loss] *isn't discovered until much later …."*

> *"… Also, understanding medical insurance benefits is time consuming … learning about and applying for governmental assistance, in tandem with continuous learning about how to overcome such challenges is burdensome while maintaining a full-time job with commute, along with child care."*

> *"… Many are living below the poverty line, and lack of Medicaid funding and state audits have caused almost all local providers to no longer provide services to our neediest children. School districts try to foot the bill with limited resources themselves."*

Families

The model shows Families, shown at the left in pink, as its own system. Families includes household compositions, familial resources (e.g., financial resources, time), and social connections. Family systems also include families' beliefs, attitudes, and culture along with knowledge they have about deaf and hard of hearing children and the professionals/systems involved with EHDI and deaf education. Families provide the critical foundation for deaf and hard of hearing children's developing language competence from birth through adolescence. They are unique and have their own journeys while learning about and raising their deaf or hard of hearing children. They also struggle with challenges common to families with deaf or hard of hearing children, such as: 1) finding time, commitment, and money to participate in activities (e.g., learning ASL, attending Deaf community events), 2) not knowing where or how to find the resources they need, and 3) managing their feelings about language options and Deaf culture. Some of these struggles may be exacerbated if their deaf or hard of hearing child also

has disabilities. In some cases, parent involvement may not necessarily be linked to communication struggles.

Examples of responses related to Families:

> *"... Family involvement - Is another key to human connection. Your family is where it starts; they are the first people to get to know you and are responsible for your initial advocacy."*

> *"... student looks at family as natural support automatically.* [They] *will need support from family if possible. This can be from a foster or adopted family ...."*

> *"Every family is unique, and their engagement in their child's life varies ...."*

> *"... Because language development is crucial in the very early ages of hearing loss, many times the learning curve for families takes longer, leaving the child at a disadvantage. Many times parents have many other concerns, like employment, other children, money, just to name a few ...."*

> *"In my experience, students with support from their families progress and achieve better than those from families who do not support hearing loss or use of amplification. Often this causes language delays and is a struggle to increase academics while language is low ...."*

> *"... I am hearing and my child is deaf. She is now 15 years old and I'm still not 100% fluent in ASL. I can sign, but not at a deaf person's level. It takes a lot of work to learn and engage while working full-time careers and taking care of your other children ...."*

> *"... Some families are still not comfortable with the various modes of communication offered (ASL, Cued Speech, etc.). They are uncomfortable engaging in the Deaf community or not familiar with Deaf culture. They don't know where to turn to get the best information for their youngsters. Families with students with disabilities might have no time to engage or participate in various activities or professional development due to working overtime to support their children."*

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"Parental involvement is critical for a child's education. The foundation for a child's language begins at home. I've seen success from students who have parents (deaf or hearing) that are actively involved. We assume that if there is communication at home, a child will have language. I disagree. I have students with Deaf parents who have excellent communication skills but the students are delayed. The parents are not actively involved with them …."

Decisions and actions made by families to communicate with and support their deaf or hard of hearing children from birth through high school are impacted by families as a system. The relationship between resources families have and their decisions and abilities to support their deaf or hard of hearing children is described in two ways. On one hand, families, particularly those with limited resources, do not: 1) seek out services or resources, 2) follow through in a timely way, or 3) have the emotional or linguistic capacity to engage with their deaf or hard of hearing children. On the other hand, descriptions of families' struggles focus on system and resource issues (e.g., employment, difficulties with accessing resources, transportation), creating barriers for families to support their deaf or hard of hearing children.

Examples of responses related to the relationship between families' decisions and actions and families as systems:

"… I work in a public school system with socio-economic statuses that vary. Those with limited resources often do not follow up in a timely manner with medical interventions …."

"Many of the students I see live in low income neighborhoods. The caregivers (parents, grandparents, whatever) do not seek out early intervention support, nor do they learn sign themselves, so the children arrive in kindergarten with little or no language. It is rare that parents or guardians, even in homes with higher incomes and education, learn sign, so most of the students I see in school do not learn to sign or use an interpreter until they start kindergarten."

"… many families in this area are economically disadvantaged. They have difficulty accessing services and need significant support to develop an understanding of the implications of hearing loss for their children. It also takes a great deal of time and energy to access services, and full-time use of hearing aids or devices is often not achieved."

"... Some families struggle so much to put food on the table and a roof over the family's head that they can't or don't become involved daily in their child's education. I often see grandparents, uncles/aunts, or single parents, etc., raising deaf children ...."

"Many families I work with do not have the resources (time, money for travel, understanding of need, nor funding for technology) to adequately support their children. Many are living below the poverty line ...."

"Many students come to school with little to no language. Hearing parents, especially non-English speakers, are not equipped or emotionally able to interact with young deaf children on a linguistic level that prepares the children for school ...."

"... We don't have as much resources out here on the reservation for his disability ... I'd like to have him attend school here at home. Closer to his family. It's difficult having him gone all the time."

"Limitations in access or transportation for deaf/hard of hearing students who live in remote or rural areas to have access to programming and peer interaction. These students may need parental/caregiver expectations and encouragement to participate in activities aside from school."

Parenting deaf or hard of hearing children requires investment of personal resources (e.g., time, money) and management of competing priorities while navigating systems focused on services and/or programs for deaf and hard of hearing children and their families. Parents' decision making and actions are influenced by these systems.

Systems Specific to Deaf and Hard of Hearing Children

Systems Specific to Deaf and Hard of Hearing Children, shown at the right in purple, are different from state and federal systems. Respondents' use of the word "system" suggests a difference between federal- and state-level infrastructures (e.g., Medicaid, foster care, state EHDI systems) and more localized systems specifically focused on deaf and hard of hearing children, their families, and the professionals who work with them. Respondents' expectations of service providers, agencies, and/or school personnel are more specific than expectations held of the federal and state systems. For example, professionals providing early intervention, ASL instruction, and counseling are expected

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to have specialized knowledge and skills to enable families to meet their deaf or hard of hearing children's needs.

Examples of responses related to Systems Specific to Deaf and Hard of Hearing Children:

> *"... I work in state EHDI, and once we have an early ID, the EI options are limited in terms of service delivery for the family. There is a total lack of qualified, trained, and experienced professionals that serve the early ID birth to 3 population. Most infants and toddlers get a mixed bag of EI and communication opportunities, likely a TC* [Total Communication] *approach. Is this good enough? Working on some learning collaboratives in our state, have identified that children entering school at age 5 have very limited and little language and communication ... this is disturbing in the day and age of universal newborn hearing screening, paired with timely FU* [follow-up] *and early IDs happening. We have perfected the screenings and even the diagnostic FU and early ID, but are now lacking in true service delivery. In my state, EI is mostly done via telepractice .... This is alarming! There is no standard for an EI staff person to work with D/HH infants and children. No required training, way to assess communication or language at entry, during EI and after EI completion, transition. This is poor and we should not expect any good outcomes if there are not qualified and trained professionals in each communication method, and no measurable outcome assessment tools. It is becoming an early ID world, and now what? Lack of family engagement and support and resources."*

> *"... Family involvement and support—Students who use ASL and are in classrooms where ASL is used need to have ASL at home, too. Families of these students need support in learning and developing their ASL skills."*

> *"... Parents and families need more. They shouldn't be left alone to navigate the stages of grief by themselves. And we can't expect that they have the means to find help on their own. It would be great if districts/programs/RDSPDs could provide more support for families. They need to know THEIR CHILD CAN. And they need to know that, when they accept that they can and exude high expectations, they will reach higher than ever!"*

Parents and families need resources and support in order to learn: 1) more about deaf and hard of hearing children's need for early, ongoing access to language, and 2)

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strategies and/or supports for their deaf or hard of hearing children from birth through adolescence. These resources need to be accessible to them in a way they can understand. If families receive accessible information, resources, and parent education (also in their native languages), then they might be better able to meet the language, linguistic, and cultural needs of their deaf or hard of hearing children.

Examples of responses related to families' resource and support needs:

> *"... It is also crucial to involve families and have their support, but many times language and communication are barriers—both with the parents and caregivers as well as to understanding the terminology and type of communication needs of the deaf child. It is important to educate the parents to prevent lack of understanding and encourage their continued involvement ...."*

> *"... I know other students who could excel in literacy so much more if their parents knew how to sign and read with them at home. How to achieve goals of having parents educated in order for them to naturally educate their children is beyond me, but it's something I would like to see. Our parents need to be more informed, willing to learn, and active in their deaf child's education in order for them to have the best chance at success ...."*

> *"... Hearing parents with deaf children do not have the same access to information and resources provided by the school due to the language barrier. Captioning all videos and announcements produced in ASL/Spanish for those parents who are emerging signers would improve the morale, collaboration,* [and] *potential resources that other parents have to offer that may not be tapped into due to 'old-school culture' ...."*

Professionals, schools, and/or organizations also need to ensure information and other available resources reach parents and families who otherwise may not be aware of them.

Examples of responses related to available information and resources:

> *"... Oftentimes as a parent, I am unaware of all of the resources that are available to aid and support my son. This is coming from a parent who works at a Deaf school and has a child that attends the Deaf school. I am constantly amazed at the resources that are available as I come across them at work and realize*

without the position I have, I would be completely clueless as to the resources available …."

"… I truly believe if parents have good information and good support, they will make choices that work for their family. However, there is often no support available because the parents don't know how to look for it."

Professionals' beliefs about language and communication systems often result in delivery of limited and/or mixed information about language options, potentially leading to parents' confusion and misunderstanding of how deaf and hard of hearing children learn and use language. Professionals' access to resources also impacts how they support families. Parents make decisions based on who they talk with, such as early intervention professionals, teachers of the deaf, doctors specializing in cochlear implantation, or pediatric audiologists. They may choose not to use any particular strategies with their deaf or hard of hearing children. Sometimes parents struggle with grief and acceptance while trying to make decisions that may not produce the results they expected to see. Also, their grief may impact other members of their household (e.g., siblings of a deaf or hard of hearing child.

Examples of responses related to the relationship between professional beliefs about language and communication and the delivery of language and communication resources:

"All of the infighting regarding communication systems is not helping parents or children. Many families are barely functioning as it is, and the burden of a special needs child is too much for them …."

"Many families are making decisions based on the first experts they meet. Information should be discussed in totality so the parents understand the various outcomes up front. This way when things don't "pan out" as planned, they are not going through the process of acceptance all over again. I've seen it many times that parents are devastated because they are not aware of all options available and have a hard time when different paths are necessary to help their child receive the education that is better suited for their needs."

"Early hearing detection and intervention - As a father of 2 deaf girls - When they were born and recognized as profoundly deaf, the doctors quickly offered cochlear implants with no other options. Of course I denied it. Many parents in the

world were lost when their child was labeled as deaf or others. They [were] *dumbfounded and jumped on the offer. In the end, 80% of cochlear implants stopped using for various reasons ... Qualified direct service personnel: It may relate to early hearing detection and intervention, so often, almost all of the time,* [when] *the parents discover that the child is deaf, the parents are lost and don't know what to do - they often follow what the doctors/audiologists tell them ... to do. They are missing out on the true mentorship of the Deaf professionalism ...."*

"... Many families are given wrong information about sign language. They are told not to sign to their child if they want them to learn to speak. I have seen the harm done by this. We need to better educate parents about language learning and that signing does not hinder speech acquisition ...."

"A necessary aid for families is to help parents with the initial, and often ongoing, emotional concerns of raising a child with extra needs. Fathers are often left out of this process, note the divorce rate among parents. Also, siblings often carry a burden of "survivors' guilt," some resentment, and lack of attention. All members of the family need support ...."

"Many times, school personnel may not know about resources or have resources, and especially if the families are not knowledgeable or aware and really advocate for the children, they will go without. Additionally, curriculum and assessment (from a teacher perspective) is not designed for modifications, so the teacher is responsible for making any modifications or differentiating as appropriate. That means the teachers may not know what to do or how to work with D/HH students. Finally, having qualified personnel is a factor for some of the same reasons above."

"... More families need to be exposed to Deaf culture and the concept of keeping language accessible for the child, but it falls on who they receive from EHDI or their teacher of the deaf ...."

Some respondents commented on the need for professionals to have specific types of training (e.g., counseling, working with deaf or hard of hearing students who have disabilities) so they can better support families of deaf and hard of hearing children.

Examples of responses related to training:

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"... There is a paucity of training for EI teachers in counseling and the grief process. Yes, parent-to-parent support is helpful, and some programs do provide social workers and counselors. However, I believe that the people who are in the homes on a weekly basis need these skills as well ...."

"... Many DHH students have other disabilities, including mine. I find that his disabilities also need addressing, and sometimes for inexperienced schools they don't know how to address or prioritize DHH needs and other needs ...."

The quality and accessibility of available information, resources, and services along with professionals' beliefs and levels of expertise influence their relationships with families of deaf and hard of hearing children. Conversely, the ways families engage with professionals also impact their relationships.

Family-Professional Connections

Ensuring deaf and hard of hearing children have early and consistent access to language from birth through high school, access to quality education and learning experiences, and meaningful social connections highlights the importance of families and professionals working together. Family-Professional Connections, represented by the maroon arrow in the middle connecting Families on the left and Systems Specific to Deaf and Hard of Hearing Children on the right, spans infancy and early childhood through adolescence and can vary in length, strength, and type over time. Family-professional connections ideally begin when deaf and hard of hearing children are first identified, and families work with early intervention professionals to ensure their deaf or hard of hearing children have early and consistent access to language. Once their deaf or hard of hearing children enter school and progress through grades, parents and teachers work together to support these children's literacy, cognitive development, and academics. The intensity of the relationship may lessen and/or evolve over time depending on how families and schools work together.

Examples of responses related to Family-Professional Connections:

"... Collaboration - Every person in a student's life is important. Teachers, professionals, families, [and] *peers will make an impact in a student's life -* [students will get] *good supports from them, and all need to be in the same loop with a goal in mind for this student to be successful. No collaboration will set up a student's failure down the road ...."*

"… Then if we have early detection and intervention but fail to get the family on board, involved and advocating as informed participants, we lose again …."

"Without early detection and subsequent family involvement, support, AND understanding, I feel the young children, including my own hard of hearing daughters, would be at a huge disadvantage."

"… After early intervention services end, parent involvement often slowly decreases - particularly within center-based programs outside of the family's neighborhood and within families that lack economic resources to ensure that members of the family continue to develop their own communication skills."

"As a DHH individual and educator, I strongly believe in implementing a strong language and communication foundation as early as possible, and that cannot be done without the family involvement and support. Deaf schools or schools with DHH resources can only do so much. It requires educating the families the moment the child has been identified [as] *deaf and developing a relationship between DHH programs and families to build a strong rapport …."*

Families and professionals bring with them expectations of and beliefs about language and the roles of parents/families and schools, impacting decisions and actions made separately and/or together. Some expectations and beliefs about parents include: 1) the perception that some parents are overly dependent on professionals and/or the government to meet their deaf or hard of hearing children's needs, 2) the expectation of parents/families to understand and follow schools' expectations of the ways they should be involved, and 3) the need to act as advocates for their deaf or hard of hearing children instead of trusting the school to meet their deaf or hard of hearing children's needs.

Examples of responses related to expectations and beliefs for families and professionals:

"… Parents do NOT acknowledge their responsibility to their own deaf or hard of hearing child/children and, therefore, expect the educators to take on a parental role and want them to do the parenting for them …."

"… Many times, we see families who are far too dependent on the system/government to "fix" or "provide" when, in reality, they hold the power to be the change agents in their homes. Learning to communicate, maintaining a safe, clean, and friendly home life are within most all parents grasp …. "

"... Some also come from families from immigrant/minority cultures which don't always have the same understanding of the role of the school and the role of the family in working together to maximize their child's success. I think many of those families don't always have the time or understanding of what they can do at home."

"Being from a rural and low income area, it is hard to get parents involved. They trust the school and sign off on whatever program is in place, but it is difficult to teach the parent to be an advocate for their child and to get involved in development even when resources are being provided."

For schools, some expectations and beliefs include the need for schools to: 1) provide and/or pay for services for deaf and hard of hearing students in accordance with their Individualized Education Programs (IEPs), and 2) create opportunities for hearing families to learn more about and interact with the Deaf community. These beliefs and expectations shape how parents and professionals decide to meet the needs of deaf and hard of hearing students (e.g., making audiology appointments, meeting educational needs, communicating with them on behalf of their parents).

Examples of responses related to expectations and beliefs for schools:

"... As a parent of a Deaf child, it is a struggle to have the IEP followed or to set new guidelines for my child's IEP. It is a fight to see who will pay for what and to have the teachers actually set up individual education tailored to my child's needs ...."

"... [School] *should provide more opportunities for hearing families to merge into the Deaf community to help their deaf kids to learn Deaf culture because hearing parents cannot provide that to deaf kids .Deaf community has to help these kids to increase their confidence. Schools, teachers, Deaf community members , [and] parents have to collaborate to see the success in the deaf kids. All family members have to merge to acquire Deaf culture to teach their kids ...."*

"... Some of our families are way over the top involved; however, most of our families rely on me, DHH educator, to facilitate acquiring personal hearing aids for them and ensuring that they are following up on audiology appointments ...."

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The quality of family-professional relationships can impact decision making and actions made by families and professionals together and separately. Determination of deaf and hard of hearing children's hearing levels depends on how soon they are identified by EHDI professionals and/or brought in by family members for testing. EHDI professionals and/or agencies they work for determine the number of hours and type of language instruction and services they can provide; in turn, families decide whether or not they can participate and/or engage with the schools.

Examples of responses related to the relationship between family-professional connections and decision making and actions by families and professionals:

> *"… The delay of or limited early intervention training paired with lack of family involvement continues to create a climate that causes our children to be extremely language and communication delayed. Many only have access to language "instruction" and communication 20 hours a week for the preschool years and only one hour a week or less during early intervention IF the parents have chosen a modality but have not studied enough to be ahead of their child …."*

During the school years, the parent-professional relationship can range from positive to adversarial. Some parents may feel they are not supported or heard during IEP meetings; others believe schools should not be trusted. On the other hand, some professionals believe that parents choose not to avail themselves of services; some parents may have concerns about the school but have not taken action. As a result of these adversarial relationships, some parents have had to resort to using their own personal resources (e.g., funding, time) to get services (e.g., ASL instruction) for their deaf or hard of hearing children.

Examples of responses related to these relationships:

> *First and foremost, I believe we parents need to be proactive, understand our children's rights, and we need to educate ourselves. Far too often, parents place their faith in the professionals who quite honestly don't have* [our} *child's best interests in mind, rather their own careers/agendas/beliefs.*

> *"… I also believe that families are afraid to ask questions during IEP meetings and throughout the school year, so it is hard for them to be active participants in their*

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child's education when they aren't clear about the expectations of the professionals."

"In my case, lack of communication with teachers, I would like to be more aware of what is at school with my daughter. I also need more resources to give my daughter to learn more ...."

"... They should have more patience with the children. I have seen problems at school (with my child) and I have not said anything."

"Despite the magnanimous efforts of education professionals, some families do not take advantage of available services that would help them learn to communicate with their deaf children ...."

"... My daughter has unilateral hearing loss and is mainstreamed. By the medical, school, and school for the deaf outreach consultants, she has been viewed and pushed to be a hearing student. Through our own devices, we sought out ASL instruction after school hours and with our own funding source. ASL was never addressed as a language concern by teachers or deaf school outreach educational consultants ...."

Decision Making and Action

Decision making and action, shown in light orange with diagonal lines, represents separate and interdependent processes situated in specific and dynamic contexts across time and space. Decision making includes families' learning about their deaf or hard of hearing children's needs, making language choices, and making commitments to support their deaf or hard of hearing children in different ways, such as ensuring their deaf or hard of hearing children consistently use hearing assistive technologies or learning and using ASL regularly. Actions include taking steps to learn about the needs of their deaf or hard of hearing children and making use of resources to be involved with them. Families make decisions and take actions at home, in school, and in other spaces in which they move, beginning in the early years and throughout their children's lives, even after they leave high school.

Examples of responses related to decision making and action:

"... So, it is critical that families make every effort to be involved in their child(ren)'s education which encompasses not only academic but social-emotional and

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psychological development throughout the life of the child(ren). This is not only focused on the early years of the child(ren)'s development but throughout high school and beyond. Children always seek and need support from their families, even after graduating from high school. So, a strong bond between deaf/hoh child(ren) and their families is of paramount importance."

"... Technology is another area. If the student does not have consistent access to the equipment and technology, then it is difficult for them to make progress. Family involvement and support is a HUGE factor. Without family involvement, there would be no expectations for the student to wear their amplification or continue their therapies ...."

Descriptions of families' decision making included learning about the needs of their deaf or hard of hearing children, making language choices, and committing themselves to supporting their children in different ways.

Examples of responses related to decisions made by families:

"Children lack early access to language. Families need time to process their child's hearing difference and then take steps to support communication opportunities ...."

"... Once diagnosed with hearing loss, I believe some parents continue to have the expectation that their student will hear. I have a particular student whose family participates in "no hands time" at home despite the student being profoundly deaf and [using] *ASL as her means of expressing language ...."*

Descriptions of families' actions included learning about the needs of their deaf or hard of hearing children through research, using services available to them, taking and attending ASL classes, supporting their children by signing and/or speaking with them, developing emotional connections with their children, and supporting their children's academic learning in various ways (e.g., homework at home, reading with them).

Examples of responses related to families' actions:

"... I think parents show their support to [their] *deaf child to let her/him know that life will always be obstacles in education, medical, or legal settings and* [the] *deaf child does not have to be overwhelmed with all problems by herself/himself*

without a parent's support. (No interpreter/cart in school is one of these examples.) ...."

"... Family involvement is key. Support needed at home, early reading, and continuous assistance and follow-up ...."

"... I encourage families to attend D/HH functions and visit the schools for the deaf in their areas because I see so many children struggle with depression and social isolation in the mainstream ...."

Inaction—to not do something (e.g., to not learn ASL)—is also a decision, and it is sometimes impacted by resources available to families and/or systemic barriers. Some instances of inaction may relate in part to expectations of what parents should be doing to support their child. Thus, some respondents suggested actions families should take to support their deaf or hard of hearing children.

Examples of responses related to families' decisions not to act:

"... Early intervention services are made available, at least to families in urban areas. Many families receive these services (but not all). However, families do not seem to realize the commitment required on their part to help their child develop critical language skills. If the family chooses sign as their primary communication modality, then all family members should learn sign and become proficient so as to provide the vocabulary and language models needed for their child to develop language skills. If the family chooses listening and spoken language as their primary communication modality (often with cochlear implants or hearing aids), they need to realize that is also a commitment. The child needs to wear the hearing technology all waking hours, not just when at school. Speech/language therapy (not just at school) and language modeling are necessary for the child to develop speech and language skills. Many parents seem to think that the CI or hearing aid is a magical device that will "fix everything." Amplification is only part of the equation."

"... Deaf children also struggle to acquire sign language because it is not being reinforced in the home environment. Children, such as preschoolers, are only in school for a few hours a week as opposed to being home for the majority of their time. Some families' first language is Spanish, and that creates another barrier."

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"... Most of the families that I deal with as an educator have never bothered to learn ASL (which is their child's main form of communication). They also do everything for their child and do not expect them to gain independence or do not think that their student is capable of said independence because they see their child as broken ...."

"... So many parents do not talk to their children. They do not read books with their children ...."

"My deaf son is in a mainstream first grade classroom and, as a hearing parent, I am struggling with how to support him at home with reference to his reading and writing requirements ..."

Professionals, schools, and organizations make decisions and/or engage in actions (or not), as a result of policies, funding, and/or limited professional knowledge, that impact parents' ability to support their deaf or hard of hearing children and meet their needs.

Parents and caregivers talk about struggles to get appropriate educational services (e.g., evaluation, FM and other auditory access) for their deaf or hard of hearing children. These struggles are due in part to school district personnel and teachers not understanding or making judgments about the needs of these students as a result of: 1) not having worked with them before, 2) not understanding the "educational label" or providing a vague educational label, and 3) making uninformed decisions about meeting these students' needs (e.g., deciding a deafblind student doesn't need an FM system because that student can speak well or that a student does not need ASL because of vision challenges). Some of schools' decisions are attributed to a lack of funding to pay for services and/or adherence to policies based on their interpretation.

Some examples of responses related to families' struggles in getting appropriate educational services for their deaf or hard of hearing children:

"... Curriculum was chosen. Because we moved to a new school district that supposedly has never had a DHH student. Their refusal to provide services ended up with us having to spend precious money on an attorney. It continues to be a hardship due to the school expecting him to conform to their curriculum versus the other way around. We have asked for an evaluation at the new school from [name of program from state] *so that the school might better understand his*

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needs. We were told the evaluation could not be done due to lack of staffing at [school]. *Again, back to policy and regulations (i.e., money)."*

"The special education director of the school district I'm in wasn't even aware that 'deafblind' was an educational label used to give a student an IEP. My son is visually impaired from ROP and hard of hearing from Usher syndrome. The school could not figure out what educational label to give him until I provided documentation. The fight continues, and his IEP label is still a vague 'early childhood developmental delay.' The use of ASL for students who are hard of hearing (not deaf) is poorly understood and under-researched. When we tried to move our late-identified hard of hearing child to the HI [sic] *classroom, we were told he wasn't 'deaf enough.' He remained in a special education preschool room despite the fact that his largest lags in development were in receptive language skills. He speaks so therefore he must be able to hear. They didn't provide for his hearing needs. We requested an interpreter and finally got an FM system. When it was discovered that he had Usher syndrome, his teacher said, 'He's not going to need to learn sign if he's going blind.' This sampling of experiences is evident to the brokenness in the education system regarding collaboration, expectations, lack of understanding, lack of language and communication, lack of qualified direct service personnel, and the budget strains districts face that negatively impact deaf and hard of hearing kids ...."*

"School systems continue not to provide services to students who are deaf or hard of hearing. They insist they must show an education deficit; they don't take into account how hard a student is working to keep their grades up, to learn. They don't take into account the fact that families have outside tutors, they work long hours at home with students to keep them on target."

The decisions and actions of families and professionals can also influence deaf and hard of hearing students' decision making and action. For example, if deaf or hard of hearing students do not receive the support they want from their families, they may develop relationships with other adults who can provide the encouragement or emotional support they need. An example of this is as follows:

"... If deaf people do not get any support from family members or encouragement [from other] *deaf people, then deaf people will likely be depressed and* [have] *low esteem. Many deaf people will likely think of having no purpose in their lives.. If*

deaf people do not get any support from [their] *parents or any family members, they might look for a deaf teacher or other people who can support them ...."*

These decisions and/or actions occur within the spheres of families and professionals as systems navigating relationships at different points in time and space. Family-professional connections occur and/or evolve in complex, embedded social contexts influenced by systems, laws, and societal beliefs. These dynamic relationships impact deaf and hard of hearing children's development in different ways, including but not limited to, language, literacy, and social relationships.

Deaf and Hard of Hearing Children

Deaf and Hard of Hearing Children, shown in dark orange in the model, is located in the Decision Making and Action layer. Decisions made and actions taken by families and professionals, whether jointly or separately (dependent, in part, on family-professional connections and on resources available to them), have an impact on deaf and hard of hearing children's developing language, cognitive, literacy, and academic skills as well as on their well-being. Early in deaf and hard of hearing children's lives, families make decisions about language and communication that are fundamental to young deaf and hard of hearing children's language learning and interaction. These decisions translate into family members' ability to communicate with and support their deaf or hard of hearing children in all aspects of their lives. Family members' difficulties with communicating with deaf or hard of hearing children can lead to their delayed language development, difficulties with relationships, social isolation, lower literacy and academic skills, and limited reinforcement of children's academic learning at home.

Examples of responses related to Deaf and Hard of Hearing Children:

"... When families do not support their deaf or hard of hearing child, the child experiences significant isolation. I've seen this firsthand, and the social-emotional impact was devastating. In this case, there was cultural bias and linguistic barriers. The family only spoke Spanish in the home. Due to stigma and hope that the student would acquire hearing over time, the family did not seek ways to communicate with their child. Then he entered the school system, where only English is spoken. The student did not learn expressive language skills until he entered school, at which point he learned ASL. He was unable to truly communicate with his family and could only communicate with friends through an interpreter. When I met him in his 8th grade year, he was so isolated that he spent most school days shut down ...."

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"… My son learned to read at a young age from the support I gave him; however, there are so many kids who are below grade level for reading that it makes living life a struggle to comprehend the world around them."

"The high school students I work with have minimal family support and parents are not able to communicate with their children in sign language … What is learned in school is not reinforced at home, and we really see significant language and literacy delays in high school …."

"… With depressed language levels upon entering school, our children with a hearing loss are tasked with a monumental feat: they are often learning two languages simultaneously while having to learn how to read and write without having linguistic mastery in either language. As the school years progress, this gap widens exponentially without appropriate interventions and linguistic access. Children who have had access to sign early on, born to parents who are deaf, or have hearing parents who are committed to becoming a family of skilled ASL users, have significantly higher achievement levels than those that enter kindergarten with limited ASL skills. It all begins with language. We teach hearing infants to sign to increase their language levels well before the spoken word develops. Why would we deprive our children with a hearing loss of this same opportunity which has been proven to increase linguistic growth and potential when the possibility of not developing spoken language is greater? …"

"… If family members are not involved with the deaf student's education, the student misses out on language acquisition at home, reading opportunities, gaining math skills, and personal relationship skills …."

Specific child outcomes are a result of complex, dynamic influences. They are also placed in the larger picture of deaf and hard of hearing children's overall development from birth through adolescence and transition to adulthood.

Overall Development and Transition to Adulthood

Deaf and hard of hearing children's development and progression from birth through adulthood, shown at the bottom of the model under the black arrow, are influenced by: 1) families as a system independent of and in conjunction with 2) professionals (representing different systems) who work with them and/or their families engaging in decision making and actions that reflect, in part, beliefs and attitudes each hold about

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deaf and hard of hearing children and the roles each play in supporting these children. Those beliefs and attitudes also relate to the type and quality of family-professional connections, which are, in turn, influenced by systems, laws, and societal beliefs that impact families and professionals.

Examples of responses related to Overall Development and Transition to Adulthood:

"... family involvement and support is the key to deaf or hard of hearing children's early language acquisition, which will help improve their literacy, social skills, and transferable soft skills for future employment. Also, it establishes a foundation for deaf or hard of hearing children for helping maintaining their physical and mental health and integrating them into the society and economic development."

"... Research has shown time and again that the more involved parents are in their child's life/education, the more successful the child is. This problem is not unique to d/hh ...."

"As a mental health professional, I see that the family is a much overlooked factor. Almost ALL of my clients are grieving from lack of connection to their families, not only as children, but also as adults ... But without FAMILY connection, the individual never gets over that gap, which affects [their] *sense of self, place in the broader world of work, AND creating their own family. Too often they create the same dysfunctional communication dynamics with their own children that they had with their parents. A higher priority needs to be placed on the WHOLE child. Family. Language. Education. Mental health."*

"Families that are consistently involved in their child(ren)'s education significantly make a difference in their lives. Children who are continually being supported by their parent(s)/family members are positively encouraged to develop their potential to the fullest. So, it is critical that families make every effort to be involved in their child(ren)'s education, which encompasses not only academic but social-emotional and psychological development throughout the life of the child(ren) ...."

Conclusion

There are many barriers preventing deaf and hard of hearing children from realizing their academic, linguistic, and socio-emotional potential. Family involvement and support, one

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of those identified barriers, clearly has a significant impact on how deaf and hard of hearing children progress and on how well they achieve their goals from birth to adulthood.

Research shows that parents and professionals are influenced by their beliefs, shaped in some part by societal beliefs and by the laws and systems that determine the type, availability, and accessibility of resources for families of deaf and hard of hearing children and the professionals who work with them. Ongoing feedback from both families and professionals is necessary to ensure deaf and hard of hearing children's needs are being met in a way that allows them to overcome these barriers so that they can thrive.