

Chapter 25

The Foundational Role of Advocacy in the Early Intervention & Education Systems

Janet DesGeorges; & Cheryl DeConde Johnson, EdD

From the day a family learns that they have a child who is deaf or hard of hearing, there is a foundational need to learn advocacy skills that will carry them through all the years of raising their child.

Introduction

Families tend to learn the ropes one step at a time as they move through systems that have been designed to help them achieve effective outcomes for their child who is deaf or hard of hearing (D/HH). These “systems” include:

The education system:

- Transition to Part B services (at age 3).
- The education years—Part B (ages 3-high school graduation).
- Transition to post-secondary education and training or the workplace.

From the day a family learns that they have a child who is D/HH, there is a foundational need to learn advocacy skills that will carry them through all the years of raising their child. This includes taking an active role in the decision-making process for the needs of their child, especially in the areas of communication, language development, technology options, and educational considerations. The education years are often the time when families are most likely to

The 1-3-6 EHDI system:

- Screening (by 1 month).
- Identification (by 3 months).
- Enrollment in Early Intervention—Part C (by 6 months).

1-3-6
 Rule

utilize advocacy skills to address the needs of their child. Effective advocacy skills should be developed in families as early as possible.

For those working within these systems, there is often a myopic view when determining success of the system. For example, in the screening process of the 1-3-6 model of EHDI systems, success is often measured in percentages of babies screened, reduction of loss to follow-up rates, and timely screening of infants. While these are all essential elements of a successful program, they represent just the first step toward achieving the outcomes families seek. Professionals who focus on one area of the system should be aware of and support families towards their ultimate goal—in other words, “beginning with the end in mind.”

The term “advocacy” can be defined as the act of pleading for, supporting, or recommending a course of action. Advocacy begins with a thorough understanding of the “what”—what you’re advocating for and what you need to know to advocate for it effectively (Johnson, DesGeorges, & Seaver, 2013.) The skills needed in today’s early intervention and education systems to ensure successful outcomes for D/HH children and youth are at the core of the advocacy conversation. While learning about the implications of their child’s hearing status, families should begin to learn the tools that will help them, including laws, policies, and best practices that pertain to each part of the system. This chapter will lay the foundation of what families should know about early intervention and education systems for their child.

What Is Special Education?

Special education is the specialized instruction and related services that are necessary for children with disabilities—birth to age 21—to receive a free and appropriate public education. The Individuals with Disabilities Act (IDEA) has defined and regulated services and other supports since the law was passed in 1975. Laws are passed by Congress (or state legislatures), and

regulations are developed by the appropriate oversight governmental agencies. Part C of IDEA pertains to the development of infants and toddlers with special needs or disabilities. For children age 3 and older, three laws, each containing slightly different provisions, prevail: Part B of IDEA, Section 504 of the Rehabilitation Act, and the Americans with Disabilities Act (ADA). Effective educational advocacy requires solid knowledge of each of these laws.

Foundations in Advocacy

The early intervention years are a prime period to begin to model the involvement and advocacy skills that a family will need to safeguard their child’s success through the education years. The effectiveness of interactions throughout the EHDI system journey can make or break a family’s first impression of their own acceptance as equal and respected partners in the choices and decisions they are making for their own child. Hospital screeners, audiologists, early intervention providers, and other professionals that families encounter throughout this period of time can set a receptive tone by affirming and believing that any parent, regardless of their race, ethnicity, marital status, religion, and other often-cited demographics, can learn effective involvement as well as advocacy skills.

Consider the following two opposite experiences by moms of deaf daughters.



Photo courtesy of NCHAM

The skills needed in today’s early intervention and education systems to ensure successful outcomes for D/HH children and youth are at the core of the advocacy conversation.

First mom's experience . . .

“The first professional that worked with our daughter after she was identified at age 2 as hard of hearing changed my life. I fully expected this professional to come through the door and tell me what to do. She was the expert, after all. But what she did in those early days laid a foundation that, many years later, still moves me to tears. She treated me like I knew what to do and that she believed I would make the right choices. I was young, scared, and unsure of myself. I didn't have the information, knowledge, or expertise I needed. I even begged her to “just tell me what to do.” But she knew that she would not be with me for the rest of my life—that I had to learn to be the decision maker and advocate and to be meaningfully involved for many more years to come. She knew that while she was in our lives for a short period of time, I would be the one that would need to have the skills to get my daughter to success. She resisted the temptation to see herself as the only expert in the room and valued what I had brought through the door on Day 1.”

Second mom's experience . . .

“My young daughter's hearing loss was misidentified for 3 years—anywhere from a mild to profound loss. As a parent, I felt the diagnosis did not fit what the professionals were saying. During this time, we began early intervention therapy at a center where parents were taught various listening and speech strategies in a home-like environment. I was always told what to do and even reprimanded when I didn't follow through on the “homework” exactly as prescribed, especially use of hearing aids. At the time, my daughter would not keep her hearing aids in for more than a few minutes—usually only as long as I could distract her with an activity. Rather than listening to me and investigating the hearing aid fitting, the therapist told me to continue making her wear the aids. Eventually I stopped going to the therapist—it was too frustrating to me and my daughter.”

Recognizing the Power of Parents from the Beginning

From Day 1, families generally walk through the door with a basic foundation of valuable assets that no one else can bring to the table:

- A mother's and/or father's love.
- Seeing their child as a whole human being.
- Understanding the family's priorities and values.
- Ultimate responsibility for their child.
- A lifetime commitment.
- The right to make choices on behalf of their child.

When these assets are valued from the beginning, self-confidence grows for the family. Self-confidence is a precursor to effective advocacy. Families gain self-confidence when they have a sense that

they have something to contribute, and that their contributions are affirmed and acted upon in some way. These experiences lead to the realization that they are truly the experts of their own child, and that they can effectively advocate on his/her behalf.

Collaborative Partnerships

Professionals play a vital role in the lives of families, particularly for children who are at risk. These professionals also bring to the table much-needed assets:

- Educational background
- Experience
- Expertise
- Passion, dedication, caring

The collaborative relationship in early intervention and education programs between parents and professionals is essential. When a partnership begins to emerge, the assets of both parents

and professionals begin to synergize towards successful developmental and educational outcomes. Children do not develop effective literacy skills that are taught at school if parents do not join in the effort by teaching their child to read at home.

Utilizing Other Parents as Models

Programs strive to connect families to one another through a variety of methods. Often this effort is intended to provide emotional support and community opportunities. One of the often-overlooked purposes of parent-to-parent connections is the opportunity for families to see positively-modeled behaviors of effective parent involvement and advocacy from their peers—other families. Hands & Voices, a parent-driven support and advocacy organization (www.handsandvoices.org), has repeatedly seen that parents who seemed unengaged, and who were even considered “deadbeat parents” by those that were serving their children became involved when they met other parents who were participating in and taking responsibility for the education of their own children. This type of modeling seems to be true across the spectrum of the different types and diversity of families. Asking families who are actively involved in programs to lead activities for other families can begin an “infestation” of involvement!

Families Need to Learn Advocacy Strategies

It is a well-known fact in parent advocacy circles that parents must learn to become effective advocates to enable a child with special needs to get an appropriate education. At the same time, there is a continuum of a family’s ability or desire to advocate based on their hierarchy of need (e.g., it’s hard to attend an advocacy workshop if you don’t know how you are going to put food on your table).

However, when one family advocates for their child, it can help other children whose families may not be able to effectively advocate for their own child. This explains why so much of family involvement is done at the systems level—to better the systems for all children. Nevertheless, all parents should be given the opportunity to increase their advocacy skills. There are websites, supports, and programs in almost every community for advocacy training. Acquiring effective advocacy strategies enables families to develop attitudes that will lay the foundation for being meaningfully engaged, such as:

- Believing in their rights and role as “equal partners.”
- Developing endurance—accepting their lifelong parenting role.
- Being principled and persistent.
- Having a sense of humor.
- Building relationships.

Advocacy Triggers

The regulations that govern and guide early intervention and education programs and services for children who are D/HH are further clarified through case law. While most regulations address procedural requirements, there is a growing focus on what children are learning as a result of their services (outcomes). For each age group, there are certain trigger areas that often require advocacy efforts by parents (see *Tables 1 and 2*). As families move from the family-centered early intervention system to the child-centered school-age system, there are more trigger areas. These triggers are briefly summarized here. Readers are encouraged to seek a greater understanding of each topic in publications, such as the Educational Advocacy Guidebook by Hands & Voices (www.handsandvoices.org) and Wright’s Law (www.wrightslaw.com), as well as websites for the National Association of the Deaf (www.nad.org) and AGBell (www.listeningandspokenlanguage.org).

It is a well-known fact in parent advocacy circles that parents must learn to become effective advocates to enable a child with special needs to get an appropriate education. When one family advocates for their child, it can help other children whose families may not be able to effectively advocate for their own child.

Table 1

Infant and Toddler Trigger Areas

| Eligibility Criteria | Multidisciplinary Evaluation | Provider Specialization |
|--|--|---|
| <p>Eligibility under IDEA, Part C, is based on a developmental delay or known conditions to cause delays rather than a specific eligibility category like those that exist under Part B of IDEA. Though hearing loss is a condition known to result in delays, infants with hearing losses that are thought by some to have less impact on development (e.g., unilateral hearing loss, conductive hearing loss) may not be eligible until a delay is confirmed, which may be several months into the child's life.</p> | <p>Even though the primary concern is usually language development, all areas of development should be assessed and monitored, as some deficits become apparent as the child grows. Language assessment must be thorough to track every aspect of receptive and expressive language development. Team members can be determined by the parents with their Part C provider and adjusted as concerns arise. Payment procedures vary state to state and will be determined based on insurance and Part C resources.</p> | <p>Families should have early intervention providers who have credentials and/or demonstrated expertise in early childhood D/HH education. In early intervention, the general goal is to maintain typical developmental milestones to prevent gaps from developing. Providers should be knowledgeable about communication modality options and proficient in the modality choices of the family. They must be able to assist families to connect with role models in those modes. Opportunities to meet other families of children who are D/HH are also essential.</p> |

Natural Environments

Natural environments are settings most like the ones that a typical peer without a disability would experience. IDEA requires that, to the maximum extent appropriate, services for infants and toddlers occur in natural environments. The parents and Individual Family Service Plan (IFSP) team can determine other environments when early intervention cannot be provided satisfactorily in natural environments. Considerations for full communication access using direct communication, as well as visual and/or auditory accessibility, must be discussed.



Photo courtesy of Centers for Disease Control and Prevention

Table 2 School-Age Children Trigger Areas

Eligibility Criteria

The transition from Part C to Part B requires both disability and eligibility determination. The disability label should be either deaf or hearing impairment, unless there is concrete evidence of another primary disability. Schools often identify the hearing disability as a speech-language impairment based on the need for this service and available service providers. This practice must be avoided, because

(a) districts may use it to deny providing a teacher of the D/HH or other necessary services, and (b) it reduces the count of actual numbers of students who are D/HH. Eligibility is determined by each state's definition of "adverse effect," which is the impact of the disability upon learning. Eligibility determination is based on more than academic performance—communication skills, social interactions, behavior, and

access skills, such as use of assistive technology and self-advocacy, must also be considered.

Increasing numbers of children who are D/HH are denied eligibility at transition to Part B, because they do not meet the state eligibility criteria. In these cases, supports and accommodations under Section 504 and ADA must be considered (see below).

Special Factors

Perhaps the most important regulation within IDEA for children who are D/HH is 34 CFR 300.324 (2) (iv) "consideration of special factors," which can be broken into five main components:

- Language and communication needs.
- Opportunities for direct communication with peers and professionals.

- Academic level.
- Full range of needs.
- Opportunities for direct instruction in the student's communication mode or language.

Additionally, 300.324 (2) (v) addresses the need for assistive communication devices and services consistent with the requirements of 34 CFR 300.5-.6. IDEA states that IEP teams "must" consider each component of this

provision. However, often there is simply a check off on the IEP form to indicate that they were considered. Rather, each one deserves a discussion, so that they are clearly defined and a plan developed for how each one is addressed.



Photo courtesy of NCHAM

Placement & Services

A common problem in school placement decisions is the lack of options for the various settings where a student's services might be delivered. IDEA requires that placement decisions must consider a continuum of options that include the school district's options, as well as other programs within the state that might meet the student's needs. In many school districts, the only available placement is the local school where the child typically attends. Larger school districts may have "center" schools that provide

a full complement of support services intended to support a larger number of students with similar needs. Sometimes smaller districts will contract with larger ones to serve their students, or they can be part of a cooperative that provides special education services to schools in a region or area. It is often a win-win for both districts to collaborate on these specialty placements.

Services include the various supports and accommodations that are provided through the IEP in the setting where

the student is receiving his/her education. Services should include special education as well as related services, such as audiology, speech and language, counseling, educational interpreting, transportation, and parent counseling and training. Accommodations are the supports that a child needs to access their educational program. Some common considerations include special seating to enhance visual and auditory access, interpreters, assistive technology, such as an FM system, and captioning.

Table 2 (continued)

Qualified Providers

Teachers of the deaf and hard of hearing (TODHH) have specialized training in deaf education, often requiring a master’s degree. They may provide direct instruction, supportive instruction, such as preteaching or tutoring, or consultation to the general education teacher. Current regulations require that secondary level TODHHs who are providing direct instruction have content knowledge in the specific areas they are teaching, such as English, math, social studies, or science. The expertise of the TODHH should

guide the development of the IEP and help ensure appropriate services are provided. The TODHH is often the child and parent’s best advocate to help navigate the educational system. When a TODHH is not regularly available, a general special education teacher may provide instructional support. The appropriateness of this situation should be judged on several factors, including the student’s needs, the expertise of the teacher, the availability of the TODHH to provide consultation, and the progress that the student is making.

Use of qualified educational interpreters is essential, because they function as the communication link between the teacher and student. If the interpreter cannot accurately convey the teacher’s instruction, the student is being denied an appropriate education. The interpreter’s signing system (ASL or English) should be matched to the student’s language. The qualifications of other related service providers should also be determined to identify whether they have some knowledge and/or experience with students who are D/HH. When they do not, additional training or support may be necessary.

Access under ADA

D/HH students have rights under ADA as well as IDEA. Title II nondiscrimination requirements may institute additional accommodations beyond the IDEA requirements of “reasonable” accommodations to ensure communication is as effective

as for nondisabled peers. ADA also applies to all children with hearing loss regardless of their IDEA eligibility. Additionally, the communication preferences of the student (or parent, in the case of young children) are paramount when determining

appropriate auxiliary aids and services. Accommodations, such as qualified interpreters, captioning, and hearing assistive technology, may be considered individually or in combination, depending on what is required to achieve effective communication.

504 Plan

When students do not qualify for services under IDEA, a 504 Plan should be developed to provide communication and other necessary accommodations. Like Title II of the ADA, 504 applies to schools that receive government funding. Since the 504 Plan does not have the same procedural safeguards as an IEP, and there are fewer requirements for managing the plan, parents have a critical monitoring role. Recommendations are only as good as how well they are implemented. Therefore, parents—and later their child—must be vigilant to ensure the school is meeting their obligations under the plan.

Least-Restrictive Environment

Administrators usually consider least-restrictive environment (LRE) to be the placement most like that of typical peers. However, it is important to note that the regulations also say “to the maximum extent appropriate.” LRE for children who are D/HH may require language and communication with peers, teachers, and other adults who are able to communicate directly rather than through an interpreter, as well as the ability to maintain a fully visually accessible environment. Often the LRE for D/HH children is referred to as a “language-rich environment.” LRE is an important part of the considerations that emanate from the special factors discussion.

Assessment

An appropriate assessment under IDEA, Part B, must be comprehensive and conducted by a teacher of the D/HH and other professionals with sufficient expertise to be able to accurately select, administer, and interpret test results. A comprehensive assessment should include academic and nonacademic content based on the specialized needs of each child. Expanded core curricular areas that are unique to D/HH children, such as speech, listening, audiology, sign language, and self-advocacy, are equally important to assessing academic performance.

Families who know they are critical to the educational life of their children see the reward of their efforts in the successful, independent thinkers their own children can become.

Summary

Advocacy must be a shared responsibility between the family, child, and systems that support them. Everyone has a role to ensure that developmental and educational milestones are achieved, and that each child has all the necessary opportunities to achieve his/her goals.

Those within the EHDI system can build the foundation for parent involvement from the beginning of the family's journey by clearly communicating a desire for families to be engaged and valuing their contributions. Families who know they are critical to the educational life of their children see the reward of their efforts in the successful, independent thinkers their own children can become.

Parts of this chapter are derived from an article written by Janet DesGeorges at <http://www.communityplaythings.com/resources/articles/2010/the-power-of-parents-supporting-families-towards-effective-advocacy-and-involvement>

References

Johnson, C. D., DesGeorges, J., & Seaver L. (2013). *Educational advocacy for students who are deaf or hard of hearing: The Hands & Voices guidebook*. Boulder, CO: Hands & Voices.

