



REFRAMING SELF-ADVOCACY: A GLOBAL INCLUSION APPROACH FOR DEAF AND HARD OF HEARING STUDENTS

WHITE PAPER

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ABSTRACT

Self-Advocacy for students who are Deaf and Hard of Hearing is integral to their social-emotional development. Fostering self-advocacy skills in students who are Deaf and Hard of Hearing (DHH) is essential so they can effectively communicate their access needs, particularly as those needs become increasingly important with age and independence. This paper defines the concept of self-advocacy, highlights the importance of self-advocacy for students, outlines the supports necessary from the educational team, community, and parents, and identifies the Carter Hears! difference. This exploration moves beyond traditional perspectives of examining self-advocacy solely from a Deaf and Hard of Hearing perspective and propels the importance of moving into a global model of inclusive partnering. At Carter Hears!, self-advocacy is addressed through a developmental and whole-child approach. Finally, what is presented in this paper will highlight the Carter Hears! Difference in modeling, teaching self-advocacy, and inclusive partnerships.

Introduction

The question that many individuals face is, "Who am I?" Individuals must learn to understand themselves and their role in the everyday environments in which they interact – home, community, school/work. Now, think about this challenge as an individual who is Deaf and Hard of Hearing (DHH). As they apply the knowledge of self, an important skill to learn is developing self-advocacy to understand how to communicate their needs, wants, and rights. For a student who is DHH, their response to personal hearing acuity is not based on the degree of loss, what type of hearing assistive device is used, or the age of onset. Instead, it is based on how the student feels and interacts with their hearing level, communication preferences, and/or the technology being used, if any. Their response is also based on their identity, concept of self, and personal attitude choices as they have new experiences which change or support how he/she feels. The research on self-advocacy and self-concept development shows that students build confidence in self-identity as they discover their communication preferences, needs, wants, and rights (Price, L., 2016). Developing self-advocacy skills in DHH students requires a global inclusion approach. Without this approach, these challenges have negative impacts on their future success, advocating for themselves and developing self-identity as they embark on their futures and careers. Carter Hears! is an organization in the Carolinas that provides services for DHH students in education, such as Teachers of the Deaf, Educational Interpreters, and Language Facilitators. The model implemented by Carter Hears! is mission-focused on whole-child development. An integral part of this development is social/emotional skills and self-advocacy in tandem with the academic, functional, and spiritual success of the student in conducive learning environments. Carter Hears! addresses self-advocacy development through targeted, developmental approaches, integrative teaching practices, the Quill Model® Language Facilitator Model, school partnerships, and community partnerships. Community partnerships are intentional at Carter Hears! rooted in our commitment to engaging professionals and individuals who are DHH and represent diverse communication modes, lived experiences, and backgrounds. These partnerships reflect a commitment to inclusion, representation, and diverse perspectives within community engagement.

What is Self-Advocacy?

"Self-advocacy refers to an individual's ability to understand and effectively communicate their own needs, desires, and rights in various contexts. This involves a combination of self-awareness, assertiveness, and strategic communication skills to navigate personal, educational, and professional environments" (National Center for Learning Disabilities, n.d.). For DHH students, self-advocacy can include understanding their own hearing level, how they express their communication preferences, knowing what accommodations they need, and how to request them. DHH students can learn about what services benefit them and how they can obtain those services, as well as the legal knowledge of how to explain and advocate for their rights by reviewing the Americans with Disabilities Act, Section 504, Individuals with Disabilities Education Act, and the National Association of the Deaf website.

Learning self-advocacy skills typically begins at a young age. Parents and caregivers take the helm and model this behavior, while children observe the practice. As these children grow, they are given opportunities to practice these skills for themselves until it becomes part of their natural behavior.

Many children who are DHH often do not have exposure to adults who are DHH, who can be natural role models of self-advocacy. When Carter Hears! implements the Quill Model® Language Facilitator Model with a student who is DHH, whose primary language is American Sign Language, the ideal candidate is a professional who is DHH. This provides the opportunity for a natural language role model, who models self-advocacy as they work with classroom teachers and school staff, for the student to observe and learn from. As an example, a facilitator who is DHH working with the classroom teacher must ensure their access needs are met as well, such as captioning of videos/media content, positioning of the classroom teacher for instruction, or the communication between the teacher and facilitator.

How Does Language Play a Role in Self-Advocacy?

The critical period for language acquisition skills is approximately the first 5 years of a child's life, where there is an elevated neurological sensitivity for language development (Hall, et al., 2017). Absence of a fully developed natural language can result in significant consequences for neurological development. Language deprivation occurs due to a chronic lack of full access to a natural language during the critical period of language acquisition (when there is an elevated neurological sensitivity for language development), approximately the first five years of a child's life (Hall et al., 2017). When students who are DHH lack a natural language to communicate even basic wants and needs, a child's ability to develop a self-concept that leads to strong self-advocacy is nearly impossible. Incidental learning opportunities, where one picks up information unintentionally in one's surroundings, are severely impacted.

"Approximately 1 to 3 out of every 1,000 children in the United States are born deaf or hard of hearing. Over 90% of these children are born to hearing parents" (ASHA, n.d.). Only 22% of hearing parents with deaf children learn sign language, yet there is not sufficient data to confirm the actual percentage (Stine, 2019). In a survey of ten states focusing on families with children between the ages of 2 and 6, the National Center for Assessment and Management showed that 12% of the surveyed families use Cued Speech along with Spoken English or vice versa (NCSA, 2018).

Self-advocacy skills are addressed through evidence-based research and practices by the Teacher of the Deaf and through the Quill Model® *Language Facilitation Model*, that is implemented by Carter Hears! with students who have language deprivation. The Language Facilitator works directly with the DHH student throughout the school day in a mainstream school setting. This allows the Language Facilitator to observe the student in various academic settings, peer and staff interactions, and their behavior and language expressions in each of these areas.

As the DHH student struggles with social/emotional interactions, they also struggle with self-advocacy and Theory of Mind skills. "Theory of Mind (ToM) refers to the ability to understand others have thoughts, beliefs, intentions, and perspectives that may differ from one's own"(Hall, M. 2016). Struggles with Theory of Mind will influence their ability to interact with others socially and emotionally, and thus hinder their ability to self-advocate in those situations. The Language Facilitator as a role model can help facilitate those situations to help the DHH student to understand communication breakdowns, model positive outcomes and experiences, and learn how to advocate in future situations for themselves to maintain relationships.

What Does it Look Like?

Every individual is unique, and self-advocacy is expressed in many forms of communication and behavior. These outlets evolve as DHH individuals age from childhood into adulthood. As children, understanding self-awareness does not happen incidentally and takes explicit modeling and teaching in various settings. "Self-advocacy relies heavily on the ability to assert oneself. Effective self-advocacy involves being able to communicate one's needs, understand one's rights, and make informed choices about one's own life." (Wehmeyer, M. L. (2013). The following skills should be assessed when analyzing a student's self-advocacy.

Communication Needs

Can the student share what their communication needs are? As a Language Facilitator, this can be modeled in a few different ways. The Language Facilitator can show the student how to ask the teacher to mute or unmute the remote FM microphone used with their Hearing Assistive Technology (HAT) when the classroom teacher addresses the class or another student directly. Another instance is when given directions by the classroom teacher, the student learns to ask for things to be repeated or explained more if the student demonstrates a misunderstanding.

Requesting Accommodations

Does the student know what their accommodations are and why? The Language Facilitator can model this for the student by reminding the classroom teacher of the accommodations outlined in the IEP, such as captioning on videos, and requesting that the captions be turned on. After modeling, this can be reinforced for the student by encouraging them to do it themselves. Utilizing scaffolding, the student will then be ready to practice advocating for themselves by requesting this without modeling or prompting being provided.

Peer Interactions

"Students who are deaf or hard of hearing are often at risk for not developing social relationships because they may not have the language skills or have not learned how to engage in socially appropriate behaviors, such as carrying on conversations, making friends, and dealing with conflict" (Hauser & Marschark, 2008; Stinson, Whitmore, & Kluwin, 1996). Peer interactions require a child to have Theory of Mind, social/emotional skills, and executive functioning skills – specifically inhibition and self-control. Who can model and directly teach this behavior? Every adult in a DHH child's life can provide these modeling opportunities, such as parents, teachers, school staff, Language Facilitators, and peers in different environments with varying levels of intensity. Learning self-advocacy skills is important not just for academics and the learning environment, but for social interactions and improved quality of life. A Language Facilitator can model this in the classroom as they engage with their peers by asking the teachers questions that relate to Theory of Mind, self-advocacy, and social/emotional skills. Examples include recognizing when a peer is upset or crying, and after asking if something is wrong, respecting their decision not to share rather than pressuring them for more information.

Deaf and Hard of Hearing Adult Role Models

When DHH students are paired with other professional DHH adults in a mentoring situation, there are many benefits, including:

- DHH adults model how they navigate their environment with confidence and ease.
- DHH adults demonstrate possibilities and hope for the future.
- DHH adults can help students develop self-confidence and a positive DHH identity.

The primary choice for a Language Facilitator at Carter Hears! is a qualified Deaf or Hard of Hearing individual, as they can serve as a role model while targeting language in a developmental path in the mainstream school setting. Research has been shown and highlighted in *Addressing Language Deprivation using Deaf Community Models* by Kandice Hunt, Allen Sanderson, and Rylina Dey (Hunt et al., 2023) . Many resources outline the above areas as well for Self-Advocacy development and more. These resources include, and are not limited to: [Minnesota Compensatory Skills Checklist](#) , Lynne Price's Steps to Success curriculum, and [Iowa's Expanded Core Curriculum](#).

Setting a Student Up for Self-Advocacy Success: Development of Self-Advocacy

The development of self-advocacy skills occurs gradually as the student progresses through stages of development. When a student is in preschool/elementary school, advocacy comes from parents, professionals, and teachers. How well a student navigates the educational setting depends largely on the environment that is set up for them.

As a student becomes older, the expectations and responsibility for self-advocacy increase. However, as a student ages, other factors can inhibit their ability to advocate for themselves. For example, a student may become withdrawn and shy as they become older. Additionally, new life challenges influence the development of identity. "We respond to challenges according to our self-concept, how we see ourselves in a situation, and our interactions with others" (Price, L. 2016). As language becomes more sophisticated and social groups develop, the DHH student may develop reluctance when it comes to implementing self-advocacy skills. Personality and social/emotional development also impact self-advocacy skills.

Here are 6 questions to consider when evaluating self-advocacy development for a student:

1. Does the student understand their hearing loss/levels/identity? (Hard of hearing/Deaf/Deafblind/Deaf Plus/Deaf disabled) And can they explain it to others?
2. Do the student and education personnel understand how to address communication access (Asking for clarification, use of FM system, use of captioning, use of interpreter, etc.)
3. Is the student's environment set up for communication access?
4. Does the student have access to effective peer interactions? Interactions with positive adult role models?
5. Does the student feel supported by educational personnel?
6. What is the student's level of ability to self-advocate? (Advocates assertively, moderately, or not at all).

Some strategies for overcoming barriers to a lack of self-advocacy skills can include educating students about their legal rights, including their right to a qualified interpreter. Establishing peer support networks and mentorship programs where Deaf individuals can receive emotional support from other Deaf individuals and learn strategies for navigating a hearing world. Educating and spreading awareness by spotlighting the challenges the Deaf community faces and advocating for a more inclusive environment. Teach students about access with the use of technology such as speech-to-text apps on their phone, Video Relay Services (VRS), ASL friendly programs, captioning, Communication Access Realtime Translation (CART) services, and typing programs with large fonts. This can help reduce reliance on other people and provide more autonomy for the Deaf individual.

Importance of Self-Advocacy

As a young child, many decisions are made by parents and professionals as students encounter daily interactions at home and school. However, when a decision does not align with a student's wants and needs, often a response of negative behavior or language is expressed. "DHH students often rely on behavior to express their needs and wants, especially when communication barriers exist. When these behaviors are negatively expressed or misunderstood, it can result in further communication breakdowns and punitive responses, further exacerbating the initial issue." (Powers, S. W., & Johnson, E., 2012).

The following case studies illustrate the importance of having strong self-advocacy skills and some of the challenges that can arise when these skills are not taught:

Case Study 1:

Raphael is a 23-year-old Deaf man who was diagnosed at birth. He grew up in an all-hearing family that spoke only Spanish. The family moved to the United States from a Spanish-Speaking country when Raphael was 8 years old. The family did not have access to DHH resources, nor could they communicate directly with their son. Most of their communication was through pointing and gestures. Raphael attended a mainstream school and had an ASL interpreter attend classes with him. However, the interpreter struggled to understand him and vice versa. The interpreter never let anyone know for fear of losing her job. Raphael never spoke up to share that he could not understand what the ASL interpreter was saying, nor did he request a new one to give him access to information and communication. His self-advocacy skills were not developed, so he lacked the ability to advocate for himself. Raphael graduated from high school with a certificate of attendance, a 1st grade reading level, and severe language deprivation issues that were never addressed. He couldn't tell anyone about his hearing loss, what accommodations he needed for communication success, or what his hopes and dreams were. This student will often smile and nod when asked questions instead of sharing a response to answer the question.

Due to language deprivation issues and lack of self-advocacy skills, finding programs to serve his needs proved challenging. Today, as an adult, he is having issues with walking off jobs, leaving his family home for walks, and going into his neighbor's yards and touching their things. Cops are frequently called on him because the neighbors do not know he is Deaf and think he might be on drugs. One neighbor pulled a gun on him while demanding to know who he was, while he stood there smiling and shrugging. He lacks the language skills to articulate who he is and what he wants/needs. Currently, he feels frustrated, isolated, and angry. His family is looking into group homes for him because they feel like his communication and behavior challenges are too much for them to handle. These are issues that, if worked on diligently while younger through a targeted and

developmental process, might have helped to avoid many of the challenges he faces currently.

Raphael and his family's struggles are more common than many realize for DHH individuals and their families. Understanding the areas under self-advocacy that were lacking correlates with the experiences and outcomes for Raphael. "Students who are unable to advocate for themselves may end up unemployed, underemployed, and unable to live independently" (Bowe, 2003; Wheeler-Scruggs, 2002). Helping Educate and Advance the Rights of the Deaf, HEARD, estimates that there are tens of thousands of DHH people incarcerated in the U.S. "In a 2016 survey by the federal Bureau of Justice Statistics (the most recent report available), roughly 10% of surveyed state prisoners and 6% of federal prisoners reported having a hearing disability." (Thompson, Dehler 2023). Focusing and practicing self-advocacy skills when DHH individuals are young, with the globally inclusive approach guided, taught, and modeled by the educational team, families, and peers, will greatly impact their post-education success. Theory of Mind and social emotional skills were lacking as well for Raphael, as he was unable to understand the feelings of others, differing from his own, and the ability to interact with others from this understanding and disarm those who reacted negatively to his behaviors.

Case Study 2:

John was a junior in high school in a mainstream setting, with moderate-to-severe hearing loss and minimal support services. In high school, a Teacher of the Deaf was added to his IEP. John scored a 94% in discrimination ability on his audiogram, so for years, the school district assumed he needed little accommodation in the classroom. In high school, John was struggling in several of his classes, especially when interactive work was required. John was not comfortable advocating for access and in many cases, he wasn't even aware of what he was missing in the classroom. An advocate suggested that his mother do a "TV/Radio" test to determine how much John was really comprehending what he was hearing. This consisted of listening to a TV/Radio program for 30 seconds at a volume that was comfortable for the parent (because real life doesn't operate at a higher volume for deaf/hard of hearing kids) and repeating back what he understood. John's mother determined he was only understanding about 40%. She was shocked at how much he was missing as she and the educational system assumed that John was "doing just fine" throughout the years. The advocate suggested adding real-time captioning in the classroom. It took five IEP sessions to convince the team to add captioning. Throughout each meeting, John gained confidence while watching the advocate (who happened to be deaf) focus on obtaining access for him. From this modeling and exposure, John slowly gained confidence and became more comfortable with his ability to advocate for himself. John graduated with higher grades and graduated from college with honors.

This case study highlights the importance of providing greater access in the classroom, no matter how high the discrimination score is on the audiogram, and the importance of connecting students with deaf and hard-of-hearing role models at early ages. For a validated test to understand what students or individuals can hear, the Functional Listening Evaluation (FLE) (DeConde Johnson, Ed.D., 2013) is recommended.

The two case studies here are just a glimpse of the connection between self-advocacy development and the impact on students when they become adults.

A Global Approach to Inclusive Self-Advocacy

Traditional models of self-advocacy often put the focus on developing skills within the student so that the

student can be ready to employ advocacy skills when needed. While the skillset is a valuable one that the student can apply to many situations in life, a global inclusive approach to self-advocacy takes this skill and expands it into a model.

Traditional Approach to Self Advocacy



In this diagram, the traditional model of self-advocacy requires a student to moderate themselves in various situations all day long. The difficulty with this model is that the responsibility is increasingly placed on the student as they age up into the educational system. The weak link in this model happens when access is not 100% supported and the student is expected to identify and remedy the lack of access. For example, in a noisy lab environment, the student misses a critical piece of information due to the noise but is unaware of this omission—there is no way for the student to advocate for something that they are unaware of missing out on. “Students cannot know what they missed hearing because they didn’t hear it in the first place, yet they are often held accountable for receiving and fully comprehending that information.” (Supporting Success for Kids with Hearing Loss, n.d.).

With a global inclusion approach to self-advocacy, the entire system surrounding the student has an increased level of awareness and inclusivity, which reduces the load of responsibility on the student.

When a global inclusion approach is implemented, the following is in place:

School

Staff at all levels receive training about how to communicate and engage with the student. The inclusion model is practiced, even when the student isn’t there. Additional examples include the entire school learning to sign/cue a school song, captions are on all the time in all classes/events and hiring Deaf and Hard of Hearing presenters for school activities. The student’s access and needs are regularly checked by professionals, such as a Teacher of the Deaf. Objective tools such as rating scales are used to ensure that the accommodations provided are effective and to determine if additional accommodations are needed.

Global Inclusion Approach to Self Advocacy



- Community** Events are accessible, captions turned on everywhere, Deaf and Hard of Hearing role models and leaders involved, and build technology access into new buildings/transportation systems. Furthermore, the student and their family are taught about what is available in the community and what they need so they can advocate.
- Peers** Peers who have training and understanding about DHH students are more likely to form friendships, be inclusive, and collaborate in the classroom. The training/awareness can come from parents, teachers, DHH leaders, Teachers of the Deaf, or other professionals.

The Carter Hears! Difference

It's important to begin addressing self-advocacy development as soon as a DHH child enters school. Therefore, this area is assessed and addressed within evaluations and through Individualized Education Plans (IEPs). Understanding the importance of whole-child development, Carter Hears! Teachers of the Deaf are trained and coached on resources and practices that involve a targeted, developmental approach. Lessons are integrative, and skills targeted do not stand alone. This means that although the student may be working on a specific language skill, play and social/emotional skills are integrated into the session. As a simple example, the student may be working on prepositions and using them in sentences. The teacher integrates the prepositions into a board game, and the child practices advocacy by choosing game pieces and providing directions. Then the Language Facilitator can incorporate these strategies in the classroom in various ways, such as the classroom teacher giving a choice of which order to complete given assignments, partner work, highlighting how to ask where to find the resources, or how to ask another peer to work together. The goal of Language Facilitators and the process of Language Facilitation can be further explored in "A Meta-View on Language Facilitation: The What and Why" (Thibodeau, et al., 2023, pp. 4, 7) publication.

A Language Facilitator can model self-advocacy in a natural way in the classroom setting for the student to communicate their wants, needs, and rights. Through modeling and a team approach, the DHH student learns how to apply their knowledge in different environments, and not only in classroom environments. There are many examples to model these opportunities for DHH students in various academic settings.

Some examples include:

- Asking the teacher for help on assignments or clarification
- Participating in class discussions about content
- Creating new peer and staff relationships. For example, saying hi to those who walk by in the hallway, and when an opportunity is presented, introduce yourself and learn their name and who they are.
- Strengthening sense of self-identity as they practice Theory of Mind skills with peers and staff, for example, the Language Facilitator can model the Theory of Mind skills in partnership with the Teacher of the Deaf through role-play, and how to do this with peers.

Carter Hears! Teachers of the Deaf incorporate the entire educational team in the student's self-advocacy development through consultative services, monitoring progress in the classroom through rating scales, and integrating staff within the school environment to practice targeted skills. In addition, Carter Hears! focuses on partnerships in the DHH community, such as Hands and Voices, Beginnings, and Vocational Rehabilitation

Services to provide education, consultation, and workshops that include areas of whole-child development and self-advocacy. These opportunities allow professionals and parents in the community to share resources and discuss the importance of self-advocacy skills with students and individuals.

DHH students need a road map as they navigate their education, and it requires a concentrated effort from the student, educational team, and parents. Self-advocacy skills are not the DHH student's sole responsibility to develop without support from the education team and parents. The team of professionals working with DHH students in education carry a responsibility to target developmental success for language, social/emotional skills, self-concept, and self-advocacy. The opportunities that will be presented to DHH students who practice self-advocacy skills to communicate their wants, needs, and rights are endless as they pursue their passions and professions. In essence, this is what the Carter Hears! team strives to implement.

Conclusion

Self-advocacy, paired with a global inclusive approach, can create a setting in which a DHH student can tap into their full potential and thrive. A DHH student navigating their needs, wants, and rights as they age is less challenging when their self-advocacy skills are supported with a global inclusive team approach from an early age. The Carter Hears! difference is the focus on whole-child development using a global inclusion approach. Students who are DHH need models and access to understand their self-concept and identity as they face different experiences in their journey.

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