

Supporting families with children who are deaf & hard of hearing



## Supporting Self-Advocacy Skills in Children who are Deaf or Hard of Hearing

As parents, we may not always have patience when our child insists on doing things by themselves, especially when we are running late, but this independence is a sign of self-advocating. Self-advocacy skills are important to encourage in children who are deaf or hard of hearing (dhh). When a young child or infant is first identified as dhh parents, educators, audiologists, and health professionals make educated decisions to help support the child's needs. When children are infants or very young and have little or no language skills of their own, parents often rely on their instincts to make life decisions on their child's behalf. Parents are their child's front-line advocates and always will be, but especially until the child is capable of self-advocating. When children do start to self-advocate, parents can then follow their lead.

Wrightslaw, leading website for special education law and advocacy, offers this content-packed definition, "Self-Advocacy is learning how to speak up for yourself, making your own decisions about your own life, learning how to get information so that you can understand things that are of interest to you, finding out who will support you in your journey, knowing your rights and responsibilities, problem solving, listening and learning, reaching out to others when you need help and friendship, and learning about self-determination." http://www. wrightslaw.com/info/self.advocacy.htm. This definition of self-advocacy is written

to span over a person's lifetime and is relevant to children and adults of all ages.

Your child's experience as an individual who is dhh is uniquely their own. When it comes to what helps them best access information and develop language, only they can answer this question. This is why it is especially important for children who are dhh to learn self-advocacy skills as early as possible. Learning selfadvocacy skills can begin as infants and toddlers. Parents naturally help build their child's self-advocacy skills just by helping them become self-aware. Making eye contact, showing affection, imitating their expressions, and responding to a crying child are all ways parents help them learn about themselves and the power of communication. Self-advocacy begins in many small and meaningful ways.

Ideas to encourage self-advocacy in young children (list adapted from Milestones Autism Resources, http://milestones.org/individuals-with-asd/self-advocacy/).

- Teach how to say "yes" and "no"
- Encourage self-determination by honoring requests when reasonable
- Foster connection between asking (or advocating) for a toy and receiving it
- Expose the child to problem-solving by showing how to handle a problem (like showing how tracked in dirt is messy, figure out which tools to use, and then the ease of cleaning up)

- Encourage the ability to communicate preferences for clothing, food, activities
- Foster decision-making by offering two good choices (apple or banana, a book or a game)

There are many resources for developing self-advocacy skills in school-age children who are dhh. Educators will sometimes use two worksheets specific to students who are dhh to assess emerging self-advocacy skills, the Guide to Self-Advocacy Skill Development and the Informal Inventory of Independence and Self-Advocacy Skills for Deaf/Hard of Hearing Students.

"Access CANNOT be fully achieved with the use of hearing technology, visual communication, and teacher accommodations alone. Full participation requires that the student advocate for his or her own access/learning needs. Work begins in preschool to recognize how hearing loss and the listening situation impact understanding and what THEY can do,"

 Karen Anderson, Director of Supporting Success for Children with Hearing Loss.

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The Guide to Self-Advocacy Skill Development lists self-advocacy skills and a grade level to expect these skills to emerge. Every child develops differently so do not focus on the grade level; it is important to factor in your child's unique characteristics, cognitive abilities, and other specific needs. The guide is geared for an educational environment, but parents can adapt it to support and promote self-advocacy skills at home. For example the first skill listed in the quide at the preschool level reads, "Be responsible to put own hearing devices on and report when problems occur." Designate a central location in your home as a hearing device station to charge batteries, find replacement batteries, and store their hearing devices at bedtime. Take time with your child to practice checking batteries, putting on their hearing devices in the morning, changing batteries, and how to properly store them at bedtime. The Guide to Self-Advocacy Skill Development is made available through Supporting Success for Children with Hearing Loss at http:// successforkidswithhearingloss.com.

The Informal Inventory of Independence and Self-Advocacy Skills for Deaf/Hard of Hearing Students provides a list of goals or skills to look for over the years and check competency on a scale from 1 to 5. Students, parents, and the educational team use the inventory collaboratively to set Individual Education Plan goals for self-advocacy. The worksheet looks at the student's level of independence and selfadvocacy in the areas of student services, peer interactions, and community. This inventory is geared for older students (middle school to transitioning to adulthood) highlighting common everyday activities that are sometimes a

challenge for individuals who are dhh. For example, under the community section, the inventory reads, "Demonstrates independence skills in community at large (orders for self in restaurants, makes own purchases, etc.)". Families can create opportunities to practice these selfadvocating skills earlier and more often. Informal Inventory of Independence and Self-Advocacy Skills for Deaf/Hard of Hearing Students, by George Clark, MS.Ed, CI, NAD IV, Certified Interpreter & Laura Scheele, MS Ed, Teacher of the Deaf/ Hard of Hearing (2005), can be found at http://successforkidswithhearingloss.com/ wp-content/uploads/2011/12/informalinventory-of-independence-and-selfadvocacy-skills-for-deaf-hard-of-hearingstudents.pdf

A parent's ability to effectively advocate for their child who is dhh depends greatly on their emotional state, coping skills, their own life experiences, and over all understanding of the issues facing individuals who are dhh. The same is true for children who are dhh working on developing effective self-advocacy skills. Parents of an older child can help them help themselves by advocating in three parts: ASK + LISTEN + ACT.

- ASK what do they want, what do they need, and how can you help?
- LISTEN to what your child is really saying, do not project or assume.
- ACT: if your child gives you a task or an action item; follow through is critical.

Self-advocacy skills are important to develop over time. Parents are advocacy role models in the beginning as their child starts to understand their needs, and later as their lives become complex and they venture out in the world. Sometimes supporting self-advocacy just takes letting your child know you're in their corner.





## Lineup Owner Deb Erickson and Daughter, Trisha

MNH&V volunteer and Lineup business owner, Deb Erickson and daughter Trisha made 75 pilot caps for MNH&V Parent Guides to bring to new families. Lineup makes dance and cheerleading costumes and the caps were made with the scrap material. The pilot caps are in a variety of colors and patterns in baby/toddler sizes.

MNH&V is so grateful for the donation and will be sending them to the guides throughout the state to give to families who may want/need them.

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