



“What Parents Need to Know”

Spotlight on: 

Self-advocacy for Deaf and Hard of Hearing Students



The deaf or hard of hearing (d/hh) student of today benefits from the civil rights movement that has made its presence known in issues of gender, race, and disabilities. Far-reaching effects still continue, with a spotlight now on practices of transition for young people with a variety of disabilities as they transition from the structure of school into the realm of making their own choices. Self-determination, as the movement is now known, and self advocacy that is a part of that whole idea, is not often included in state’s written standards of education. Parents and teachers may find training in these life skills difficult to locate, though several programs throughout the country now have curricula addressing this crucial set of skills.(self

advocacy homepage: www.uncc.edu/sdsp

What is self-advocacy?

One definition stands out in the literature: "The realization of strengths and weaknesses, the ability to formulate personal goals, being assertive, and making decisions." (Martin, J., et al., 1993) What a powerful concept that is! What parent doesn't hope and work towards the outcome that their child will be able to:

- ❖ describe his/her own skills and needs
- ❖ set his own goals and a create a plan to reach them
- ❖ know the how, who, and when to ask for assistance
- ❖ Make decisions and then take the responsibility to deal with the consequences of those decisions.

The end goal is the passing of the torch whereby the young person becomes his or her own advocate. How can parents and teachers assist in meeting this ultimate goal? Innovative parents and teachers start this process early. Even in the earliest grades, a child can be encouraged to speak up when they can't see the teacher, the interpreter, or their FM system isn't working. Often, the simplest barriers limit a student's full access to communication. Our deaf or hard of hearing children must learn to take action to avoid missing out on important academic and social information. How can they know what to ask for if they don't know what they are miss-

ing? That is, indeed, the crux of the issue.

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Understanding Hearing Loss: A Place to start

...A dad is preparing dinner while his 4 year old son vies for full visual attention from him. Dad can explain (and will again, for years to come) that he can hear the child without looking at him.

...A 4th grader rises from her chair in class to shut the curtains when she can't see the teacher in the glare of the sunlight.

...A 17 year old senior shares his own goals for the year at his final IEP meeting, having asked ahead of time to put the IEP on transparencies and use an overhead projector.

When a child understands his own hearing loss, it makes comprehending needed accommodations much easier. Starting early, a child can grasp simple concepts like:

- ❖ "I 'hear' better when I can see you talking."
- ❖ "I can explain to you what my hearing aid does for me."

As a child's cognitive abilities mature, this changes to:

- ❖ "I need to sit closer if I want to

get the most out of this."

- ❖ "It helps me to tell the substitute that I need directions in writing."
- ❖ "My cochlear implant processor isn't working correctly. I need to get an appointment and let the interpreters know before 1st period."
- ❖ "I really get the best scores in classes with CART (computer assisted Real Time Captioning) ; that's what I want for my college lectures."

An outline for a lifetime course in advocacy training:

What does a young d/hh person need to know in order to be a self advocate?

In any field of endeavor, one needs to know the rules. In education, it's all about IDEA, LRE, IEP's, standardized testing, and access to communication. In the early grades, students should have opportunities to make choices from limited options, and a chance to live with those choices. They should be exposed to not just academic instruction, but real time problem solving.

Sally's early interventionist suggested to Sally's mom that she "talk about what she is thinking" during the day while home with Sally. Early exposure to everything from "my button broke and I can't go out in this shirt!" to "this lady won't get off the phone and I need to go!" and the thinking skills that solve these problems models for a young child with hearing loss that people have opinions, that they make mistakes, that they change their minds. "Thinking out loud" begins to create a Theory

of Mind for these kids, enriching their intellectual capacity and understanding. (Theory of Mind: see <http://spot.colorado.edu/~schick/ToM/ToM.htm>)

While it is easier for an adult to quickly do something alone than explain the task or even help a young child complete a task, the child misses out on a whole host of neuron connecting moments without the hands on experience. Providing feedback after a task can begin to link cause and effect, and model the ability to evaluate one's own work. "Does your sandwich look like this one?" and similar mentoring comments can lay the foundation for self management skills later on.

Without the hands on experience, a child is at a loss to know what they are "good at" and where they need help. A child in the early grades can also be exploring interests through trial and error. A young person who knows their own strengths and interests has many advantages over one who is still unsure when they reach the end of a high school education.

In the middle school years, a child is ready for more complex tasks of managing a schedule and evaluating their own performance. What is often needed is guidance to know when and how to ask for help, and identifying who might be a good person to "recruit". At this stage, a child might be analyzing potential options (how to

choose electives ie. Foreign Language, Band, Shop) with related pros and cons. Personal and academic goals can be set and a plan to achieve them. A parent or teacher's role as coach remains critical at this stage. "Ready for more complex tasks" doesn't mean a child will succeed at a higher level without occasional supervision, redirection, feedback, and the knowledge that adults important to the child are interested in his development.

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In the late middle school/high school years, students should be encouraged to make their own decisions that affect them, such as extracurricular activities, outside jobs, academic goals, schedules, how to organize their "stuff", and their own daily routines. With this experience of a longer leash, so to speak, students can begin to see the outcome of the daily decisions and choices they make without the safety net of parents and teachers. Also, a student might need assistance in breaking long term goals into short term, attainable goals.

From 14 years of age onward, the IEP process dictates that the student be invited and transition needs begin to be

addressed. Inclusion of the student in the IEP, as the consumer of all this special education, can certainly be started earlier. This process is a powerful tool in which to model and teach life skills such as goal setting, relationship building, effective communication, and directing their own learning.

Can self-advocacy skills be part of IEP goals? Yes. When these skills are modeled, facilitated, and nurtured, students have a higher degree of satisfaction and achievement in the school setting (Pocock, A., et al. 2002)

Setting the bar higher every year for self-advocacy can lead to stories like these:

"One of my students advocated for herself when she went to a community college by asking for someone to take notes for her, and even educated the professor about NCR paper."

"Several of my high school students have learned to advocate for their needs regarding non captioned films. They let the teacher clearly and succinctly know that they are unable to watch the interpreter and take notes at the same time. They request either an alternate assignment or captioned version of the film."

In the years leading up to graduation, a student also needs to learn the basics of the Americans with Disabilities Act, (ADA), especially in regard to access in secondary education or employment, based on their

own communication method and needs.

Sounds like a lot of work? It is. High expectations, communicated often and with support, set the stage for achievement of these skills that will last a child a lifetime.

When deaf and hard of hearing adults are asked where they learned their self-advocacy skills from, their parents are often the people they refer to the most. As a child, when a parent stands up for, and advocates for the child – whether it be in the educational setting, or

out in society – that child learns their own value. They begin to understand they have a right to stand up for themselves and set their expectations high.

References:

Martin, J., Huber-Marshall, L., & Maxcon, L. (1993) Transition policy: Infusing self determination and self-advocacy into transition programs. *Career Development for Exceptional Individuals*. 16(1), 56.

Pocock, A., Lambros, S., Karvonen, M., Test, D., Algozzine, B., Wood, W., et al., (2002) 'Successful strategies for promoting self-advocacy among students with Id: The LEAD Group.' *Intervention in School & Clinic*, 37, 209-216.

Self Advocacy Homepage: www.uncc.edu/sdsp/self_advocacy.asp?filename+project_directory

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The "What Parents Need to Know" Series

The "What Parents Need to Know" Series includes full articles and two-page synopsis of the following topics:

- ❖ **Socialization and the Child who is Deaf or Hard of Hearing**
- ❖ **Self-Advocacy for Deaf and Hard of Hearing Students**
- ❖ **School Placement Considerations for the Deaf and Hard of Hearing Student**
- ❖ **From High School to Post-Secondary Education: The Transition Process**

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