

A Sound Foundation Through Early Amplification

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The path to self determination

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Abstract

Although audiologists generally talk to children¹ about the importance of auditory access, using their amplification devices, and identifying accommodations to enhance communication, we still have many teens who do not understand their hearing status, are not using their technology, and are unable to articulate helpful access

accommodations. This discussion walks through the journey that can lead children to be self-determined, with the goal of increasing informed personal responsibility for one's actions, particularly as they are related to communication access and use of technology. Self-determination theory and instruction are discussed as well as strategies to promote identity, knowledge, and self-advocacy.

Introduction

The benefits of remote microphone hearing assistance technology have repeatedly demonstrated improvements in listeners' access to auditory information (AAA, 2008). Moreover, even greater listening advantages have been shown with digital technology advancements (Wolfe et al., 2013). However, among children in school and especially teens, usage rates remain low (Franks, 2008; LaFratta, Gabbard, Thomson, & Johnson, 2013; Davis, Gustafson, Hornsby, & Bess, 2015). Although attempts to address the behavioral, social, and other reasons for this gap have been made, effective solutions to the deeper issues behind this reticence have been limited. Self-advocacy skills are recognized as an important component of independence yet getting students to advocate successfully for their communication access needs remains a challenge.

A necessary reminder is that technology is a tool and, to be effective, tools need a basis with which they can be used. Using the analogy of a building, the foundation is built first, followed by a framework that is filled in with walls and other elements to complete the structure. For children to understand and advocate for use of recommended technology, a strong foundation has to be developed that acknowledges a person's identity and fosters understanding and acceptance of self. With time, skills and confidence advance. Knowledge gained through self-determination leads to the ability to accept responsibility for oneself and to advocate for one's needs.

Self-determination theory (Deci & Ryan, 1985, 2000; Ryan & Deci, 2000) has gained interest as a means to motivate individuals to gain control and self-regulate their behavior. Self-determination theory has also gained prominence in classroom practice (Wehmeyer, Palmer, Agran, Mithaug & Martin, 2000; Niemiec & Ryan, 2009) including transition planning (Wehmeyer & Schwartz, 1997). This article explores self-determination and its relationship to use of hearing assistance technology as well as a model for self-determination learning instruction and other strategies that help students navigate the path to becoming self-determined as it relates to their hearing status.

Identity

The first step in understanding children who are deaf and hard of hearing is to recognize their individual personal characteristics such as traits, preferences, and beliefs. In response to specialists, such as audiologists, whose primary focus is the disability and its consequences, children remind us they are not a "set of ears", an "audiogram", or a "disabled" or "impaired" They simply want to be like their peers and

recognized and treated the same as "normal" people. The development of identity, and how it is impacted by hearing status, is critical for learning, understanding, and accepting oneself. Identity is formed in part from family and peer group interactions and experiences. Ultimately, children should be able to address questions about themselves such as:

- Who am I?
- How am I different?
- Why am I different?
- When is the difference an asset?
- When does the difference become a challenge?
- What should I do in challenging situations?
- What am I willing to do in challenging situations?

Audiologists generally have a goal for their students, or patients, to be autonomous responsible users of the technology that has been selected. Achieving that goal might involve a circuitous path.

Changing the notion of disability

The World Health Organization (WHO), within their International Classifications of Functioning, Disability and Health (ICF), promotes a social model of disability based upon a person's differences and needs as contrasted with a medical model that focuses on a person's deficiencies (WHO, 2002). Table 1 describes the basic differences between the two models. A major shift that results from this definition is changing how disabilities are perceived. However, altering the label from "disability" to "difference" requires more than a word change. Rather, the shift has to reflect and promote a renewed understanding and acceptance that each person has differences; that the differences do not diminish that person's value but rather illustrate characteristics that are unique. Furthermore, at one time or another, everyone is expected to experience challenges and have to negotiate them within their social context. Because the social model emphasizes personal interactions, self-determination is a critical element of human development in order to participate meaningfully in daily interactions.

Medical Model	Social Model
Disability is a deficiency	Disability is a difference:
Located within the person	Located between the person and society
Disability is negative and should be ameliorated	Disability is neutral in life's context
Remedy is individual's problem	Remedy is negotiated interaction with society
Agent of Remedy: Health care professional	Agent of Remedy: Person and people with whom the person interacts

Table 1. WHO: Comparison of Medical and Social Models of Disability

Self-determination theory

Self-Determination theory is based on the concept that all individuals have the right to direct their own lives (Wehmeyer & Schwartz, 1997). Wehmeyer (1992) defines self-determination as "the attitudes and abilities required to act as the primary causal agent in one's life and to make choices regarding one's actions free from undue external influence or interference" (p. 305). A person's actions are self-determined if he or she:

- acts autonomously
- regulates his or her behavior
- initiates and responds to events in a manner indicating psychological empowerment, and
- behaves in a manner that is self-realizing (Wehmeyer, Kelchner, & Richards, 1996).

Studies have shown that students with self-determination skills have a stronger chance of being successful in making the transition to adulthood, including employment and independence. Specifically,

- at one year post graduation, students with higher levels of self-determination in high school were more likely to be living outside the home, employed for pay, and earning more per hour than those with lower levels of self-determination (Wehmeyer & Schwartz, 1997); and
- self-determination in students with disabilities was a significant factor in transition planning, particularly self-regulation and self-awareness/self-knowledge (Wehmeyer et al, 2007).

Critical to this discussion is the fact that self-determination is not achieved solely because a person has certain knowledge and skills; rather, they must also be supported by key persons and institutions in that person's life who provide a context conducive to self-determination (Deci & Ryan, 1985, 2000; Ryan & Deci, 2000). There are a number of roadblocks, especially relating to disclosure, that impact acquiring self-determination skills for individuals with disabilities or differences. These are described in Table 2 along with roadblocks for use of technology and accommodations that are common with students who are deaf or hard of hearing.

Choose not to disclose	Parents who deny the need for, or do not support, hearing instrument technology
Wait to disclose AFTER they have significant problems	School cultures that are not flexible to meet individual needs of students
Anxious about a "new beginning" and do not want to be labeled	Technology that does not work

Table 2. Roadblocks to Self-Determination and Use of Technology and Accommodations.

Parents are key to the development of self-determination for their children. Expectations must be discussed with parents in the early intervention years so that the skills are cultivated and supported as children develop. When asked, "What does self-determination mean for you and your child?", parents replied with a variety of statements that are captured in the wordle in Figure 1 (Hands & Voices, 2016).



Figure 1. Self-determination priority themes expressed by parents.

Roadblocks to Self-Determination	Roadblocks Regarding Technology and Accommodations
Difficulty acknowledging and/or accepting a difference	Students who are not supported to use the technology
Unprepared to disclose their disability	Self-advocacy attempts that are thwarted by the teacher

Statements included skills such as:

- Know oneself
- Identify needs
- Know solutions
- Owning and understanding needs; gaining confidence to convey these needs
- Ability to make decisions about her own life and future
- Being able to decide your life
- Be heard, understood and respected
- Set goals & see them through
- Self-advocacy
- Not allowing others to define or limit you
- Internal motivation and goals
- Ability to be successful in life and knowing what you want from life
- Identifying own needs wants, goals, and advocating for those
- Knowing and owning your story
- Ability to motivate oneself by focusing on your personal strengths
- Ability to identify yourself comfortably and confidently
- Being confident, liking who you are
- Knowing your value
- Striving for your full potential while encouraging others to do the same
- Caring for self
- Being a competent, productive adult
- Feeling confident and having goals
- Taking responsibility for oneself
- Accomplishing one's goals
- Not giving up, finding other ways to do things
- Independence, self-confidence

Hearing assistance technology

Even with improvements in technology, use of personal hearing assistance technology (HAT) has been variable and remains significantly underutilized. Formal and informal surveys of students indicated usage rates at 22% (Franks, 2008), 28% (LaFratta et al., 2013), and 64% (Davis et al., 2015). Some survey findings lead to the conclusion that social reasons cause a decline in usage as children get older. Franks (2008) targeted children ages 8 years and above and found the primary reason for non-use was social. The La Fratta et al. (2013) survey represented high school students. Davis et al. (2015) included 1st through 7th graders and only 12% of the group met the criteria for consistent users; HAT also included sound field systems that were not personally worn (47% had sound-field systems, 4% had personal FM, and 13% had both sound-field and personal); and the majority of children (65%) with reportedly available FM systems were between 1st and 4th grade. However, the reasons for whether or not the student used personal hearing instruments were varied including level of motivation, degree of hearing loss, whether the student felt the devices provided

benefit, and device issues related to functioning, ease of use, and comfort.

Strategies and solutions

Self-determined learning

An important role of audiologists is to identify, discuss, and support student goals. This process should provide information and guidance but not be directive. The Self-Determined Learning Model of Instruction (Wehmeyer, 1999) lays out a straightforward method to guide the learning process. When implementing the plan, focus on work with the students in goal areas where audiologists typically have expertise, such as communication access. Even broad goals, such as making new friends, improving grades, or going to college, have a component of communication access that can be supported. Each phase of the plan should be implemented in a manner that provides adequate time for students to think through and implement the activities of the goal areas. Students need to determine their goals and be able to respond to the questions with as little prompting as possible. To begin, a simple goal might be recommended to illustrate the process, such as in the following question and answer example about a hearing aid.

Phase 1: Set a Goal

1. *What do I want to learn?* How my hearing aid works. I want to know what makes it stop working at times and what to do about it.
2. *What do I know about it now?* It makes sound louder. Sometimes the hearing aid makes funny sounds. I cannot understand people talking when it gets noisy. When I get hot and sweaty the hearing aid cuts out or stops working.
3. *What must change for me to learn what I don't know?* I need to ask questions to someone who knows the answers.
4. *What can I do to make this happen?* I can talk to the audiologist. I hope the audiologist can help me. Maybe I can learn how to take my hearing aid apart to see what is inside and fix it to work better.

Phase 2: Take Action

5. *What can I learn from what I don't know?* What to do when my hearing aid cuts out or stops working.
6. *What could keep me from taking action?* I don't want to miss class. I have to remember to ask the audiologist to see me when he visits my school. I don't know how to contact the audiologist except when he checks in with me at school.
7. *What can I do to remove these barriers?* Ask my teacher if she can contact the audiologist to come to see me.
8. *When will I take action?* Today.

Phase 3: Adjust Goal or Plan

9. *What action have I taken?* I met with my audiologist and he told me many things about my hearing aid. He opened up the hearing aid so I could see the parts inside. The hearing aid computer is very tiny.
10. *What barriers have been removed?* I got my audiologist's email address and now I can email him when I want to see him.
11. *What has changed about what I don't know?* Sweat causes my hearing aid to cut out. The audiologist gave me a special cover, a sleeve that I can put over my hearing aid to keep out the sweat. He showed me another thing but I can't remember the name. I also learned about how a hearing aid works but he said we will talk some more the next time he comes to my school.
12. *Do I know what I want to know?* I am excited to try the hearing aid sleeve to see if it works. We will talk more about my questions I have when we meet again. He is very nice.

A simple student-driven problem solving sequence is another approach to promote self-determination. The sequence has four basic steps. This activity works well with small groups and can also be adapted to a mind-mapping format as illustrated in Figure 2.

1. Identify the problem
2. Identify potential solutions to the problem.
3. Identify barriers to solving the problem.
4. Identify consequences of each solution.

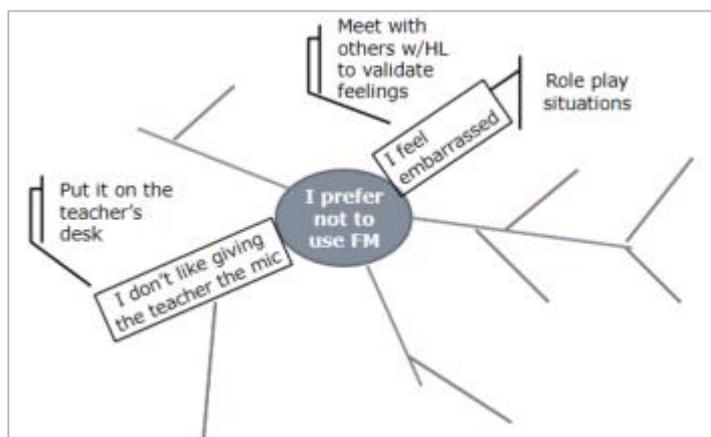


Figure 2. Student mind mapping example: challenges and solutions for not using FM.

Tips for promoting self-determination (Schoeller, Kachgal, & Bremer, 2003) are suggested in a brief by The National Center on Secondary Education and Transition (p.3). These include:

- promote choice-making
- encourage exploration of possibilities
- promote reasonable risk-taking

- encourage problem-solving
- promote self-advocacy
- facilitate development of self-esteem
- develop goal-setting and planning
- help youth understand their disabilities (p. 3).

Judicious use of amplification

The AAA Clinical Practice Guidelines for Remote Microphone Hearing Assistance Technologies for Children (2008) provide explicit procedures and recommendations for candidacy, selection and fitting, and management of HAT devices to assist current practice. Step Two in the guidelines addresses considerations for HAT candidates prior to proceeding with device selection and fitting including acoustical, social/emotional, functional, and other supports. At this point, identity and self-determination should be considered and, when contraindications are present, the process should be delayed until the student is ready to proceed. Specific areas to consider include the motivation of the child and his or her family, the motivation of the teachers and school, attention and fatigue, self-image, self-advocacy, social acceptance, classroom culture, and family support.

Many of the other issues that students identify as potential reasons for not using HAT are solvable with diligent management. Technology selection and function should be completed with the student having a voice and a choice. An implementation plan must include training to ensure that the technology is used as recommended and that it functions consistently. Validation is also necessary to demonstrate that the technology is providing the anticipated benefit. Management of technology is required under both the Individuals with Disabilities Education Act (IDEA) and the Americans with Disabilities Act (ADA, Title II).

Testimonials are also effective to share with students. Be sure to screen them prior to showing to eliminate any potentially embarrassing scenes or messages and to prepare follow-up dialogue. The following links are examples using Phonak Roger Pen devices. These videos are evidence of the importance of autonomy the Roger Pen offers to students.

- Ethan (high school):
<https://www.youtube.com/watch?v=TMv5UuSAsDs>
- Nicole (17 years old):
<https://www.youtube.com/watch?v=mjTSp4fC-ws>
- Audrey (15 years old):
<https://www.youtube.com/watch?v=tqWKzvTOUms>
- Audrey (18 years old):
<https://drive.google.com/file/d/0B2y6mNHf9IWwR25jUnJ3Z0hvTlk/view>

- Teen Stories using Roger
<https://www.phonak.com/us/en/hearing-loss/being-a-teenager-with-hearing-loss.html>

Resources

There are several products available from various sources to use as materials with teens:

- Phonak's *Guide to Access Planning* is a learning guide with self-assessments, rights, self-advocacy materials, hearing access technology, activities, and other resources. The Guide is designed to promote self-advocacy and personal responsibility in teens and young adults as well as support high school post-secondary transition planning. There are 2 sections: Consumers, <https://www.phonak.com/us/en/support/children-and-parents/planning-guide-for-teens.html> and professionals, <https://www.phonakpro.com/us/en/resources/counseling-tools/pediatric/guide-to-access-planning/guide-to-access-planning.html>.
- Ida Institute, Denmark, has several consumer support resources for all ages: *Motivational Engagement*, *Communication Partners*, *Living Well with Hearing loss*, *My World Pediatrics*, and *Group AR Guide*. The latest release is the *Transitions Management* tool that is based on the principals of self-determination and intended to help children and their families manage the transitions from early childhood through adulthood. <http://idainstitute.com/toolbox/>.
- Pepnet's *Map-It* was developed through a federally funded project of the U.S. Department of Education to provide training in self-determination for teens and young adults who are deaf and hard of hearing. All videos are presented in American Sign Language with captions. The training is organized into three sections: Who Am I?, What do I want?, How do I Get there? <http://www.pepnet.org/map-it>.
- Audiology Self-Advocacy Checklists (Johnson & Spangler, 2013) provide a guide for self-advocacy skills development for management of hearing loss/deaf related areas from elementary school through high school. <http://www.adevantage.com/Resources.html>.
- <http://successforkidswithhearingloss.com/transition/> by Karen Anderson contains a variety of materials to support self-advocacy and transition.

Conclusion

The audiologist's role supporting students who are deaf and hard of hearing extends well beyond traditional assessment and management practices. The development of underlying well-being for identity and self-determination is fundamental to our students' ability to be responsible for their hearing status and to advocate for communication access and full participation in their family, school, and community living events. Implementation of a program to develop these skills relies on respect and patience for the individual as well as effective tools and supportive home and school environments.

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