

# Building a Foundation for Effective Self-Advocacy: Tools for Caregivers

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- \* **Financial disclosure:** Katie McCarthy is a salaried employee with Boston Children's Hospital.

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# What is Self-Advocacy?

<http://canlearnsociety.ca/>

|                                |  |  |  |                    |   |   |
|--------------------------------|--|--|--|--------------------|---|---|
| Speaking<br>Up for<br>Yourself | Learn<br>how to<br>get<br>Infor-<br>mation | Finding<br>out who<br>Will<br>Support<br>You | Know<br>Your<br>Rights<br>And<br>Respon-<br>sibilities | Problem<br>Solving | Reaching<br>Out to<br>Others<br>When<br>You<br>need<br>help | Learning<br>about<br>self<br>deter-<br>mination |
|--------------------------------|--|--|--|--------------------|---|---|

[www.rule-the-school.com](http://www.rule-the-school.com)



- \* “Despite this widespread agreement, self-advocacy skills and opportunities to self-advocate are frequently not included in the instruction of students who are deaf or hard of hearing (Garay, 2003; Ingraham & Anderson, 2001; Velaski-Sebald, 2005). The consequence can be severe—students who are unable to advocate for themselves may end up unemployed, underemployed, and unable to live independently (Bowe, 2003; Wheeler-Scruggs, 2002).”

Luckner, John L, Becker, Sharon, J. 2013. Fostering skills in self-advocacy: a key to access in school and beyond. *Odyssey*, 34-38



# Self-Advocacy Goals

- \* Describe their own skills and needs
- \* Set their own goals and 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

*Resource: Hands and Voices web site*

[handsandvoices.org/articles/education/advocacy/V8-4\\_selfAdv.htm](http://handsandvoices.org/articles/education/advocacy/V8-4_selfAdv.htm)



# Self-Advocacy Needs

- \* Early exposure to solving problems
- \* Critical thinking skills and turn-taking
- \* Confidence building
- \* Peer and adult mentors
- \* Awareness that they are not alone and others share in this need
  - \* [youtube.com/watch?v=\\_dZDFP05ZGA](https://www.youtube.com/watch?v=_dZDFP05ZGA)



# Teaching Self-Advocacy: A Conceptual Model

| Knowledge of Self                             | Knowledge of Rights                                    | Communication  | Leadership  |
|---|--|--|---|
| Know his/her interests                        | Know their own rights as a Deaf/Hard of Hearing person | Be able to interact with individuals and within small groups | Act as leaders in small groups                              |
| Be able to describe his/her own hearing level | Know their rights in their educational setting         | Has the ability to communicate using body language           | Lead IEP meeting or transition meeting                      |
| Identify strategies that help performance     |  | Has the ability to use language to persuade and negotiate    | Present about their hearing levels; mentor younger students |

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# Teaching Self-Advocacy Skills

- \* Explicit Instruction
- \* Modeling
- \* Provide opportunities for practice
- \* Role Play

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# Where Does Self Advocacy Start?

## *at home with family*

Parents can:

- \* go through their own process of acceptance
- \* “own it” so their can feel confident with their hearing
- \* model strategies and behaviors (e.g. use good eye contact; tap children to get their attention)



# What can you or your child do at home?

- \* Your toddler's hearing aid flashes that the battery is dead.
- \* Your child complains that the music at a restaurant is too loud.
- \* Your child can't understand you in the car.
- \* *Build self-advocacy skills early!*



# Adult Involvement

- \* Adults are encouraged to be considerate and conscientious
  - \* Children should not have to worry if an adult knows how to use an FM system
- \* Adults are encouraged work to minimize the child's possible anxieties, so the child can maximize self-advocacy
- \* Adults are encouraged to coach children on strategies for enhancing access
- \* Professionals should be knowledgeable about hearing loss in any proposed placement and aware of the child's needs
  - \* Considerations may include: available prior assessments, and how to reduce the risks for the child in their environment



# Communication “Survival Skills”

- \* The “Bobblehead”
- \* “I don’t know” tactic
- \* Dominating conversations; not taking turns
- \* Bluffing and asking later



# Clarifications and Rephrases

- \* No yes/no questions: “Do you understand?”
- \* If the child does not understand your question or comment, rephrase with more familiar vocabulary in ASL or English
- \* Give a visual signal when instructions are given. “Listen this is important” so you know the child is paying attention
- \* If you did not understand the child, repeat what you understood and ask for the rest of the information
- \* Reduces frustrations and missed information



# Empowering the Child: Communication/Hearing Preferences

- \* The child can develop their own handout for the teacher or for the class (Here's how I communicate... sheet)

Name: \_\_\_\_\_  
Date: \_\_\_\_\_

I can explain my hearing! Here's how...

Finish the sentence.

1. I need my hearing aid/cochlear implant, because \_\_\_\_\_  
\_\_\_\_\_

2. The FM helps me, because it \_\_\_\_\_  
\_\_\_\_\_

Circle the correct word or phrase to complete the sentence.

3. I use: hearing aids. cochlear implants.

4. I have conductive (or) sensorineural hearing loss.

5. My hearing loss is: unilateral. bilateral.

6. I hear better from my (left) (right) ear.

7. My hearing loss is:  
Mild  
Moderate  
Severe  
Profound



- \* Problems and Solutions worksheet that the child can fill out and talk with their caregiver or teacher
  - What is the problem?
    - My interpreter could not understand me.
    - My teacher did not give back the FM
  - What is the solution?
    - I need to let my TOD know. Advocate for a new interpreter.
    - Raise my hand and ask for it back next time.



# Case #1: K, 5 years old

- \* Scores on language testing in English were average
- \* In a mainstream setting
- \* He didn't have friends in school
- \* Parents were advocating for speech and language goals on the IEP related to social skills and self-advocacy

Even with average scores on testing, children can still benefit from specialized goals on an IEP for skills not always evaluated by formal testing



# Case #2: F, 4 years old

- \* Newly diagnosed mild-moderate reduced hearing levels
- \* Uses spoken English and attends a private preschool
- \* Recently obtained hearing aids
- \* Articulation challenges
- \* Parents benefitting from support from professionals to have a clearer understanding of reduced hearing and the impact and the importance of wearing hearing aids (since spoken language was the goal)





# Case #2 continued

- \* Step one: supporting the family
  - \* Understanding of HL
  - \* Acceptance
  - \* Consistency with technology
- \* Step two: role playing with the child
  - \* If hearing aid battery dies in school
  - \* If the child can't hear the teacher
  - \* If the child plays sports, how can he/she access the coach more easily



# Self Advocacy: Advice from a High School Student

- \* “know your people”
- \* Communicate your needs with teachers
- \* Using my FM... “makes my life 10 times easier” (less fatigue)
- \* Attend your IEP meeting (typically at 14)



# From clinic to community



**Boston Children's Hospital**  
Deaf and Hard of Hearing  
Program *Outreach and Support Services*



**Boston Children's Hospital**  
Otolaryngology and  
Communication Enhancement  
**Family Education and Advocacy Team**

Transitions • Workshops • Connections ... beyond the clinic  
Funded by the Decibels Foundation and The Caroline Bass Fund



# Helpful Resources

- \* <https://successforkidswithhearingloss.com/for-professionals/self-advocacy-skills-for-students-with-hearing-loss/>
- \* [www.hearinglikeme.com](http://www.hearinglikeme.com)
- \* <https://www.nationaldeafcenter.org/resources>



# Skill Development Checklists

## Guide to Self-Advocacy Skill Development

### Suggestions for Sequence of Skill Attainment

This sequence provides suggestions for ages of acquisition. Early skill development relies on consistent use of hearing devices, including FM and personal responsibility expected. Children in early childhood programs who are given the responsibility of charging the FM and handing it to the adult are more likely to become reliant self-advocates as compared to students not held responsible until grade 2 or later.

| Suggested age/grade | The student will....   |
|---------------------|--|
| Preschool           | Be responsible to put own hearing devices on and report when problems occur  |
| Preschool           | Be encouraged to ask for repetition when it is evident that s/he did not hear message  |
| Grade Kdgn          | Recognize effect of distance re: easier ability to listen to close speech versus far speech ( <i>Early Listening Function item demonstrations, discussion via My World Tool</i> )                  |
| Grade Kdgn          | Self-select or move to an appropriate seat in proximity to the teacher or desired class peers ( <i>discussion via My World Tool</i> )  |
| Grade Kdgn          | Appropriately ask for repetition of messages missed (i.e., more slowly, clearly, louder)   |
| Grade 1             | Recognize effect of interfering noise that occurs in learning environment ; demonstrate by closing classroom door, moving away from noise or requesting reduction in noise                         |
| Grade 1             | Use pre-determined signal with teacher to indicate challenges listening/understanding  |
| Grade 1             | Request that FM microphone be passed, remind teacher to turn on FM microphone  |
| Grade 1             | Report simple names and purposes of hearing device parts and what can go wrong (no sound, intermittent, distorted ( <i>Hearing Aid Tic-Tac-Toe Bingo, FM Bingo</i> ))                              |
| Grade 2             | Describe purpose and use of FM in simple terms to classroom teacher, with assistance   |
| Grade 2             | Increase awareness of recognizing when s/he has missed information ("When do you know that you didn't hear or hear everything?" (Relate to <i>Before LIFE, Student LIFE items</i> ))               |
| Grade 2             | Be able to report "When is it hard to listen/hear/understand?" (discuss situations from <i>Children's Home Inventory of Listening Difficulties (CHILD)</i> ; illustrate via <i>My World Tool</i> ) |
| Grade 2             | Recognize when a question/direction is nonsensical ( <i>Responding to Oral Directions</i> )  |
| Grade 2             | Appropriately use simple addition communication repair strategies (Take the part that you heard and substitute a clarification question. COMM)   |

<https://successforkidswithhearingloss.com/wp-content/uploads/2011/12/Guide-to-Self-Advocacy-Skill-Development.pdf>



## Self-Advocacy Competencies for Students Who are Deaf or Hard of Hearing

Developed by examining the work of Clark and Scheele (2005), the Douglas County School District (2009), the Iowa Department of Education Bureau of Student Family Support Services (2010), and the Laurent Clerc National Deaf Education Center's (2006) K-12 program, the chart below allows students to be evaluated on knowledge and skill competencies for each component necessary for successful self-advocacy.

|   | 1 | 2 | 3 | 4 | 5 |
|---|---|---|---|---|---|
| <b>KNOWLEDGE OF SELF</b>  |   |   |   |   |   |
| <i><b>Individual</b></i>  |   |   |   |   |   |
| Understands strengths and weaknesses  |   |   |   |   |   |
| Identifies interests and goals  |   |   |   |   |   |
| Understands his/her hearing loss  |   |   |   |   |   |
| • Type/degree of his/her hearing loss   |   |   |   |   |   |
| • Potential impact of his/her hearing loss on communication and learning                      |   |   |   |   |   |
| • Technology, amplification, and assistive listening devices                                  |   |   |   |   |   |
| • Responsible for care of technology, amplification, and assistive listening devices          |   |   |   |   |   |
| Evaluates postsecondary options with respect to skill level and personal goals                |   |   |   |   |   |
| <i><b>Environmental</b></i>   |   |   |   |   |   |
| Understands impact of the environment on learning (e.g., noise, distance, attention, fatigue) |   |   |   |   |   |
| Understands classroom factors that may help or hinder learning                                |   |   |   |   |   |
| Understands accommodations  |   |   |   |   |   |
| Understands modifications   |   |   |   |   |   |
| Cultural awareness and preferences  |   |   |   |   |   |
| <b>KNOWLEDGE OF RIGHTS</b>  |   |   |   |   |   |
| Indicates basic wants and needs   |   |   |   |   |   |
| Understands the concept/definition of self-advocacy   |   |   |   |   |   |

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<https://files.eric.ed.gov/fulltext/EJ1018884.pdf>



# Closing Thought

“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 an 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.”

[www.handsandvoices.org](http://www.handsandvoices.org)



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# QUESTIONS

