

Self-Advocacy

awareness

public accommodation

communication



Self advocacy

In today's society, people who experience hearing loss are a minority of the population. As with any minority group, the needs, experiences, and obstacles faced by individuals with hearing loss are largely unknown to the hearing majority. In order to get their needs met, or to explain accommodation and compliance issues, at home, school, and work, individuals with hearing loss must act as educators. Being an effective educator requires proficient self advocacy skills.

This booklet will highlight some primary considerations for self advocating in a hearing world. Ultimately, large scale change (i.e.: awareness, access, public accommodation) becomes possible when a significant sector of the hearing population understands the experiences of individuals with hearing loss and work with the deaf and hard of hearing to generate systemic change. This kind of transformation requires individuals with hearing loss to use self advocacy and effective communication in order to propel the movement forward and build the awareness of the hearing majority.

Understand your hearing loss

If you don't fully understand your hearing loss and its affects, how can you expect someone else to understand it? Thoroughly understanding your hearing loss

may require some research, some reflection, and perhaps some discussion with others close to you.

One of the first steps in understanding your hearing loss is to understand your audiogram and know how to interpret it for others. The audiogram is a graphed representation of the pitches (frequencies) and volumes (intensities) that one is able to hear. If you don't have a copy of your most recent audiogram, request a copy from your audiologist. The audiogram is the key used to unlock access to many public accommodations at school and work. The ADA requires medical documentation of a disability and for individuals with hearing loss; this typically means a copy of your audiogram. Being able to read and interpret your audiogram is an important skill that will serve you well.

If an individual has diabetes, it's reasonable to believe that knowing about the disease, understanding her diagnosis, and being clear about what treatment works for her and why, are significant and potentially life-saving pieces of information. Knowing about your hearing loss is no less important. In order to educate others about your hearing loss, you must be willing to educate yourself. Here are a few questions to consider:

- Can you explain your hearing loss (what you are and are not able to hear) to others?
- Do you know how your communication needs vary depending on the situation, environment, or people involved?

- Do you know what accommodations are available for you to use?
- Do you know what accommodations, services, and adaptations work for you and why?

If you answered “no” to any of these four questions, you may want to do some further investigating.

The most comprehensive competency for effective self advocating is self awareness. Knowing your strengths and weaknesses, understanding the typical communication pitfalls related to your hearing loss and knowing what accommodations or adaptations best meet your needs, you are more equipped for managing self advocacy in everyday life.

Communicate your needs

When you clearly communicate your needs and request to others, you play an active role in ensuring that your needs met. Here are some suggestions for more effective communication:

- Consider your audience – Does this person know that you have a hearing loss or will you have to disclose that information first? When is a good time for him/her to have this conversation? What experience might he/she have with working with individuals with hearing loss?
- State the problem clearly – Explain why and how the situation is not meeting your needs. Identify the behaviors, environmental factors, or specifics of your hearing loss which are contributing to the problem.

- Offer specific solutions – Often people will hear the problem and start worrying and wondering about how to correct it. By laying out some tangible solutions: “I can only hear one person at a time,” “Please write new vocabulary on the board,” or “After handing out the agenda, I need a moment to read it before you start talking,” people are more likely to be able to effect immediate changes.
- Keep emotions out – When making requests of others, it’s useful to detach the request from your emotions. People are more inclined to listen when you remain level headed, provide clear descriptions, and communicate your request without becoming angry, sad, or frustrated. It’s alright to be passionate, but be aware that strong emotions detract from people’s ability to hear your message.
- Anticipate problems and questions – What might the other person’s concerns about this request be? What would make this request more clear? What questions might he/she have about how to implement the solution? What impact is this request going to have on the classroom, group, or staff?
- Include others in the solutions – When more than one accommodation or plan might meet your needs, involve others in the process of determining the best approach for all of you. This will provide an opportunity for collaboration and further invest others in a successful outcome.
- Give feedback – After the fact, make time to share your gratitude or suggestions about how the solutions are working, what else might be

necessary, or other useful information to keep communication open and continue towards the goal of getting your needs met more consistently.

Effective communication takes practice and varies with every audience, setting, and request. Taking a few deep breaths, writing down some of your thoughts in advance, and assuming the best about others are a few things that may help communication go more smoothly. When it's evident that you are not placing blame and that your requests are valid and doable, people will be better able to listen to you and make the appropriate changes.

Involve others

No one has the stamina to help manage and police communication all the time – it's exhausting work! In order to maximize your ability to participate and keep from *a/ways* being the one who asks people to slow down, take turns, or repeat themselves, enlist the assistance of other hearing allies, friends, family members, and coworkers. In specific situations (staff meetings, family gatherings, discussion groups, etc.) ask one person ahead of time if he or she would act as your communication advocate. Explain what kinds of situations are most difficult for you to participate in, ask for his/her help with those situations and initiating reminders to the group. By virtue of having a hearing loss, you are not always the best judge of what spoken communication you missed.

Having another participant who can, for example, 1) notice when you are responding in a way that was not consistent with the question asked and can

therefore stop the conversation and get further clarification, 2) observe you being excluded by the pace of the conversation and intervene to remind people about speaking at a more reasonable pace, or 3) remember to remind people to take turns when more than one person is talking at a time; these kinds of tangible assists can make communication much more successful and alleviate you of the sole responsibility of communication advocacy. Shortly after the event make an opportunity to talk about and debrief the communication. Check in with your advocate about how things went for him/her, how things went for you, what ways the situation could continue to improve, and whether he/she is willing to continue in the role as communication advocate for future events and meetings.

When others are included in the solutions, they are more invested in the outcome. The more hearing advocates and allies we cultivate, the closer we move toward a world where the hearing majority remembers to consider the needs of individuals with hearing loss.

Practice

No one becomes an expert at a new skill without practice. If advocating for yourself does not come naturally to you, find ways to practice some self advocating in smaller, lower stakes situations so that you can build your confidence and competence.

Sometimes self advocating with our families is the most difficult. We have had a long time to develop our identity, communication styles, habits, and relationships with family members and these things take time to change. Additionally, our emotional involvement with our family is often more deep and complex than relationships with bosses, co-workers, friends, and service providers. By starting with less risky interactions, one can build the confidence necessary to eventually work on self advocacy in more close interpersonal relationships.

Start by practicing self advocacy skills with the server at a restaurant, employee at a movie theater, or the bus driver. Gaining experience in advocating for your needs builds assurance and those skills can be translated into other situations. By returning your soup when it's too salty, clarifying that you did not want butter on your popcorn, or asking the bus driver to notify you when you reach your stop, you are practicing the skills of self advocacy in low intensity ways that may not even be connected to your hearing loss. In so doing, you are enhancing your skills. It is also useful to role play higher stakes conversations with friends. This has a number of potential benefits: a) you are getting a chance to further practice and refine your self advocacy skills, b) you have the chance to get feedback from someone you trust about how you could be more effective, and c) you are educating and raising the awareness of one more person about the needs of individuals with hearing loss.

Finally, it is important to remember to lean on others for support. We do not succeed in this world alone.

Resources

<http://www.hearingloss.org>

The Hearing Loss Association of America exists to open the world of communication for people with hearing loss through information, education, advocacy, and support.

<http://www.nad.org>

The National Association of the Deaf's mission is to promote, protect, and preserve the rights and quality of life of deaf and hard of hearing individuals in the USA.

<http://www.earinfo.com/howread1.html>

Step by step instructions and explanation of interpreting the audiogram. This site includes example audiograms and the effects of having different audiological profiles.

<http://www.usdoj.gov/crt/ada/cguide.htm>

Overview of eleven federal laws related to disabilities, links to federal agencies, and contacts for further information about rights and grievance procedures.

http://www.wou.edu/education/sped/wrocc/training_technology.htm

This page has links to information about different technological accommodations including telephone access, assistive listening devices, and alerting and signaling devices.