Stigma and Self-Advocacy

There are two kinds of stigma. Stigma is a perceived negative attribute that causes someone to think less of the whole person.

Public stigma refers to what a naïve public does to the target group when they endorse the prejudice about that group. In other words, public stigma is external and has to do with what other people think about the target group.

Self-stigma refers to what members of the target group may do to themselves if they internalize public stigma. Self-stigma is inwardly focused, and is related to what target group members think about themselves.

There are a few concepts linked to stigma. The first is stereotyping. Stereotypes are categories or characteristics about a specific group of people that are generally agreed upon. They can appear to be positive (e.g., "people with hearing loss have other abilities to compensate for it") or negative (e.g., "people with hearing loss are incompetent). Even though they are generally agreed upon by most people, stereotypes may not be accurate, and may not apply to every member of the stereotyped group. For example, some individuals with hearing loss may be able to lip-read or use sign language, but this is not true for every single person with hearing loss.

Prejudice and discrimination are linked to stigma as well. Prejudice refers to attitudes people hold, whereas discrimination is the actual behaviors they perform. Stigma can show up as attitudes in the case of prejudice, or behaviors in the case of discrimination.

For public stigma, an example of a prejudicial attitude is thinking that people with hearing loss are incompetent. The discriminatory behavior associated with that prejudice may be refusing to hire someone with hearing loss for a job.

With self-stigma, the person may believe they are incompetent because of their hearing loss – this is prejudice – and because of that refuse to apply for jobs or seek out opportunities – discrimination against themselves.

This self-discrimination can be harmful as these behaviors interfere with functioning and self-improvement, particularly in the long run. For example, if you believe that you are less able

than your peers and deny yourself access to opportunities that benefit you, you might eventually become less able because of that, rather than because of the hearing loss.

Self-discrimination can also mean setting lower expectations instead of pushing yourself, and isolating self from peers instead of establishing deep relationships with others. Over time, such behaviors are likely to lead to poorer outcomes in terms of academic or work achievement, interpersonal relationships, and overall quality of life.

How can we address self-discrimination? One way to do so is through self-advocacy. Self-advocacy involves the ability to specify your needs and seek support or other resources to address those needs.

The ultimate goals of self-advocacy are to improve personal wellbeing and your situation, at least the aspects that are within your control. Self-advocacy means standing up for what you need and/or want, and to recognize that you have rights to opportunities just as much as anyone else.

We will outline a few steps that you can follow for self-advocacy. The first is to clearly state your needs. To do so, you will need to identify the issue you are struggling with. What is the problem exactly? What might be causing the problem? If you are able to describe your problem in specific terms, it will be easier to identify the support you need. For example, rather than saying you are having difficulty hearing, saying that you are having difficulty hearing your teacher talk when the background noise is too loud will help with the problem solving process. The problem could even be, “I am having trouble identifying the cause of my hearing device malfunction.” Once you are clear on what you are struggling with, you can proceed to the next step.

Once you have identified the specific issue, find out what you need to solve the issue. It could mean figuring out a solution by yourself, or even connecting with someone who can help with figuring out a solution. In either case, having a clear grasp on the problem will tell you what to do from here. Resources can take the form of yourself, experts like your audiologist, more experienced people like your friends, institutions, teachers, etc. Be creative and willing to ask around until you find the answers you need. You are entitled to a conducive learning/work/social environment, just like everyone else around you.

Now that you have identified a possible solution, implement it. Try it out.

And assess how well it’s working for you. Is it helping you to solve your problem and achieve your goals? If so, great. If not, go back to Step 1. Maybe the problem was inaccurately identified,

or maybe the solution was inadequate. Remember that the ultimate goal here is to improve your wellbeing and your situation.

If you are a parent of a child with hearing loss, you may be interested in teaching your child to advocate for themselves. The area of self-advocacy will change depending on their developmental stage. Once your child is off to elementary school, and will have to cope with interactions with teachers and peers, and making sure their hearing device is functioning throughout the day, self-advocacy becomes an important skill. Training your child to speak up for themselves can start while they are young, so they grow up understanding that self-advocating is the norm as well as experiencing the benefits of self-advocacy. As parents, you can help to shape this behavior by providing your child with specific instruction and guidance.

When should your child be speaking up? When they are uncomfortable? When the batteries are low? How should they speak up? What words should they be using? Who should they be speaking with? While these steps may be more straightforward to us, children may need guidance to figure out exactly what self-advocacy looks like. Part of this learning will occur through trial and error, which means mistakes will be made. That is OK; mistakes provide rich learning opportunities, and give you space to give your child feedback. Focusing on what they did right, rather than what they did wrong, tends to be more helpful in developing this new behavior.

In addition, you can give them corrective feedback. If you don't like something your child did, tell them how you would like them to do it instead. This makes it more likely that your child will follow through with the feedback, compared to if they tried to figure out the "right" way on their own. By doing these things, your child will know what actions they should continue to take, and they will have a foundation from which to experiment with different ways of speaking up.

Self-advocating is hard. Different barriers can get in the way. They can be cognitive, emotional, or social.

Cognitive barriers refer to the thoughts that we believe to be true, that are generally unhelpful. For example, if you believe that trying isn't worth it, then you might stop trying once you encounter difficulties.

Emotional barriers refer to feelings we have that make it difficult to do things, including embarrassment, fear, or even shame. When we allow these feelings to take over, we may act in ways that are less helpful to us.

Social barriers refer to external variables, such as people who are unwilling to help. The similarity across these variables is that they are difficult—or even impossible—for us to control.

In addition to the main issue, some of these barriers may need to be addressed as well. Here are a few ways to address them. What works for some people may not work for everyone, so if these methods are not helpful, be creative and find other approaches that fit you. For unhelpful thoughts, rational thinking or noticing may be helpful. For example, if you have the thought that you are incompetent, examine the proof supporting that thought. What evidence is there that you are indeed less competent? Another approach is noticing the thought as a thought, and treat it like any other thought. You don't have to buy into the thought; you can just acknowledge that it is there.

With emotions, although we are wired to try to get rid of them, that does not always work. Even when we try to feel less afraid, fear is still present. In these cases, we can practice being open and willing to experience the feelings, without letting them control our lives. In other words, we can do things we are afraid of, and we don't have to use fear as an excuse. Meditation can be helpful for practicing openness to our feelings.

Finally, for social barriers, we can practice negotiating with other people when we are advocating for our needs. For example, when your family goes to a restaurant it may be helpful to be seated in a quiet corner. For this to happen you will express your needs to the hostess. In other situations, you may need to negotiate with more than one person. For example, for your child to hear well in the classroom, you may need to talk with the teacher and the audiologist.

Self-advocacy takes practice. Be patient with yourself and your child as you learn and become more confident using self-advocacy skills.