

Self-Advocacy: Your Voice is Important

By Caitlin Starr

This article contains information from the self-advocacy workbook created by the Maryland Traumatic Brain Injury Project.

Self-advocacy. We hear this phrase a lot when people are looking resources, or when families are looking for help for their loved one who has had a brain injury. So what does that really mean? Self-advocacy is the process of speaking up for yourself and your needs, and, if the situation calls for it, also doing what you need to, to make sure your needs are met (Madison, 2018). Examples of self-advocacy include working with professionals, family members, and loved ones to help make life choices, being able to control your quality of life, and voicing your own wishes and needs. These examples could also be categorized as self-determination. Self-determination is the idea that all individuals deserve to have control over their lives and their futures. People with disabilities are often told they cannot or should not control their own lives, but all people deserve to direct their lives and supports. One way to do this is to learn self-advocacy skills. Developing these skills often requires taking stock of your unique strengths and possible challenges. If you or the people close to you anticipate issues, you can then work on identifying strategies to help navigate those challenges. Self-advocacy can also mean giving support to a cause. Since your experience with brain injury is unique, you have a special opportunity to contribute your knowledge and experience within your community, whether it is at a legislative level, in support groups, or through helping another individual navigate the system you have been through.

But how can something that sounds so simple be so hard?

Post-injury Challenges

It is common for individuals, family, and friends to have never heard of brain injury before their accident, or to believe it is only something that happens to football players. It is becoming more widely known due to celebrities like Tracy Morgan and George Clooney, becoming more open about their injuries. However, after their injury, individuals need to learn how to understand their injury, and the new physical, cognitive, and medical issues that accompany it.

After an individual has sustained a brain injury, the ability to be a self-advocate can become limited. Communicating wants and needs can become difficult, and sometimes impossible, at least temporarily. An individual may have memory problems, be unable to say what they are thinking, or have difficulty to making decisions. In these situations, family members, friends, or attorneys may need to step in to provide assistance with getting connected to services or resources and assisting with communicating wants and needs. Having these individuals step in to help may only be for a short time during the recovery progress. However, once the

recovery process advances, the individual who sustained the injury may need to learn how to advocate for themselves and be more involved in their own recovery.

If people are unable to advocate for themselves in the beginning, a family member or friend may step in to provide assistance. However, stepping in to advocate for an individual can be challenging. Assisting an individual can be difficult if the individual is not able to communicate their wants and needs or if they minimize their deficits. Family members and friends also carry their own views, wants, and needs for the individual, which may not align with what the individual wants. Stepping in as a caregiver can also be challenging for friends and family members who have never fulfilled this role before or have not been in this role for several years.

Having a family member, or friend can also be an issue for an individual who has sustained a brain injury, because family members or friends may not understand brain injury, and believe that a brain injury could heal like a broken bone or a cut. They may not know who to reach out to for resources, or have time dedicated to learning about brain injury. Additional challenges arise when the individual and their family member do not agree on the resources or the services they are attempting to access. If this situation happens, it is time to start the conversation about brain injury, and how it affects you.

How to Talk with Others About Brain Injury

Talking about brain injury can be difficult, especially when the person you are speaking with does not understand. Sometimes, disabilities cannot be seen which causes confusion and misunderstanding on the part of family members, friends, employers, etc. A thing that may help you to explain what you are currently experiencing is providing them with education. Whether it is providing an article, or book that helps explain what you are experiencing, or keeping a personal log of issues that you or a family member are seeing, there are many ways that you can educate the individuals in your life about your injury and how it is affecting you.

Things to consider are the areas you have experienced changes in.

For example:

- Physical Changes
- Energy Level
- Memory Issues
- Judgment
- Performing Tasks
- Anger Management

Another area to consider is how the injury has affected thinking and learning. You may experience a decrease in attention span, concentration, problem solving or planning. Noting any changes will help you understand yourself better, advocate for proper services, and improve your relationships.

Along with changes in thinking and learning, your injury may have affected you emotionally. You may experience changes in your confidence, your motivation to do things you love, or your awareness of your needs. Emotional changes can also be quicker to anger, irritability, changes in social skills, or increased substance use. These changes could make it hard to get along with the people you encounter.

Finally, it is important to know what you need help with. Keeping track of how family members or friends assist you can help you advocate for yourself. Whether it is with planning and organizing activities, making decisions, developing safety and emergency plans, cooking, cleaning, transportation, or assisting you with expressing your wants and needs, knowing where you need help will allow you to ask for it when you need it.

Things to Consider

There are resources that can provide a one pager of information listing your likes, dislikes, what is important to you, what your strengths are, and how best to serve you. Resources like this can be beneficial because you are able to take it to medical appointments, programs, and support groups to show the most effective way to communicate with you and provide you with the help you need. Other strategies to help you advocate would be keeping a journal or a calendar to write down issues that you are seeing, or questions you want answered. This tool can help you keep track and stay on task when you are advocating for yourself.

Self-advocacy is not only for medical settings. You have the potential to change regulations or laws. You may want consider sitting on advisory boards to represent brain injury, or reaching out to your state legislator to educate them about brain injury. People who make laws that affect individuals with disabilities should hear from individuals with disabilities themselves.

Self-advocacy is a skill that needs to constantly be practiced and strengthened. Whether it is letting people know your choice about food or fighting to change legislation, your voice matters. Make it count.

REFERENCES

“A Self-Advocacy Workbook for Individuals with Brain Injury: Starting Points for a Journey.” *The Maryland Traumatic Brain Injury Project*, 2003.

Madison, E. (2018). Self-Advocacy: Definition and Skills. Retrieved from <https://study.com/academy/lesson/self-advocacy-definition-skills.html>

Resources:

<https://factoregon.org/wp-content/uploads/2019/11/blank-onepage-handout.pdf>