

Advocating for Yourself: First Hand Perspective

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Knowing how to self-advocate is useful in a variety of settings, such as with your friends and relatives, at an educational institution, or on the job. How and when you advocate for yourself depends on how open you wish to be about your diagnosis and on how overt your symptoms are. I have written this tip sheet directly to and for people on the spectrum. However, for any parent, professional, or relative reading this, you are welcome to take this advice and adapt it to the people on the spectrum you are involved with.

The following are some general pointers on self-advocacy:

Contrary to the popular perception, you do not necessarily need to disclose your actual diagnosis when you advocate for yourself. Instead, you can just provide a description of the specific behaviours that are relevant to the situation at hand. For example, if a teacher or a friend thinks that you are not listening because you are not looking at them when they talk, you can convey that you tend to pay attention better when you are looking away as visual movement is distracting to you making it difficult to both look and listen.

Although every person discloses differently based on individual preferences and abilities, it is crucial to learn how other successful people on the spectrum have disclosed to get a better idea of how to go about it. The book “Coming Out Asperger: Diagnosis, Disclosure, and Self-Confidence” (edited by Dinah Murray) is a collection of people’s experiences with disclosure, which includes both good and bad experiences to learn from. Another book I recommend, “Ask and Tell: Self-Advocacy and Disclosure for People on the Autism Spectrum” (editor Stephen M. Shore), provides more explicitly practical advice about self-advocacy.

Knowing yourself well is crucial to successful self-advocacy. Although reading literature about other people on the spectrum, especially biographies, can be very helpful in achieving this goal, real-life experience and feedback from others is absolutely necessary. Start off by joining a local group for people with ASD in order to learn about their experiences and to get their feedback on your behaviours. If you receive any feedback that you perceive as “negative”, avoid reacting to it emotionally and just incorporate it into a general picture of what others think of you. Remember, there is no such thing as “good” or “bad”; these are relative terms and are never absolute. As you gather more and more opinions, you will start to see recurring comments. Since so many people have confirmed these comments, they are likely to be the most accurate. Take these comments and think of how you can advocate for yourself accordingly.

In order to self-advocate appropriately, it is also important to know how the non-autistic brain works and how non-autistics perceive you. People, who are older than you, such as your parents or your teachers, are the best sources of honest opinion and advice as they are most likely to tell you the truth about how you present to others, your strengths, and your weaknesses. While it is okay if you don’t want to fit in and conform socially, it is important to understand the non-autistic communication style because you inevitably have to communicate with non-autistics on a regular basis throughout your lifetime. This knowledge will help you understand how you are different and why it can be difficult for you to socialize or to be in certain environments, which is the information you need to self-advocate well. Personally, reading literature about ASD written by non-autistic professionals has helped me understand how non-autistics might perceive

me and react to me. As an added bonus, gaining this knowledge will help you appreciate the commonalities that you share with non-autistic people and will thus help you connect more effectively with all people, whether autistic or non-autistic.

There is a difference between “advocating for yourself” and “making an excuse”. Something is more likely to be perceived as an excuse if it is a very general statement. For example, do not just say you do this and that because you have Asperger’s or autism. When you advocate for yourself, you need to provide a rational explanation as to why you do something, as well as giving a possible solution to the situation. For example, you may know that you have a tendency to be truthful and straight up with everyone about everything. However, people sometimes get angry with you because you said something they perceived as rude and it hurt their feelings. Next time this happens, saying “sorry, I did this because of my Asperger’s/autism” will not suffice, because the person may not even know what Asperger’s/autism is or might be misinformed about it. Instead, it would be more helpful to not even disclose the diagnosis, but say something along the lines of: “I apologize for hurting your feelings. I tend to talk very factually about things and don’t think about how other people might react to what I say, because my emotional response to things tends to be different from other people. However, I did not have the intention to hurt you. For the future, I want you to know that all of my actions toward you are well-intended.”

Having read the above, you might ask: Why should I go through all this trouble to learn how to advocate for myself? Wouldn’t it be easier to try to fit in with everyone else and hope that, someday, you will no longer be autistic? The truth is that, no matter how much you try to fit in, you will still have certain autistic patterns of behaving and thinking, and will thus still have some challenges associated with being on the spectrum. Therefore, you will still need to know how to advocate for yourself if you hope to be successful at reaching the goals you have set out for yourself. Even though you are autistic, you can still do well in life due to the strengths that come with being on the spectrum, but learning self-advocacy skills will be one of your keys to success. While the above points are the general ways you can get better

at self-advocating, how you advocate for yourself properly varies across situations. Here are some scenario-specific guidelines for self-advocating:

With family and friends:

Give them some in-depth information about autism/Asperger’s to read through before you begin to bring up specific things about you that you want them to understand. You have a close enough relationship with these people to be able to have them spend extended periods of time researching about the condition. The people who are not as close to you, like co-workers or teachers, will not have the same commitment to improving your life as they are busy and have a lot of other work to do/clients to serve. It is also not part of their responsibility to provide you with extensive attention.

At school/college/university:

If you need any additional accommodations to the ones you are getting through disability services or as part of your IEP, you need to be proactive. I believe that anything you might have difficulty, with which could surface in the curriculum, needs to be addressed within the first week of class, preferably during the first class. If you have difficulty with group work, for example, you need to ask your instructor whether there will be any group work happening in this class. You will also need to tell the instructor that group work tends to be difficult for you because of your communication struggles and ask how the instructor could possibly accommodate for this. The curriculum sometimes changes throughout the year, so the instructor will need to know about any and all accommodations that you might need. Also, if you are still in grade school and are not satisfied with your school environment, make sure you attend your IEP meetings and let your needs be known. You need to go to school and it is up to you to make it a stimulating, interesting learning experience.

At work:

When advocating for yourself at work, the most important part is to explain what specific accommodations can help you when solving any challenges. People at work are very

busy and need to get their work done no matter what. Therefore, if you have difficulty with any of the work you are given, you need to provide specific information as to how the employer can accommodate for you. That way, the employer is less likely to get annoyed with you because you have shown that you are still capable of doing the work despite your challenges.

Remember to always put an emphasis on your strengths and to take on responsibilities that make the most use of your abilities, not disabilities. Proper self-advocacy will allow your challenges to not appear strange or annoying to others. This will allow people to pay more attention to what you can do as opposed to trying to figure out ways to accommodate you. Additionally, knowing how to advocate for yourself will show others that you are responsible, aware of your own behaviours, can speak up for yourself, and have the capacity to problem-solve well. These are all important life-skills to learn and will help you on your path to success.

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