The ABC’s of Basic Advocacy and Negotiation skills

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What is Advocacy?

Advocacy generally refers to the process of trying to persuade others to support your position or point of view. It can take place in many contexts, both formal (such as in an IEP meeting, in a courtroom, or on Capitol Hill) and informal (such as when a teenager makes a case to his parents to be allowed to stay out late).

The Importance of Advocacy

Advocacy is essential for a variety of reasons. First, while we may think our concerns are or should be obvious, frequently that is not the case. It is essential that you communicate your concerns and your desired solutions. For example, your child’s school may not recognize that you are unhappy with his progress or that there are ongoing behavioral issues at home that are not being addressed in his educational program. It is important to make your concerns known because if not than an understaffed school district could be unaware of them or avoid addressing them altogether.

As a parent, you are very likely the one primarily responsible for securing your child’s future. As a result, it is necessary for you to be proactive in ensuring that his needs are met within the family, in school and ultimately, in the community. It is likely that at some point you will need to advocate on his behalf for services, support and acceptance.

Finally, it is also extremely important that your child learn to advocate for himself, by developing self-advocacy skills. Depending on his age and ability, this can mean anything from communicating his preferences in the home (e.g., letting you know he’d rather have an apple than an orange for a snack) to letting an employer know that he needs a reasonable workplace accommodation (e.g., a change in workspace lighting).
Why Teach Advocacy Skills

It is important to look at advocacy as a process. It is not sufficient simply to present your wishes or “demands” or to be knowledgeable about and invoke your rights. Of course, it is important to be well informed and understand your rights and entitlements. However, it is also important to get others to acknowledge and adhere to them. You want to be strategic in your advocacy. You ultimately want either to enlist that party in working with you to meet your goal, or let them understand that you will be persistent and insistent in asserting your rights.

It is also important to know that the advocacy process doesn’t need to be confrontational. Of course, there are times when you may need to assert your rights more forcefully or even seek the help of a professional advocate. But your goal should be to get others to support your position. This is especially true if you will have an ongoing and hopefully collaborative and constructive relationship with them.

There are specific steps in the advocacy process that you can learn and that will help you be more effective in your advocacy. This tool kit will focus on helping you develop those skills. The goal is to provide insights and perspectives on the advocacy process, so that you can learn to formulate your own strategies about how best to pursue your goals, solve problems, resolve conflicts and achieve positive outcomes.

Teaching Basic Advocacy Skills

It is helpful to think about the advocacy process as a series of steps that can be taught and learned. Most of those steps relate to preparation. Before you even begin to “advocate,” you will want to have determined your goal, thought about how you will proceed, and developed a plan.

Steps:

1. Identify the goal of your advocacy.
   a. What are you hoping to accomplish?
   b. What are some acceptable outcomes?

2. Develop a plan or strategy.
   a. What facts and arguments support your position?
   b. If relevant, what rights do you have, what laws apply, what resources exist or what benefits or services are you entitled to?

3. Consider the perspective of the party to whom you are advocating.
   a. Anticipate and understand their positions and their arguments.
   b. How might you counter those arguments?

1. For this discussion I am indebted to Betsy Krebs and Paul Pitcoff, my former colleagues and founders of Youth Advocacy Center and authors of On Your Own as a Young Adult: Self-Advocacy Case Studies and On Your Own as a Young Adult: Facilitator’s Guide, (JIST Publishing, Inc., 2006).
4. Be aware of emotions – on all sides.
   a. Your advocacy should be rational. It is important to avoid being governed by emotion and to avoid making your advocacy personal.
   b. The other party may be governed by emotion. It is important that they understand that your advocacy is based on rational considerations and is not personal to them.

5. Understand to whom you are advocating and to whom you ultimately need to advocate.
   a. Does the person you are addressing have the authority to grant your request or resolve your situation?
   b. What constraints does s/he face?

6. Present your “case.”

7. Consider possible resolutions that might be acceptable to all parties.

**Reviewing the Steps**

Consider the scenario mentioned earlier in which your child is not progressing satisfactorily in his school and continues to engage in problematic behaviors at home that you feel are not being adequately addressed. While you feel the staff has been conscientious, you believe that they lack the expertise necessary to help your child and that the services he is receiving are not sufficiently intensive. As a result, you request a meeting with the school team to discuss his program.

1. The first step in the process is for you to **identify your goal**. Of course, your goal as a parent is to attain the best possible outcomes for your child. But what is the point of your meeting? What are you hoping to achieve through this process? Perhaps there is a program in a neighboring school district that you feel would be perfect for your child; placement there would be your ideal outcome. Are there other outcomes that are acceptable? Perhaps additional hours of home ABA therapy would also suffice.

2. You then need to **devise your plan**. What evidence can you gather to support your view – i.e., to demonstrate to the team that there is a continuing problem? What is your child entitled to? How will you demonstrate that his current educational program is not appropriate?

3. and 4. In preparing for the meeting, **consider the perspective of the other party**, in this case, the members of the team. You may have several goals: you want them to support your request for a new placement or at least for additional services. You also want to preserve a good working relationship with them, if possible, especially if they will continue to play a role in your child’s education. If they have been conscientious and dedicated to your child’s education, they may take personally your request to move your child out of district and view it as criticism of them personally or professionally. That is, their reaction may be based on their feelings and emotions. The school district itself may be concerned about its budget, payments to another district, or setting a precedent and opening the floodgates to requests that it can’t accommodate. All of these factors may shape the response you encounter.

   The perspective of the other party, or the possible personal reaction to your advocacy, will not necessarily shape your goals. However, it should shape your strategy. You need to be mindful of both the legitimate
concerns and the feelings of the other side and plan your approach accordingly. For example, in this scenario, you want the school team on your side, especially if your child ends up remaining in the school district or classroom. To ensure an ongoing cooperative relationship, you might plan your pitch to ensure that you praise them and make clear your concerns are not personal to them.

5. You are bringing your concerns to your child’s teacher and school principal. But are they empowered to grant your request? If you are advocating to someone who lacks sufficient authority, no matter how hard you press – and regardless of whether they are sympathetic to your position – they will be unable to grant your request. Arguing won’t accomplish your goal and may wind up creating an adversary. In this scenario, the school team may require consent from the district superintendent. The goal of your advocacy with the team might then be to get them to support you in bringing your request to the district level – to make them allies and not opponents. Think back to step 3 and remember their perspective as you plan your advocacy. They may want to help, but they may also face certain constraints – e.g., state budgetary mandates or career concerns if it appears that they cannot adequately serve your child.

6. After thinking about your strategy, you attend the meeting at the school and let them know your concerns and your point of view. That is, you present your case.

7. In some cases, your goal will be absolute. Your child may be entitled to certain services as a matter of right and you will ensure that they are provided. In many cases though, there may be a number of possible resolutions. In this scenario, your ideal goal may be that perfect out-of-district placement. But are there other resolutions that might provide an appropriate education? Perhaps additional hours of ABA home therapy will be sufficient. In your advocacy, you should be open to and anticipate other resolutions that may be acceptable to all parties.

A Word about Negotiation

While advocacy and negotiation go hand-in-hand, it is important to remember that the processes are distinguishable. When advocating, you are usually trying to convince the other party of the merits of your position. But in a negotiation, all parties have a stake and are generally trying to work toward a mutually acceptable agreement. When negotiating, both parties engage in discussion and bargaining, with the goal of reaching a settlement or compromise.

Becoming an Advocate for Your Child

When your child was given a diagnosis of autism spectrum disorder, you were probably introduced to a world you never imagined, full of alien terms and acronyms (e.g. ASD, ABA, IEP, SLP, BIP, etc.). As a parent, you need to be able to navigate multiple bureaucracies (e.g. healthcare, educational, insurance, state office of disabilities, etc.). You need to be sure that your child is receiving the services to which he is currently entitled, and that you are pursuing all the services for which he may be eligible both now and in the future. You need to be able to speak up for his needs, ideally without alienating those who work with him and with you. You want to be sure that your perspective is heard, respected, and taken into account. Even if the school district, the doctor, or the social worker is well meaning, they may not be aware of your concerns and may have limited resources with which to address them. Nobody can look out for your child’s welfare as effectively as you can. You can’t afford to be passive, and must be assertive in getting answers to your questions, seeing that your child’s needs are met, and gaining the best possible outcomes for your child. In short, you will need to advocate.
Becoming a Self-Advocate

Like anyone else, individuals with autism need to be able to speak up for themselves in order to obtain the help and support of others. In other words, they need to develop and use self-advocacy skills to whatever extent they are able.

As in any advocacy situation, an individual with ASD will begin his self-advocacy with some type of goal based on what he wants or needs. For one person, this may mean letting a parent know which videos he wants to watch, which clothes he prefers to wear or that he doesn’t want to wear a hat, through ways such as words, gestures or behaviors. For another, it may mean convincing a prospective employer to hire him or requesting a particular change or accommodation in the workplace.

Sometimes, communicating the goal may pose a significant challenge for a person with autism. First, he has to recognize that the other person may not know or understand what he needs and therefore that explicit communication is necessary. He must also have an effective means of communicating, verbally or otherwise. Asserting himself in this way is the first step, and in many cases may lead directly to his desired result. In the examples above, he may choose the movie he watches or the clothes he wears (and may even get away without wearing the hat).

Some people with autism who is less severely affected may be able to learn more sophisticated self-advocacy skills and use them in more complex situations. It may be his goal, for example, to obtain a particular job. With this goal in mind, he can, perhaps with coaching, think about the arguments in his favor and devise a plan. He will demonstrate to the potential employer that he has the necessary skills and qualifications for the job. He will explain that although he may initially need a very detailed explanation of each assigned task, with very literal, step-by-step instructions, once he masters a task he will do it correctly each time with great accuracy and focus.

As a self-advocate, a person with autism will also need to take into account the perspective of the other side. The very nature of autism spectrum disorder can make this inherently challenging. For example, suppose the job applicant in the previous paragraph is successful. He begins work, but soon finds that he needs an accommodation: he needs to be in a quiet area of the office, away from many of his co-workers and the copy machine, because he doesn’t respond well to noise. He may need to advocate on two fronts. Knowing his rights, he asks his employer to change his work station, explaining that this will enable him to work without distraction. She readily agrees. Now, he may also want to advocate to his co-workers. He should consider how his colleagues might interpret his behavior. Perhaps he doesn’t laugh at their jokes or join in their conversation and now has asked to be isolated from them. In this case, his goal is to ensure that he has a successful professional relationship with his colleagues. He may want to explain to them that he has autism, and that while he sits away from them and may not get their jokes, it is not meant to be unfriendly or taken personally. In this scenario, our employee has made his needs known and advocated with his boss for an accommodation and with his coworkers for understanding.
Of course, to the extent that self-advocacy is about speaking up for yourself, your wants and your needs, it is also about making your own choices. Thus, it is important for a self-advocate to develop decision-making skills. If he is going to make his own choices, then he needs to be able to think critically about his decisions and their potential consequences. Of course, the negative consequences of some potential “wrong” decisions may be minor and far outweighed by the individual’s desire for personal autonomy and self-expression.

In other situations though, it is more important to examine the consequences of a choice. Choosing what to wear is a very basic form of individual expression. However, it is necessary to consider the circumstances and appropriateness of a potential choice. To the extent that he is capable, again perhaps with coaching, the individual with autism may explore the possible outcomes. What might other people be wearing? How might other people react to his choice? Will his outfit generate unwanted and negative attention? Will the choice of a particular outfit be interpreted as disrespectful? While this is a relatively simple scenario, it illustrates the need for a self-advocate to learn to think critically about his decision-making if he is going to assert himself with respect to more fundamental and essentially adult decisions. A parent or coach can help in the decision-making process by asking the kinds of questions that might help the individual with ASD to explore the possible consequences of a particular choice.