



## Guide to Autism Advocacy





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# About This Kit

The goal of this tool kit is to provide a basic knowledge of advocacy and negotiation skills. The kit will show how to apply these skills to different situations throughout the lifespan of an individual with autism. The information in this kit has been provided by experts in the field who have both professional and personal experience with advocacy and autism. Each section has been prepared by a different person or group of people whose expertise is in that specific area. We hope you will find the information informative and relatable.

■ The **blue text** indicates a link that you can click on for additional information.





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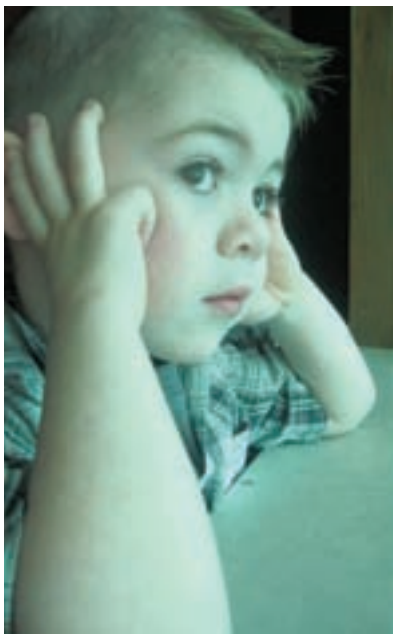


# The ABC's of Basic Advocacy and Negotiation skills

*This section was prepared by Ann Shalof, a nonprofit professional focused on youth advocacy and empowerment. Most recently, as Associate Director of Youth Advocacy Center, she worked to advance the teaching of self-advocacy skills to older teens and young adults involved in the foster care system or otherwise at risk as they prepare to transition to independence. A graduate of Harvard Law School, Ann joined YAC after a career in business, as owner and Chief Executive Officer of Allerton Press, Inc., and prior to that practiced law in New York. Her teenaged nephew has autism and is a student at REED Academy in Oakland, NJ.*

## 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<sup>1</sup>

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.



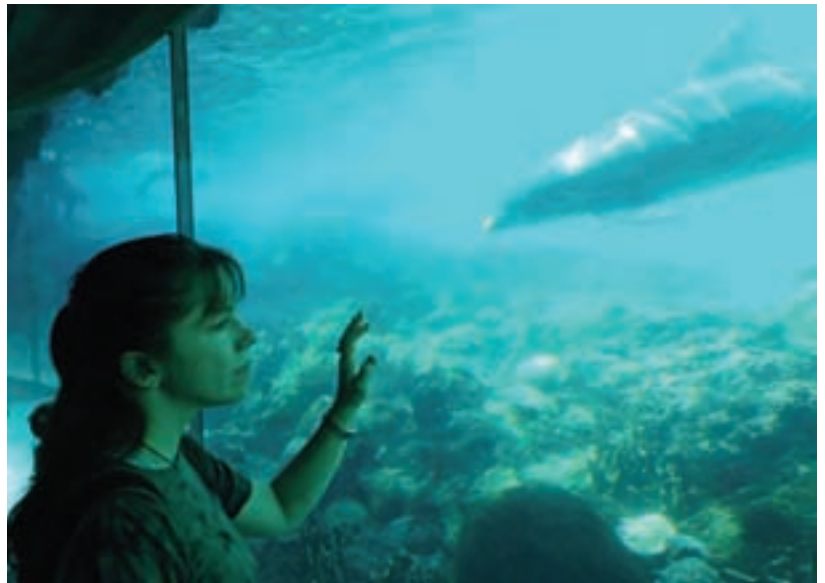




## Becoming a Self-Advocate

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.

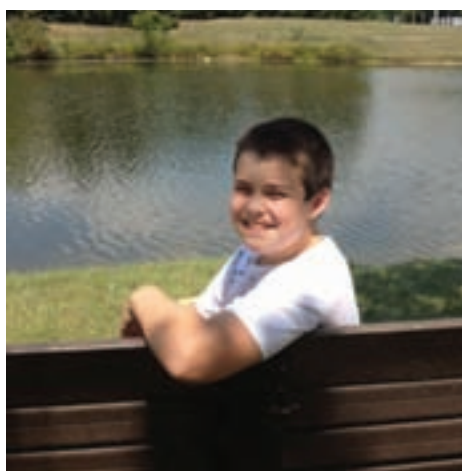
As a self-advocate, a person with autism will also need to take into account the perspective of the other side. The very nature of autism spectrum disorder can make this inherently challenging. For example, suppose the job applicant in the previous paragraph is successful. He begins work, but soon finds 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.





# Learning the Skills

In order to learn how to best apply the skills in the previous section, we are going to include examples throughout the kit based on the family described below. Using these examples we will highlight the important skills and how you might use them in real life situations.

*Bob and Kate Smith have three children. Their oldest son is Jason he is 19 and neurotypical. Their middle child is Christopher he 16 and on the autism spectrum. Christopher is verbal and in a mainstream classroom but has difficulty in social situations. The youngest child, Sara, is 13 and on the spectrum as well. She has limited verbal abilities and is in a self-contained classroom. Both Bob and Kate have been very involved in advocating for their children's education and wellbeing. As they are getting older and transitioning Bob and Kate are working on teaching self-advocacy skills to their children.*

## Family Advocacy

*This section was prepared by Liane Kupferberg Carter, a journalist whose articles and essays have appeared in many publications, including the [New York Times](#), the [Chicago Tribune](#), the [Huffington Post](#), [Babble](#), [Parents Magazine](#), [Autism Spectrum News](#), and [The Thinking Person's Guide to Autism](#). She writes a monthly column for [Autism After 16](#). Liane is the mother of two adult sons, one of whom has autism. As a community activist, she co-founded the special education PTA in her school district, as well as the town's sports league for children with special needs, and co-authored a parent resource handbook for the school system. As a member of the Autism Speaks' Parent Advisory Committee, she helped review the [Transition Tool Kit](#). She has also served on the Stakeholder Board of the Autism Science Foundation, and has reviewed grants for both organizations.*

When a family member is diagnosed with a developmental disability such as autism, every person in that family is affected. Emotions can run high. Initially, families often experience sadness, anger, disappointment, or other complex emotions. Parents, siblings, grandparents, and extended family will each have their own complicated reactions. Your loved one with autism will have lifelong relationships with other family members, so you will need to develop strong foundations from the start. It helps to remember that raising all children, not only those with autism, is a marathon, not a sprint. A diagnosis of autism isn't usually a medical crisis, but it is a new way of life. You will need to advocate for your child in many areas of his life, but first and foremost you will need to do so in the family arena.





## Roles within the Family

Whether it is allowing additional time for your child with autism to make transitions, or having to cut short some family outings, your family will learn to adapt and adjust. Your first order of business is to provide a safe, loving environment for your immediate family. That means respecting everyone's needs. To make it happen, you will need to advocate for everyone's needs within the family. Every child deserves attention and care, not just the one with autism. It can be a big adjustment for a sibling to accept that a brother or sister has autism.

- Talk to your children in clear and age-appropriate terms about what it means for their sibling to have autism.
- Let them know what to expect. Be honest about the challenges, but be certain to talk about your child's many strengths. Let your children see how much you love their sibling with autism for who he is.
- Let your children express the full range of their feelings, in their own words – their disappointments, embarrassment, jealousy, fear, or anger.
- Let them ask questions, and listen without judging or censoring.
- Offer reassurance. Let them know that these feelings are normal, and that the lines of communication are always open.
- Encourage your children to find ways to relate to their sibling with autism. Help them find activities they can share.
- Try not to cancel vacations or family celebrations. There are many activities you can still enjoy as a family, with some accommodations, such as planning outings during quieter times of day. This may not always be possible; if so, don't insist your family include a disruptive child on every outing.
- Give each child one-on-one time with each parent. A child with special needs often gets the lion's share of attention in a family, and other children may feel resentment. Make time every week to do something with your other children that they especially enjoy.
- Consider therapeutic ways to support family members -- a guidance counselor, a therapist, a sibling support group.
- Remember your children will sometimes encounter stares, comments, or questions about their sibling. They may be embarrassed by their sibling's behavior, and hesitate to have friends over. Teach them to answer questions directly by modeling appropriate responses. Every time you explain your child's behavior to an outsider, you can be sure your other children are listening. Give them the language they will need.
- Teach them to advocate for their own needs by speaking up, and take their complaints seriously.
- As they grow, keep them engaged in the ongoing dialogue about their sibling's future needs. Your children have a right to their own lives, and to decide on the level of involvement they will someday have.
- Advocate for your own needs, too.
- Above all, pace yourself. If you burn out, you're not going to be able to help anyone.
- Consider joining a parent advocacy group in your community. It can be enormously empowering to see how other or more experienced parents advocate for their children.
- Ask for support when you need it. We're all familiar with the adage that it takes a village to raise any child. Over time you will find yours.







## Disclosure to Extended Family

How – or should – you reveal your child’s diagnosis to extended family members? If your child is older and/or understands his diagnosis, it is imperative that you take his feelings into consideration first and get his permission to share his diagnosis, or any of the details related to it.

### Some Things to Take Into Account:

- How often do you see that family member? Does he/she have daily or frequent contact with you and your family, or is this someone you rarely see? What is the relationship like with you? Your child?
- If you do share, how much should you tell? How much do you want to get him/her involved?
- What reaction do you anticipate? Acceptance? Ignorance? Discomfort? Disbelief? How will you handle those reactions? Be prepared for a range of gratuitous advice and responses. Some of them may possibly be hurtful to you.

When you disclose your child’s diagnosis, be calm, clear, and concise. You could say, *“Joey doesn’t act the way he does because he’s spoiled or defiant. He isn’t misbehaving. He acts that way because he has autism. His brain is wired differently. Autism makes it harder for him to speak and understand other people, which is why he sometimes needs to do things in a different way than other children his age.”*

Keep it positive. Point out, *“People come in all shapes and sizes, and Joey has strengths and challenges just like anyone else. He learns differently, but he’s smart and good at lots of things.”* For example, you might say:

- *“Joey doesn’t talk much, but he has a good sense of humor.”*
- *“Conversations can be challenging for him, but he is really good with computers.”*
- *“It’s difficult for him to play board games, but he’s great at drawing pictures.”*
- *“Parties can be hard because he gets overwhelmed when people sing the happy birthday song, but he really enjoys sitting at the table to share the birthday cake.”*

Sometimes people will overcompensate because they feel uncomfortable, or express opinions or feelings you don’t want to hear. Sometimes family members may refuse to acknowledge your child has special needs. Or they may blame your parenting for producing a disobedient/defiant/stubborn child. Others, in their wish to be helpful, may push the latest “cure” they’ve read about on you, or try to make you feel guilty if you don’t take their advice. Some family members may even try to exclude you or your child, suggesting that you leave that child at home “for your own comfort.”

Any or all of these reactions can be quite painful. Try to remember that much of these behaviors are based on ignorance. The best way to counter these attitudes is to provide as much objective information as possible. You are an expert on your child. The more you educate your extended family about your child, the better they will understand your and his needs. Provide articles, books and videos. Speak up about your child’s strengths and accomplishments. Offer suggestions on what your child likes, and how to best communicate with him. Above all, be sure you project sensitivity, respect, and unconditional love for your child. Family members will take their cues from you.







# Speaking Up for your Needs and Desires within the Family

Families of individuals with autism need support and understanding, but it can be hard to ask for those things. You may feel as if your requests are inconvenient or annoying to others, but in reality, voicing your needs will make things go more smoothly for everyone. For example, people with autism often have sensory processing issues that make it difficult or even impossible to attend family gatherings. Holidays, with all their attendant commotion, can be particularly tough. People with autism may find it hard to sit still at the table, or keep quiet during a religious ceremony; they may dislike being surrounded by unfamiliar people, find new foods aversive, or not easily tolerate changes in schedule.

You are probably all too aware of how others may act regarding your child, and feel fiercely protective. It's anxiety-producing to know that your child may not be able to meet certain expectations of behavior. But there are many concrete things you can advocate for that will avert meltdowns, and make your child, you, and the extended family more comfortable:

- Prepare before an event. Politely and firmly explain to family members that your child may not do well with changes in schedule, or have difficulties tolerating certain things such as noise, different foods, party clothing, crowds, and unfamiliar people. Be clear about what your child can and can't tolerate. For example, let them know if your child doesn't like to be hugged or kissed, but that he welcomes a high five or handshake.
- Whether it is a food allergy, sensitivity or sensory issue, share information about your child's dietary needs/restrictions. Offer to bring something you know your child will eat. If you think your hosts may be offended, you can always reassure them that it is not a reflection on their cooking.
- Just as many children with autism have food issues, a significant number of individuals on the spectrum have seizures (the current estimate is about 30%). If there are specific things that trigger seizures for your child – flashing lights or loud television, for example – be proactive. Alert your hosts before you arrive, and provide information on basic protocol for handling a seizure.
- When you know other children will be present at an event, offer to give their parents age appropriate tools so that they can explain autism to their own kids before your family arrives.
- Ask for a quiet room or space your child can retreat to during family events when he needs to get away from all the tumult.
- Be clear with your child about what to expect at family gatherings. Explain the schedule of events, or create a visual schedule, being sure to include when you will leave. Give adequate warning before changes, i.e. in 5 minutes you will need to wash your hands for dinner; when this video ends it will be time to leave. Let your child control as much as he can.
- Arrive early so your child can adjust to the environment before the room fills up.
- Be sure to bring whatever your child needs to feel comfortable – videos, books, photos, favorite toys, noise-cancelling headphones, electronic games, tablets, communication devices, etc.
- If you and your spouse think you may need to leave early with your child, consider taking two cars.





*The Smith family will be traveling for the holidays this year. Kate has some anxiety about doing this since she usually hosts the holiday party at their house and can control the environment. Before going Kate calls her cousins and explains that Sara has some difficulty when spaces become very crowded and loud. That nobody should be offended if Sara gets up abruptly or needs to leave. It's really that she needs to calm herself down and wait for some of the commotion to subside.*

*Kate also lets Sara know that it may be loud while they are there and if she is feeling uncomfortable she needs to be able to speak up and say that she needs to excuse herself. Sara will be bringing her iPad which helps her to communicate and will make these situations easier.*

## Disagreeing with your Parents/Loved Ones

You're trying to find a happy medium between getting your child's needs met and respecting the rights and feelings of other family members. It's important to remember the difference between advocacy and negotiation. Always take into account the feelings of the other person and try to see his point of view, but remember that **you** are the expert on your child. You know your child's needs better than anyone. Your child may not be able to ask for what he needs yet, but you can. Remember the saying "You catch more flies with honey than with vinegar." White knuckle confrontation accomplishes little. Be clear about your child's needs, but try to stay calm and cordial. Think of your extended family as a team working toward a common goal: ensuring your child's emotional well-being.



*Recently Bob and Kate were discussing the week's plans with their children. They noticed that Chris was very upset. He immediately went to go to his room and get away from the situation. Bob and Kate decided to go after him and find out what was wrong. They soon realized that he was no longer interested in some activities they had him involved in. Bob and Kate discussed with Chris that it's important for him to speak up for his needs and tell them his opinions and ideas. Together they worked on finding some new activities with Chris' guidance.*

If you need to disagree and do so effectively, you will need to learn how to pick your battles. Some situations just aren't worth taking on. What is really worth fighting about, or for? What is your goal or desired outcome? Do you have a plan to achieve it? Complaining doesn't help; being solution-oriented does.

If family members object to a particular behavior of your child, ask yourself: is that behavior in some way harmful to your child or others? Does the behavior prevent your child from learning and moving forward, or is it simply quirky or different? For example, if your child's rocking, hair twirling or talking to himself distresses a family member, you could explain that it is simply a self-soothing behavior. Your role as your child's advocate is to do whatever you need to make situations easier and more comfortable for him.





## Include the Individual with Autism in Certain Decisions

Some individuals with autism can verbally communicate their goals and desires while others may have difficulties with communication skills. As your family member with autism ages, he will need to learn how to assess problems, speak up and ask for what he needs, know his rights and how to negotiate. Part of this may involve learning if or when to disclose his diagnosis. If he has the cognitive ability to understand, talk to him about autism. The more comfortable and open you are with the diagnosis, the more comfortable your child will be. Don't downplay the challenges, but focus on his strengths, and assure your child that the entire family is behind him to offer love and support.



The skills you will use to advocate for your child now will be the same ones you will need to teach to your child as he grows so that he can become his own advocate as much as he is able to. He will need to communicate his needs and desires – from simple things such as telling others what he wants to eat or that he is in pain, to handling a range of real life situations that will require more sophisticated skills, such as how to ask a noisy roommate to be quieter. It helps to role play different scenarios. You could ask him, “*What could you do if your friend's radio is too loud?*” Teach him to identify options and desired outcomes; help him formulate such appropriate responses as “*I'm sensitive to loud noise and your music is hurting my ears, could you please turn down the radio?*” Your goal is to give him the skills that will someday enable him to advocate for his own needs to the best of his ability, in a work, community, or residential environment.

Teaching your child self-advocacy is as important as advocating on his behalf. It is never too early to start learning these skills. You will also find it helpful to reach out to adults with autism to learn about self-advocacy. Read their blogs; subscribe to their feeds on Facebook for important and unique insights only they can provide. If your child is cognitively able, he will need to know how to talk about his autism and how/if to disclose his diagnosis to others. Help him identify times and situations in his life where he can use these skills. The better your child learns to express himself and communicate with the people around him, the better he will someday be able to advocate for himself, cope with sensory problems and anxiety, and navigate the world outside the family.

Learning these skills is a lifelong process, and your child will do best when everyone involved works to give him as much independence, self-advocacy and negotiating skills as possible. Parents/guardians are in the best position to help children develop these skills. Model self-advocacy, and trust that as you find your voice, you will be able to help your child find his. The skills you teach him today will empower him for the rest of his life.

*Chris has been invited to spend a weekend away with his friend's family. This will be the first time Chris is away from his family in totally new surroundings. Before leaving Bob sits down with him to give him some strategies on how to advocate for himself if he feels uncomfortable. For instance, if everyone is going out to dinner and Chris' order comes and it's wrong, Chris needs to tell the waiter “I'm sorry but this isn't how I ordered my hamburger”. Bob explains to Chris that being able to self-advocate can be as simple as this and he shouldn't be afraid to speak up. Learning a few of these skills is helping Chris to feel more comfortable in situations where he is more independent and away from his family.*





# School Advocacy

This section was prepared by the following:

*Mark Woodsmall is the founder of Woodsmall Law Group, PC a law firm based in the Los Angeles area. The firm practices exclusively in the areas of Special Education, Regional Center Matters, Special Needs Trust Planning and Conservatorship. In 2006 Mr. Woodsmall joined the Faculty of the USC Gould School of Law as a Professor Adjunct, teaching in the area of special education law. He also serves as the teaching attorney in the Special Education Advocacy Training Project – Los Angeles. The SEAT Project, an innovative nationwide advocacy training project, is funded under grant from the US Department of Education and administered through COPAA, The Council of Parent Attorneys & Advocates and the USC Center for Excellence in Developmental Disabilities (Children's Hospital Los Angeles). In 2012, Mr. Woodsmall presented at the COPPA (National Organization of Parent Attorneys) national conference in Miami. He is an invited speaker at the 2013 conference.*



*Mr. Woodsmall sits on the UCLA Center for Autism Research & Treatment (CART) Community Advisory Committee. In 2012 Mr. Woodsmall received the prestigious National Ambassador Award from Casa Colina. He has been an active volunteer with Cure Autism Now/Autism Speaks, serving on the National and Los Angeles Walk Planning Committees and Government Relations Committee. In 2008 he was named to the Board of Autism Speaks – Los Angeles. He currently serves as its Chair.*

*Shima Kalaei joined Woodsmall Law Group as an associate attorney in August 2010. Ms. Kalaei earned her Bachelor of Arts in Psychology from the University of California, Berkeley in 2005 and her Juris Doctorate, cum laude, from Thomas Jefferson School of Law in 2009.*

*Ms. Kalaei's passion in serving children with disabilities is driven by her experiences growing up with her younger brother, who has autism. Throughout college and law school, Ms. Kalaei dedicated her time to assisting children with disabilities. Ms. Kalaei worked as a research assistant at the Institute of Human Development at UC Berkeley, where she tracked case studies of students with ADHD and their social, behavioral, emotional and educational development. During law school, she interned for the Special Education Project at The Alliance for Children's Rights, where she advocated for foster children in obtaining special education services. Ms. Kalaei also served as a Notes Editor for the Thomas Jefferson Law Review. Ms. Kalaei's own law review publication proposes new legislation to overcome inadequacies in the education of students with autism by better coordinating the No Child Left Behind Act with the Individuals with Disabilities Education Act.*

*Lindsay Vose joined Woodsmall Law Group, P.C. in February 2012. Ms. Vose earned her Bachelor of Arts in Sociology from the University of California, Los Angeles in 2006 and her Juris Doctorate from Pepperdine University School of Law in 2011.*







*Ms. Vose has long had a passion for helping children with disabilities. Her passion was fueled in large part by her experience growing up with a childhood friend who has autism and watching the struggle he and his family faced with his educational difficulties. Throughout college and law school Ms. Vose devoted her time to various non-profit organizations that served children with disabilities. During the summer of 2009, Ms. Vose interned for the Garden of Hope, a non-profit organization located in Chiang Mai, Thailand that provides services to children who have been victims, or at risk of becoming victims, of human trafficking. This experience furthered her desire to help children, in particular those with special needs. Thereafter, Ms. Vose took an intensive course in special education law in which she had the opportunity to gain experience in the IEP and due process procedures. She also wrote an extensive article for the National Association of Administrative Law Judges Journal on special education law on the topic of how the Individuals with Disabilities Education Act changed the reimbursement process for parents of children with disabilities.*

*Mark Ohl joined Woodsmall Law Group as an associate attorney in November 2012. Mr. Ohl earned his Bachelor of Arts in Political Science from the University of Utah in 2007 and his Juris Doctorate from the University of Southern California, Gould School of Law in 2011.*

*Mr. Ohl's passion in serving children with disabilities has been driven by his experiences growing up with his younger sister, who has Sturge-Weber syndrome. He grew up in Park City, Utah, where he volunteered with the National Ability Center, working with individuals with both physical and developmental disabilities to access recreational opportunities which are otherwise unavailable or inaccessible to individuals with special needs. Mr. Ohl previously worked as a graduate research assistant with a law professor at the University of Southern California. His legal experience also includes an in-house legal internship at Snail Games USA and volunteer work with the San Diego County District Attorney's Office.*

## Starting the Process

Special education exists to address the unique needs of a child that result from a disability, and to assure that students with disabilities receive all needed aids and services. Special education laws and regulations are meant to protect a student with disabilities and ensure that he or she gets the services and assistance that may be necessary to make effective progress. No doubt, you are concerned about how your child is doing in school, and beginning to realize that this system of laws and protections can be amazingly complex. This section will help you understand the key concepts of the law and how to be an effective participant in the special education process.

## The Evaluation Process

Before your child can begin receiving special education services he or she must be deemed eligible for an IEP (Individualized Education Program). The first step in determining eligibility is a thorough evaluation in all areas of known or suspected need.

Evaluations, also called assessments in some states, provide valuable information regarding the nature and extent of your child's disability as well as the impact the condition may have on his or her education.

Evaluations should be conducted by highly trained diagnosticians and therapists utilizing a combination of standardized testing, documented observation, parent and teacher questionnaires and past reports if any. The findings of the evaluator should be presented in a formal report which is made available for use by the IEP team. The strengths and weaknesses identified through this process form the basis for your child's present levels of performance, or your child's baseline of functioning in each area of evaluation.







## Why Are Evaluations So Important?

Evaluations identify the nature and extent of your child's disability. They will help identify your child's areas of strength and weakness. If he or she is found eligible for special education with a qualifying condition under the federal Individuals with Disabilities Education Act (IDEA), goals must then be written to assist your child in overcoming the identified problem areas. The evaluations will provide a starting place from which the progress towards the annual goals is measured. The determination of whether the district is offering your child an appropriate education depends on your child's progress throughout the year. If the baseline or starting data is artificially low for the child's ability, the district will likely be able to show that your child made some progress and therefore meet its burden under the law.

## How Often Can I Expect Evaluations Occur?

Your school district must initiate its initial assessment (for children with known disabilities) before the age of three. After these initial evaluations, the district will conduct, with very limited exception, a thorough re-assessment of the child every three years thereafter. This reassessment process, commonly referred to as a triannual or triannual review, can often be as important as the initial review. The findings provide information on the child's current strengths and needs, and can often be used as a possible basis to limit or even terminate services and sometimes even eligibility for special education.

The three year evaluation cycle is the minimum that must be done. In reality, given the complexities of child development, the dynamic nature of therapy, etc., it may be necessary to conduct assessments more frequently. With the latest version (reauthorization) of the IDEA, the district may now be asked to conduct a new evaluation one time per year.

## I Believe That My Child Needs Special Education or Specialized Educational Services: How Can I Request An Evaluation?

An evaluation may be requested by the parent, the school district, or other state agency. However, most requests for evaluation originate from the parent. Once a request has been made, an assessment plan must be made available for parent review and consent. The parents, as equal participants in this process, may request that the plan be expanded to cover additional areas of assessment or contracted if it covers inappropriate or unduly limited areas. If you are not sure, ask questions. The school district's team is charged with helping you access this system. Once you and the school district's team have arrived at a final and complete plan, you will be asked to sign and return the document. The district then has a limited time, generally 60 days from the date that the plan is approved by the parent, certain vacation periods exempted, to complete the agreed assessments and hold an IEP meeting to consider the findings. Make sure that you keep a copy of the final version of the signed assessment plan together with proof of the date that you returned it to the district. In special education, dates are very important as they directly impact your child's rights under the law.

Because of the numerous timelines involved, we suggest that parents put their request for an assessment and subsequent signed assessment plan in writing, dated and faxed with confirmation, to the district personally. We also suggest that families consider adding the following sentence somewhere on the face of the assessment plan: *"Please provide copies of all DRAFT assessments within 5 business days of the IEP meeting."* This will ensure that you have access to the information ahead of the meeting.





## The Role of the Independent Educational Evaluation (IEE)

The Independent Educational Evaluation (IEE) or parent secured evaluation serves as a second opinion in determining your child's capabilities and needs. Parents have the right to obtain an IEE at any time during their child's education, so long as the evaluation meets the IEE criteria established by the district. IEEs conducted by qualified persons and submitted to the IEP team for consideration must be **considered** alongside their district counterparts.

### What If I Do Not Agree With the Results of the Evaluation? Obtaining an Independent Evaluation At District Expense.

The law provides a mechanism for parents to secure an IEE at public expense if they disagree with the school district's evaluation. The right is conditional in that the district may refuse to pay for the IEE. However, when the district takes this position, it must initiate a due process hearing to defend its findings without unreasonable delay. Most districts are reluctant to file a due process against a parent and this is especially true where there is a strong possibility that its evaluation is flawed, inaccurate or incomplete.

Like all communication with the district, when requesting an IEE, it is wise to put your requests in writing and deliver it in a manner that will produce a proof of receipt. Fax is a preferred method as it can provide a transmission receipt and has the effect of starting the timelines immediately, without the delays associated with certified mailing.



### Final Thoughts on Evaluation

Evaluations are much like building blocks. They are the foundation of a solid plan that will allow your child to progress in his or her educational setting. Quality evaluations and accurate present levels ensure that goals are measurable year to year. We cannot afford to lose even one year of educational opportunity. Stay organized, ask questions, and maintain accountability through objective measurement.





# How Is My Child Determined Eligible for Special Education

To determine if a child is eligible for special education services, the school district must:

- (1) Draw upon information from a variety of sources, including tests, parent input, and teacher recommendations, as well as information about the child's physical condition, social or cultural background, and adaptive behavior; and
- (2) Ensure that information obtained from all of these sources is documented and carefully considered. If a determination is made that a child has a disability and needs special education services, an IEP must be developed for the child.

(The requirements for special education eligibility are outlined in the federal regulations at [34 CFR: Part 300 section 306\(c\)](#).)

## What are the Eligibility Categories For Special Education?

The federal law identifies thirteen categories of eligibility. They are:

- autism
- deaf-blindness
- deafness
- emotional disturbance
- hearing impairment
- intellectual disability
- multiple disabilities
- orthopedic impairment
- other health impairment
- specific learning disability
- speech or language impairment
- traumatic brain injury
- visual impairment (including blindness)



Depending on your state's law, additional categories of eligibility may be available. A listing of the eligibility categories state by state may be found [here](#).

## How is Eligibility Determined?

In order for a child to be found eligible for special education and related services, it must first be shown that the student is a "child with a disability," and that as a result of the disability experiences, has difficulties accessing his or her education such that he/she is in need of special education and related services.

## How Old Must A Child Be to Be Assessed for Special Education?

A child may be eligible for special education eligibility at birth. These services take the form of early intervention under Part C of the IDEA. A child becomes eligible for preschool special education services at age three. Parents may request evaluation for special education at any time through the age of 22, providing that the student has not first graduated with a regular high school diploma. (34 C.F.R. Sec. 300.102)





## Must a Child Be Eligible for Special Education Under a Certain Eligibility Category to Receive Services?

Special Education and related services are to be made available to an eligible child on the basis of individual need. A school district may not limit or restrict services to a student simply on the basis of his or her eligibility category. **Each program must be individually tailored to the child it serves.**

*Kate and Bob are working on Sara's IEP for the next year. She is transitioning into the high school and they are working with the team to make sure she is set up according to her needs. As they evaluate how Sara is doing and how to get her the proper services they review a few key advocacy steps they will need in the meeting:*

1. *Identify the goal of your advocacy.*
  - a. *Their goal is to get Sara the services she needs to have a successful and rewarding school year. They are hoping to get this through negotiating with the school. Acceptable outcomes would be continuing Sara's current services but amending them to fit the high school schedule. Or adding different services as needed.*
2. *Develop a plan or strategy.*
  - a. *Bob and Kate have put together supporting information from Sara's middle school teachers, therapists, report cards and information from her doctors. They want to make sure Sara continues to get the services she needs to succeed and is entitled to by law.*
3. *Consider the perspective of the party to whom you are advocating.*
  - a. *The Smiths know there have been many budget cuts in their school district and they are deeply concerned this will impact Sara's IEP. They are going to remember this as they go in to the meeting. Bob and Kate feel it will be important to remind the district that while there have been budget cuts it is Sara's legal right to have an IEP that give her an appropriate education. In order for that to happen she will need services in place.*
4. *Be aware of emotions – on all sides.*
  - a. *Bob and Kate have discussed that sometimes they can get emotional in the IEP meetings when advocating for their daughter. She has made a lot of progress and they want to see that continue. They know that not everyone at the IEP meeting is as well versed on Sara or as emotionally attached and that they will need to remember this to be rational throughout the meeting.*
5. *Understand to whom you are advocating and to whom you ultimately need to advocate.*
  - a. *The Smiths understand that they are speaking to the IEP team who will need to sign off on all the decisions made. They have had both negative and positive experiences at IEP meetings before so they will go in knowing they will need to advocate to the school administrator who has the authority to make decisions.*
6. *Present your "case."*
  - a. *In the IEP meeting Bob and Kate present their ideas to the team. They discuss how Sara has been doing and what they think, along with her current teachers, what she will need to continue her success.*
7. *Consider possible resolutions that might be acceptable to all parties.*
  - a. *At the conclusion of the meeting the Smiths were willing to give up a few unnecessary services Sara had to make sure that she could get things that were more important. They knew this might happen and were prepared for it. This way Sara is able to keep all of her necessary services and get some additional help transitioning to the high school with one-on-one assistant. Both Bob and Kate feel like the meeting was a success due to their advocacy and compromise.*







# The IEP Meeting – What Can I Expect?

## Meeting Technicalities (Formalities)

On the day of the IEP, you will meet either at your child's school or within the district offices. Each member of the team will introduce him or herself, and a roster will be passed around. All attending the meeting will sign the roster of attendance. A copy of the roster can be provided to you at the end of the meeting. Districts are required to ensure that the people listed below are present at the meeting. A member of the team whose area of expertise (curriculum or services) will be discussed at the IEP meeting may only be excused with **prior** written consent of the parents.



- School administrator (with knowledge of the district's available programs and authority to offer the resources of the district)
- General education teacher
- Special education teacher
- Parents
- Therapists (including but not limited to speech therapists, occupational therapists, physical therapists, adapted physical education specialists and behaviorists if their area of the IEP is to be discussed or modified in any way.)
- School psychologist
- School nurse
- Other individuals who have knowledge or special expertise regarding the child, at the discretion of the parents or district (e.g. family friends, educational advocates and attorneys)
- Student with the disability, when appropriate



After introductions, the district must be sure that it provides parents with a copy of procedural safeguards. The team then works together to identify the student's strengths and challenges, and determines the student's present levels of performance (PLPs).

## Can I Audio Tape The Meeting?

If you would like to tape the IEP you must notify the district that you will be doing so at least **24 hours** prior to the meeting date. The rules on taping and notice may vary state to state.







## What are Present Levels of Performance (PLPs) and Goals?

As you are probably gathering by now, special education is loaded with many acronyms. Yes, your child's starting place for his or her annual goals is called a PLP. The law (IDEA) requires that each IEP contain a statement of the student's PLPs, including how the student's disability affects his or her involvement and progress in the general education curriculum. PLPs are determined from assessments of the student's achievements.

The IDEA also requires that a student's IEP document contain a statement of measurable annual goals that are based on the student's present level of performance. Therefore, the IEP team must create a goal for each area of need (generally defined as an area of concern where the child falls below the skills that would be expected of a typical child of the same age.)

These goals must be designed to 1) meet the child's needs, 2) enable the child to be involved in and make progress in the general education curriculum, and 3) meet each of the child's other educational needs that result from his or her disability. Your child's goals should be achievable and appropriate for one academic year.

## Authorizing the IEP – You Must Review the IEP before Signing

At the conclusion of the meeting, the district will have drafted a written education plan for your child. This written document (IEP) should include all of the findings of the team (including the parents' ideas and suggestions). The document should clearly describe the offer of placement, services, and annual goals. The IDEA states that school district's must obtain informed consent from the parent prior to providing special education and related services to the child. Therefore, you will be asked to sign the document. You should sign the document only when you have thoroughly reviewed the document and reached agreement with the district's team, and you are certain that the plan is what will best serve your child's needs. If you are unsure of the meaning of a part of the document and would like further time to consider the proposed IEP, you have the right to take a copy home and consider it outside of the pressures of the IEP setting. School districts are required to provide parents with a copy of the IEP document at no cost.

When reviewing the IEP document, it is important to note that school districts are required to make written IEP offers that clearly define the offer (proposed placement and related services).

A few things to consider when reviewing the IEP to determine if the IEP complies with the requirements above:

- Has the team created a goal to address each area of need as determined in the student's PLPs?  
If not, has the IEP team explained how the existing goals meet all of the child's needs?
- Are the goals measurable? A well-written goal must include well-defined terms, measuring periods, and types and numbers of prompts.
- Does the offer of services specify whether the student will receive individual or group-based instruction?
- Does the offer of services specify the frequency to be received per week or month (as opposed to per year)?
- Does the offer specify when and for how long the student will be mainstreamed (educated alongside typical kids) per day?
- Does the offer include appropriate accommodations and modifications of your child's instructional material?





If you agree with some parts of the IEP and disagree with others, you can set out your concerns on a page provided in the IEP document. Should you disagree with the intensity, duration or type of services being offered, this is the time to mention those disagreements and present your supporting reasons. You may also attach a letter documenting your concerns. This is called a Partial Consent letter. This document could become the basis for further hearing (due process) on these issues. Upon receiving notice of your concerns/disagreements with the IEP, the district may provide you with a letter called a Prior Written Notice. This letter will document the district's rationale for its proposed program and may also attempt to create the most appropriate recommendation for your child. Should you continue to disagree with the district's rationale, you may request an IEP meeting to discuss your concerns.

Be sure to calmly state your concerns and disagreements. This will set the stage for collaborative problem solving.

## My IEP is Out of Date. What Steps Can I Take To Modify It?

If you believe that your child's IEP is out of date or somehow needs adjustment, consider sending a written request to the school district for a new IEP meeting. Generally, when a parent of a special education student requests an IEP team meeting, the school district must convene the meeting within 30 days of the written request. This IEP meeting is also called an Amendment IEP, and it permits the team to discuss your concerns and modify the IEP. Should you be unable to resolve your concerns at this IEP meeting, you still have the option of addressing your concerns through more formal means. Please see the section "I Disagree with My Child's IEP."

## Is Special Education Programming A One Size Fits All? What Program Types and Related Services Are Available?

Special Education can include a variety of program and placements. The programs are listed from least restrictive to most restrictive. (Restrictive is generally understood to define the degree of removal from children without disabilities.)

- **General Education Program (GE):** This term is used to describe a regular classroom setting and is comprised mostly of children without disabilities.
- **Resource Specialist Program (RSP):** This program is for students who need some special education support, but spend the majority of the school day in a GE classroom. Resource programs offer educational support to augment GE classroom instruction.
- **Special Day Class (SDC):** This term is used to describe a special education classroom for students with intensive needs that cannot be met by the GE or RSP program. A SDC provides for smaller classroom size and generally only serves children/students with disabilities.





- **Private Special Education Schools (also called Non-Public Schools):** This is a type of private school that exclusively enrolls children with special needs pursuant to an IEP, and is certified by your State's Department of Education to provide special education and related services. Most Private Special Education Schools have master contracts with school districts to provide alternative special education and services that cannot be found in the local school district's programs.
- **Home School Program:** At all times, parents have the right to educate their children, themselves in the home setting. However, this does not mean that a school district is relieved of providing home-schooled students who qualify for special education with the related services they require. There are many options. If you think that your child is a candidate for home schooling, explore your options with the school district. Often the district's representative will be a valuable source for available programs and services.
- **Residential Program:** This program is for students who, due to severe needs, must be placed in a setting in which they are living away from their home and are receiving supervision and services 24 hours a day. If a child requires this type of placement, then this program, including non-medical care and room and board, must be provided to the child at no cost to the parents of the child.

The above mentioned program placements may also include specially designed services also called Designated Instruction and Services (DIS). DIS is known as "related services." Such services may be required to help students benefit from their education. Related services include, but are not limited to, the following:

- Language and Speech Therapy Services
- Occupational Therapy
- Physical Therapy
- Adapted Physical Education
- Vision Therapy
- Assistive Technology
- Audiological Services
- Behavior Therapy
- Social Skills Training
- Recreation Therapy
- Counseling and Guidance
- Mental Health Services
- Health and Nursing Services
- Vocational Training
- Transportation
- Specialized services for low-incidence disabilities (Vision Loss/Hearing Loss/Orthopedic needs), such as readers, transcribers, and vision and hearing services.





The placement of a child in a more restrictive environment, such as a special day class, must not occur unless and until it can be shown that a child **cannot** be educated in a general education class with supports and services, or if his or her needs are such that the child being there will compromise the education of the other children in the class.

## Understanding FAPE and the LRE

There is a lot of confusion and oftentimes misinformation surrounding the legal requirements associated with a school district's duty to educate a child with special needs. Parents naturally want the very best school, teachers, and services for their children so that they are able to thrive and reach their maximum potential. It is understandable then that parents would assume that it is a school district's responsibility to help them achieve this goal for their children. However, the law is not so clear on this issue.

### The FAPE Standard

The Individuals with Disabilities Education Act ("IDEA") is the federal law requiring school districts to provide students with disabilities a Free and Appropriate Public Education ("FAPE"). The IDEA, however, does not expressly define what a FAPE is. Therefore, we must look to the courts for their interpretation of this term.

In the 1982 case of *Board of Education v. Rowley*, 458 U.S. 176, 102 S.Ct. 3034, the United States Supreme Court enumerated the following factors to determine whether a district is providing a FAPE:

1. Whether the district's proposed program was designed to meet the student's unique needs;
2. Whether the district's proposed program was designed to provide educational benefit to the student;
3. Whether the district's proposed placement was designed to provide the student with an education in the least restrictive environment (LRE); or
4. Whether the district's proposed placement conformed to the student's IEP.

The Court in *Rowley* also clarified that a child with special needs is not entitled to the *best* possible education nor is a school district obligated to *maximize* the child's future potential. Parents are understandably confused and upset when they learn that school districts are not obligated to assist students with special needs to reach their full educational potential. The standard a school district must adhere to is one of **meaningful access**. That is, the district is legally obligated to ensure that special education students have meaningful access to their educational curriculum.

Therefore, when reviewing the educational program the school district has offered a child, parents must ask themselves:

1. Does the educational program proposed by the school district, address my child's unique needs?
2. Will the placement and services provide my child a measureable educational benefit?
3. Is my child being educated in the Least Restrictive Environment?
4. Is the district providing the program that is written in the IEP document to which I have consented?

If the answer to any ONE of these questions is "no," then the district is likely not providing a FAPE to a student in accordance with the requirements of IDEA.







## Least Restrictive Environment (LRE)

Understanding what the LRE is for a child is crucial in determining whether or not that child has been offered a FAPE. IDEA defines LRE as the district's duty to ensure that:

- (i) To the maximum extent appropriate, children with disabilities... are educated with children who are nondisabled; and
  - (ii) Special classes, separate schooling, or other removal of children with disabilities from the regular educational environment occurs only if the nature or severity of the disability is such that education in regular classes with the use of supplementary aids and services cannot be achieved satisfactorily.
- 34 C.F.R. § 300.114(a)(2).

According to this law, a child may not be placed in a more restrictive environment unless it is not possible for that child to be educated in a general education environment with appropriate supports or if the child's needs and behaviors would negatively impact and hinder the education of the students in the classroom. Therefore, at all times possible, children with special needs must be placed in an educational environment with nondisabled peers.

Whether or not a child is being educated in the LRE is just one prong used to determine if that child is receiving a FAPE, but it is a very significant and important area of law that must be considered and carefully analyzed at all times.

## When Should I Begin Including My Child with a Disability In His/Her IEP Meeting? What about Transition Planning?

IDEA clearly provides the opportunity for a child to be included in the IEP team whenever appropriate. In some circumstances, a child with a disability must be invited to attend the IEP meeting. This applies only when the "purpose of the IEP meeting is to consider the postsecondary goals for the child and the transition services needed to assist the child in reaching those goals..." (34 CFR 300.321) Transition planning occurs at the IEP team meeting once the student is 16. The IDEA also permits IEP teams to begin transition planning prior to age 16 if the IEP team determines it is appropriate to do so based on the student's needs. If the student does not attend the meeting, the school district must ensure that the student's personal interests and preferences are considered in the transition planning.

Transition planning may be complicated by the fact that the student may reach the age of majority (18) while still in school. As an adult, the student is presumed to be capable of making his or her own educational decisions. Therefore, the right to make educational decisions transfers from parents to the student at the age of 18. School districts are required to respect the decisions of adult students unless a student has been determined to be incapable of making decisions via a conservatorship proceeding.

It is important for parents to consider encouraging their children to attend an IEP meeting and to assist in developing their IEP when possible and appropriate. This provides children with the opportunity to advocate and take part in their own education, learn more about the process, and to share vital information about themselves.

*Since Chris is 16 now, the Smiths felt it was time for him to join in the IEP meeting. They want Chris to be able to advocate for things that are important to him and that impact his education. Bob and Kate tell Chris what to expect and that some people from the school are going to ask him questions about how he likes his classes and what he wishes for the next year. Having Chris attend will be a good start to learning how to self-advocate.*





# I Disagree with My Child's IEP.

## What are the Steps I Can Take to Resolve Disputes with the IEP?

### What Is Informal Dispute Resolution (IDR)

Informal Dispute Resolution (IDR) is a process available where the parents and school district officials can meet to discuss the child's needs and parents' concerns. IDR is different from other forms of dispute resolution in that this process generally does not utilize the services of a court appointed mediator.

### Mediation

Mediation in special education disputes involves the assistance of a court appointed mediator. The process is a voluntary one between the parties. The process is confidential.



### Due Process Hearing Request

It is important to discuss your concerns and areas of disagreement with your school district before entering into the more formal due process procedure. True collaboration can often be the quickest and easiest way to solve a disagreement. However, if you cannot come to agreement with the school, you have the right to disagree with the school's decisions concerning your child.

Parents may request a due process hearing in situations where there is disagreement with respect to:

1. The special education eligibility category
2. The assessment results
3. The proposed placement, or the services

A Due Process Hearing is a formal, court-like process in which you and your school district each are afforded the opportunity to present your case to an impartial Hearing Officer. The Hearing Officer will issue a formal written decision. Parents will often seek the advice of an experienced representative. For a comprehensive listing of experienced attorneys and advocates who might assist, visit the Council of Parent Attorneys and Advocates [website](#).





# Autism Advocacy in the Community: A Parent Perspective

*This section was prepared by Gene Bensinger, a Managing Director in Institutional Sales with Mesirow Financial, a financial services firm headquartered in Chicago. Gene is a Board Member of Autism Speaks Chicagoland Chapter, Chairs its Programs and Services Committee and served on the Parent Advisory Committee for the Autism Speaks "Autism Safety Project". Gene also worked closely with local advocates, policy makers, and legislators to help achieve insurance coverage for autism therapies in Illinois.*

*Gene's current advocacy efforts are focused on transition and adult services, including the Advancing Futures for Adults with Autism effort, led by Autism Speaks and partner organizations. Gene also helped create a national consortium, Agricultural Communities for Adults with Autism (ACAA), which is focused on promoting the development of non-urban, community based employment and housing models for adults with autism spectrum disorders.*

*Gene and his wife, Lynn, live in Chicago and Michigan with their two sons, the eldest of whom has autism.*

The question "Can't you control your kid?!" The dreaded looks of disapproval. Unsolicited input to "improve" parenting skills or even suggestions to just not come back. Sadly, these kinds of interactions are all pretty common in our community. Sometimes they can even escalate into headlines. Bad experiences in the community can cause families to feel isolated from, rather than engaged in, common community activities. As a parent advocate for nearly two decades, I've been there. But over time, I realized that advocating or speaking up for kids with autism in our communities, rather than avoiding problems, leads to positive change for everybody.

Autism Speaks is very engaged in many ongoing "big picture" advocacy initiatives that revolve around things like public policy and legal rights, access to (and the development of) evidenced-based medical and therapeutic interventions, financial supports, housing and employment issues, the fight against discrimination, and a host of other efforts. **But what about when it's not about advocating to positively change the world for all of us?**

**When it's just one or a couple of us who want to have the most positive experience possible as we navigate beyond our familiar and usually predictable homes, schools, or jobs and out into our local communities?**

Public transportation, stores and service providers of all types, places of worship, entertainment venues, lodging establishments, parks and leisure spots (to name a few) are all spaces "in the community" that can pose some serious challenges for people with autism. Challenges can include unpredictable social interactions and possible sensory overloads, even "meltdowns" that are difficult to manage. The key to positive inclusion in all of these community spaces is detailed planning and personal advocacy to ensure a smooth process, and avoiding (or mitigating) challenges when they do appear, which they most assuredly will at some point.





## Planning ahead can't be overemphasized and advocacy should always be part of the plan.

We all want terrific results, but before we get into the details of your plan, it is important to remember that bad days do happen sometimes. If in spite of all of your effort, your goal is just not going to be achieved that day, a smart move can be a short term retreat (options for which should also be in your plan) in order to preserve the possibility of a positive community activity in the future. Don't let your plan's design become an ordeal to be endured. Be flexible.

Now, let's think through the community activity. Is the goal of the trip to visit someone? To run a typical errand? To go to a show, visit the zoo, or just walk in the park? Think through each step and consider whether there are potential stresses that may impact or impede your movements or activities (fare collection, security checks, lines, transfers, etc.)? Consider all of the potential issues that could develop (delays, noise, crowds, weather).

Next, consider any adjustments you think might help you continue your activity on a positive path if something were to negatively impact the plan (and your goal). Things go wrong all the time, but it is best to consider them ahead of time, rather than "in the moment." Might priority access, a quiet space, slower pace, or extra time help? Could extra on-site assistance help you smooth out any potential bumps? As an aside, many of us do carry an "emergency" kit when we venture out in the community. Our family's is an iPad (favorite movies and shows loaded) with earphones, books, and a few action figures. But we use it sparingly. Being a part of the community means being "unplugged" and connecting the old fashioned way! This type of "connection" is where the advocacy part kicks in.

Most organizations and service providers in the community, especially larger businesses, have some type of customer service component (often specialists on their staff) available to assist you and others with special needs or requirements. But it is critical to call them to plan ahead. Sharing your concerns and information ahead of time is essential, even if it's something like, "I'm accompanying a child with autism, a developmental disability. We're planning to do \_\_\_\_\_. I don't expect I'll need help but if I do, are there any suggestions, resources, or staff you may have available to help me?" Most "people-focused" organizations, from the Transportation Security Administration (TSA) at the airport to Disney Amusement Parks to the Cineplex at the mall, have policies in place designed to assist people with disabilities or those with special requests. If you reach out to them ahead of time, you are successfully advocating. It isn't difficult to do.

But do keep in mind that accommodations, from the perspective of service providers, aren't always available on demand (especially at peak usage times) or individually tailored. Gauge whether the organization seems responsive to your requests. If their current policies don't make sense to you, as an advocate you are well within the realm of reason to ask to escalate the matter and sit down with their management. If that doesn't work (and some folks may be inflexible), that's a good time to look for support from larger established advocacy organizations like Autism Speaks. You'll likely be directed to people who advocate professionally and can help you address your issue.

Here's a quick example of how really basic community advocacy helped my family some years ago. My son absolutely adores babies. He wants to look at them, touch them, hold them, and speak to them. It is way beyond a "typical" curiosity. But this poses some big issues. Parents are likely to (understandably) "freak out" if anyone, including a child or adolescent, makes an abrupt approach to their child. There are hygiene and health issues, too. Now, consider that infants are everywhere in the community. Babies in the neighborhood, at the store, at the playground, and especially at the pediatrician's office! That's where we had a big issue.







Even when my son was small in size, the wait to see the doctor for a wellness visit invariably involved an epic struggle to keep him from rushing at the babies around him. When he was small, scooping him up was usually (if noisily) successful. Then he got bigger. A lot bigger. We tried our best blocking moves, but they sometimes proved inadequate. He scared some moms. He grabbed some babies. No one was ever hurt but my wife and I were mortified. We thought the office staff couldn't help but notice (and probably got some complaints). But what could we do? Skipping checkups was not an option and every other practice is set up the same way (with a big, common waiting room.)

The eventual "solution" turned out to be just speaking up. We approached the practice to explore a strategy to provide us with "options". We spoke with the pediatrician, nurses, and staff. It turned out that they weren't even aware of our issue! They were jammed with filling out insurance forms, keeping the patient flow moving and the physician on a tight schedule to notice our regular distress in their waiting room. We asked if they could accommodate scheduling a first or last appointment of the day when the waiting room wasn't so jammed. Were there other "down times" during the day that they could recommend? In the event that wasn't possible, could they make an exam room available on short notice to whisk him into if he was having a tough day? The answer was a resounding, "Yes, sure we can help!" As a family, we've worked hard to positively model and reinforce socially acceptable behavior around babies (and still do!) but now we had a plan in place in case that didn't work. Visits to the doctor became a lot less stressful from that point on. All due to speaking up...advocating.

Importantly, this experience really hammered home a critical point. If the staff in a leading pediatrician's office, where they provide care for more than a handful of kids with autism and see other behavioral challenges, couldn't "see" our difficulty and didn't "volunteer" a solution to us, who would? We learned right then and there not to "expect" automatic accommodation for our son in the community (even if it seemed to us like "common sense") and, instead, to advocate for it.

**Start with the expectation that very few in the community at large will understand the supports or specific accommodation your child needs. But also start from the frame of mind that most people are happy to help you if they understand your request and are able to accommodate you without major changes in the way they operate, especially if they are given the time to respond.**

The community postal clerk, checkout person, security guard, waiter, flight attendant, theatre manager, passerby, pastor, or even first responder may not have a nuanced understanding of autism or the behaviors associated with the disorder. But because of huge social progress on disability issues over the past few decades, most people understand that when you raise an issue of disability, they need to pay attention. I think this is especially true among young people.

My generation had very little education about, or exposure to, people with any type of disability. Today, diversity (including disability) is included in most school curriculums across the country. It's now typical (and the law of the land) for kids with disabilities to be included in classrooms and school environments. So in many ways, young people are the best folks in the community to ask for help if an issue arises. They "get it", so make it a point in your advocacy efforts to include younger folks.

I've successfully used this "planning plus advocacy" approach hundreds, if not thousands, of times since that visit to the pediatrician. It's worked superbly with airlines, the toy store owner, librarian, taxi driver, security guard, greenmarket, neighbors, and so many others. There have been very few exceptions. Opening up to advocate has added benefits. It gets us talking to new folks, which is a good thing for busy parents and caregivers, and increases autism awareness and acceptance in the community.





# Community Advocacy

*This section was prepared by Valerie Paradiz, PhD, the Director of the Autistic Global Initiative (AGI) of the Autism Research Institute, a program staffed by adults on the spectrum devoted to building partnerships across stakeholder groups within the disability community. In her capacity as AGI director, Valerie serves as an NGO representative to the United Nations and as Editor-in-Chief of the ARI Adults with ASD eBulletin.*

*Dr. Paradiz is the developer of the 2010 International Book Award finalist in education, Integrated Self-Advocacy ISA®, which includes a certification training series for educators, therapists, families and support providers who wish to foster individuals with ASD in achieving greater self-determination and ability in self-advocacy. Additional publications include Lesson Plan a la Carte (AAPC, 2011), an easy planning model that helps educators and support providers to create interventions that integrate learning objectives with therapeutic supports and accommodations directly in the classroom, the community, employment or other learning settings. Valerie is also a contributor to Scholars on the Spectrum Achieving Dreams (Auricle, 2012), a collection of essays written by adults with autism spectrum diagnoses. Her memoir, Elijah's Cup (Simon & Schuster, 2003) is the story of the author's experiences raising her autistic son and their involvement together in the self-advocacy community. Dr. Paradiz has been featured in the New York Times, Redbook Magazine, The Guardian, Parade Magazine, NHKJapan, MTV's True Life and on National Public Radio. Valerie received her PhD from City University of New York's Graduate Center.*

## Transition to Life After High School

When an individual with autism completes the high school years and exits the school system, services and how they are accessed change dramatically. Although there is key federal legislation in place to support adults with disabilities, the programs and avenues of access become more complex and dispersed among agencies that facilitate and provide adult services. Before a student receiving special education services departs from high school, a thoughtful transition plan must be implemented by the school and documented according to measurable goals. The point of the transition plan is to provide a scaffold for this critical passage into adult life, with the goal of successful transition outcomes. Currently, individuals with autism face significant barriers during this transition to life after high school. Recent research indicates that “[y]ouths with ASDs are especially vulnerable during this period because of their challenges with communication and social interaction, greater reliance on others for aid, and high rates of comorbid health and mental health problems.”<sup>2</sup> Therefore, it is critical to develop advocacy strategies to meet the needs of adults with autism, as well as to support them as they become more self-determined in services planning. As a first step in the advocacy learning process, it can be useful to learn about key federal legislation that has been passed to support individuals with disabilities. Indeed, our success in advocacy as family members, professionals in the disability fields, and people with autism depends upon informing ourselves of basic rights and programs that are protected and funded by this legislation.



2. Shattuck, Paul, et.al. Post-high school service use among young adults with an autism spectrum disorder, *Pediatrics and Adolescent Medicine*, February 2011, Vol 165, No. 2, <http://archpedi.jamanetwork.com/article.aspx?articleid=384252>





# Relevant Federal Legislation

## Americans with Disabilities Act

The Americans with Disabilities Act (ADA) is the most comprehensive piece of legislation that protects the civil rights of individuals with disabilities. It was enacted and signed into law on July 26, 1990. In many respects, the ADA is an extension of the Civil Rights Act of 1964, which made discrimination based on race, religion, sex, and national origin illegal. Knowing the rights of an adult with autism whom you support, and assisting that individual in understanding these rights as well, can provide a powerful frame of reference that you may turn to in many situations that require advocacy skills.

The ADA is broken down into five sections or “titles.” These include the following categories of legal protection: 1) Employment, 2) Public Services, 3) Public Accommodations, 4) Telecommunications, and 5) Miscellaneous Provisions. A self-test activity follows. By working through this quiz, you will learn more about each title of the ADA. Keep in mind that the ADA is a complex document, and the information provided in the self-test is by no means exhaustive.

For more in depth information on the ADA, visit the official website at [www.ada.gov](http://www.ada.gov).<sup>3</sup>

## Olmstead v. L.C.

In 1999, an important Supreme Court case led to a decision that would impact the lives of people with disabilities with regard to community integration and community-based services. The decision involved Public Services, Title II of the Americans with Disabilities Act, and stated that no individual with a disability may be denied access to community-based programs and services if treatment providers have deemed that such integrated settings are appropriate. The decision came in response to the prolonged institutionalization of two women, both dually diagnosed with intellectual disabilities and mental illness, based upon the rationalization that their inclusion in community-based programs, though recommended by experts, was too expensive. This was deemed discriminatory by the Supreme Court, leading to important steps in building greater infrastructure in community-based settings.

For more in depth information on Olmstead v. L.C., click [here](#).

## Developmental Disabilities Assistance and Bill of Rights Act

The Developmental Disabilities Assistance and Bill of Rights Act of 2000 (DD Act) instituted four programs that together create a network of important research organizations, program and training centers, advocacy access, and state DD councils as follows:

1. State Councils on Developmental Disabilities (DD Councils)
2. Protection and Advocacy (P&A) Systems
3. University Centers for Excellence in Developmental Disabilities (UCEDDs)
4. Projects of National Significance (PNS)

For more in depth information on the DD Act, click [here](#).

3. Paradiz, Valerie, The Integrated Self-Advocacy ISA® Curriculum, Teacher's Edition, AAPC, Shawnee Mission, Kansas, 2009, pp. 102-104.





## The Rehabilitation Act

The Rehabilitation Act of 1973 (or Rehab Act) includes important funding authorizations that support vocational rehabilitation, supported employment, independent living and client assistance. It also includes provisions involving the rights of people with disabilities, encompassing seven titles:

1. Vocational Rehabilitation Services
2. Research and Training, including the creation of the Interagency Committee on Disability Research
3. Professional Development and Special Projects and Demonstrations
4. National Council on Disability
5. Rights and Advocacy, including establishment of the Architectural and Transportation Barriers Compliance Board (Access Board)
6. Employment Opportunities for Individuals with Disabilities
7. Independent Living Services and Centers for Independent Living

For more in-depth information on the Rehab Act, click [here](#).

## Social Security Act

Finally, the Social Security Act, first passed in 1935, has been amended across more than seven decades to include significant programs for people with disabilities and their families. These programs include the Disability Insurance Trust Fund, Medicare, Medicaid, Early and Periodic Screening, Diagnosis and Treatment (EPSDT) Services for all Medicaid-Eligible Children, Intermediate Care Facilities (ICF) for Individuals with Developmental Disabilities, and Supplemental Security Income (SSI).

For more information about the Social Security Act, click [here](#).

## Navigating Adult Services

Adults with autism are often eligible for services to support them in various aspects of their lives. Services vary from state to state, but most involve a team component comprised of the individual, family members, friends, and coordinators from an agency or organization providing the service (if the individual has qualified for services through agencies). Although the information provided on services below is not exhaustive by any means, it provides some basic information to help you and the person you support begin to navigate programs and options.

## Applying for Supplemental Security Income (SSI)

SSI is a Federal Social Security cash benefit that is available to disabled individuals who demonstrate financial need. If a child is under 18, a family's income is used to determine eligibility. After the age of 18, financial need is based on the individual's ability to earn income. Receiving SSI does not prohibit a person from working. SSI operates on a sliding scale. The amount of cash received monthly is adjusted according to the individual's current income.







Applying for SSI can take several months and involves providing detailed medical or other documentation, as well as undergoing evaluation(s) by qualified SSI medical professionals. Therefore, it is good to plan ahead and initiate the process as part of a young adult's transition plan. If the individual is school aged and already has SSI, he/she must reapply as an adult, at age 18. It is never too late to apply for SSI. The process can be initiated by a family member, support person, or by the individual directly at any time. For more information on SSI, visit [www.ssa.gov](http://www.ssa.gov) or call or visit your local Social Security Administration office.

## Accessing the Voting Process

An important step you can take to foster citizenship is supporting an individual with autism to access the voting process. It is critical to provide the necessary accommodations needed for the individual to understand the voting process and its purpose, learn about candidates in local, state and national level elections, register to vote, and vote either at polling places or remotely via US Mail. For information on how to provide this support, or to access it directly if you are a person with autism, visit the Arc of the United States' *We've Got the Power Campaign* [here](http://www.arc.org). Another good resource for voting rights for people with disabilities is: National Disabilities Rights Network <http://www.ndrn.org/index.php>.

## Obtaining Gainful Employment

While important federal legislation, such as the Rehabilitation Act, has been passed and amended over the years to support gainful employment and counter discrimination of individuals with disabilities in the workplace, “[l]ack of understanding on the part of employers and a lack of effective and accessible vocational rehabilitation/ counseling services” continue to be “barriers to regular employment for many adults with autism.”<sup>4</sup> This is due in large part to the autism community's historical emphasis on funding programs and research that focus primarily on children with ASD. Add to this the significant increase in the diagnostic rate of autism in the past 10-15 years, and our community faces a crisis in infrastructure in adult services across the board. Nowhere is this felt more dramatically for people with autism and their families than in the employment and daily living/housing sectors. Among disability groups, people with autism experience a significantly higher rate of unemployment and underemployment. Many advocates—both individuals with autism and the family members who support them—have experienced systemic failure in employment services, due largely to a lack of information and training for workers staffing programs such as Vocational Rehabilitation. Countless individuals have been denied DVR services or, when provided, have felt services were ineffective due to the profound misunderstanding of the attributes, abilities and challenges associated with autism. In this way, as a result of our advocacy as a community, employment is swiftly becoming a priority. One excellent source for the latest research, training models, advocacy initiatives, federal and state demonstration projects, and employment capacity-building efforts can be found in the VCU-RRTC Newsletter and on its associated [website](http://www.vcu-rrtc.org). Click [here](http://www.vcu-rrtc.org) to learn about the results of Autism Speaks' 2012 Employment Think Tank.



4. Van Pelt, Jennifer. Social Work Today, Vol 8, No 5, p. 12, <http://www.socialworktoday.com/archive/090208p12.shtml>





## Receiving Services from the Division of Vocational Rehabilitation (DVR)

Vocational Rehabilitation provides support to assist individuals with disabilities in preparing for finding and maintaining a job to match skills and abilities. Eligibility is based upon a person's disability and whether the disability currently presents obstacles to employment that can be remediated through vocational rehabilitation services. In order to qualify, DVR reviews medical and educational history, as well as employment experience, to ascertain how the disability affects an individual's ability to be employed. For many with autism spectrum disorders, achieving eligibility for DVR services has posed a problem, due to insufficient knowledge and training of Vocational Rehabilitation workers with regard to autism. Additionally, eligibility guidelines in some states are limited in that they are based upon IQ scores or physical disability as a core determinant in receiving services. Because some people with autism might have higher IQ scores than the cutoff point for eligibility, or because they do not possess mobility or other physical challenges, they are often readily eliminated as candidates for DVR services. This is in spite of the fact that as a population, adults with autism have one of the highest unemployment rates among all disability groups. This is a significant arena where community and personal advocacy play an important role. To learn more about applying for Vocational Rehabilitation Services, visit your local DVR office or your state DVR web site.



## Accessing Social, Therapeutic and Medical Resources, Supports and Services through the Developmental Disability (DD) Waiver

The DD Waiver provides funding for home and community-based services for adults with developmental disabilities, including autism. Eligibility is determined through a screening process conducted by the local county social service agency. When an individual qualifies, services are identified in detail in the Individual Service Plan (ISP) or an equivalent document. Generally, a caseworker is also assigned to support the individual's various needs and goals. Services can be provided wherever the adult with autism lives (his/her own

private home, in the home of the individual's parents or other family members, or in other group and residential home settings). In addition to services covered by medical assistance, the following additional supports might become a part of an individual's service plan: adult day care, assistive technology, support provider training and education, case management, consumer-directed community supports, consumer training and education, day training and habilitation services, housing access coordination, supported employment services, supported living services, transitional services, transportation services, and more.





## Attending and Participating in an Adult Services Meeting (for Individuals with ASD)

Each service provider has unique meeting requirements they must fulfill for their “consumers”, or individuals receiving their services. For example, some case workers are required to meet with an individual regularly, such as every 90 days, or they must complete a more substantial annual review meeting to address goals and program requirements. Meetings such as these usually include:

- Person-centered planning elements, such as supporting the individual’s dreams and aspirations
- Goals for community integration
- Supports to enhance independent living
- Employment programming
- Transportation needs
- Medical requirements

Sometimes individuals with autism miss out on the important experience of self-directing their supports at their adult service meetings. Reasons for this may vary. For example, the meeting environment itself might be too challenging. In other instances, individuals may not have the skills needed to lead a meeting, they may not understand their rights, or they may not have been supported enough in the creative development of their goals and programming in advance of the meeting. Reviewing the accommodations necessary to attend a meeting is a first step toward integrating an adult with autism in becoming a fuller participant in his or her program planning. Additionally, offering supports to prepare in advance for an upcoming meeting can be very effective, so that the individual knows what to expect and what he or she wishes to contribute.

## Employment Disclosure and Advocacy with Employers and Co-workers

When an individual with autism is employed, acquiring some basic advocacy skills and understanding the Americans with Disabilities Act (ADA) can be useful in maintaining the job and ensuring that reasonable accommodations in the workplace can be provided. Because people with autism experience some differences that aren’t widely understood—specifically sensory, social and communication differences—both employers and co-workers might understand an individual better if they are properly informed. However, this in turn touches upon the important issue of disclosure in the workplace and the degree to which an individual with autism wishes to disclose his or her diagnosis.

One very important aspect of self-advocacy is disclosure. Disclosure involves telling someone that you have an autism spectrum disorder. There are some instances when it is important and perhaps even necessary to self-disclose, such as in encounters with law enforcement. In the workplace, however, the ADA provides certain protections to people with disabilities. For example, during a job interview, it is the individual’s choice whether he or she wishes to disclose the disability. Upon becoming hired, again it is the individual’s right whether to disclose or not. The positive side of disclosure in the workplace is that the person may then request reasonable accommodations. Such accommodations might include adjustments to the environment to address sensory, social or communication differences. Accommodations supported by an employer can make performing work assignments easier for individuals with autism, leading to longevity of employment.





In some instances with co-workers, it might not be wise or appropriate to disclose a disability; however, a *partial disclosure* might be in order if it assists in helping others understand the need to adjust the lighting in a shared office, for example. Rather than fully disclosing and revealing the diagnosis, the individual might instead reveal that fluorescent lighting leads to severe migraines. In this way, co-workers understand the need for the accommodation and are more likely to be supportive. Finally, the ADA states that it is against the law to discriminate in the hiring of someone due to disability. Once on the job, an individual may not be fired because of a disability.

## Futures Planning

When it comes to advocacy across the life span for individuals on the spectrum, it is important to consider establishing a Special Needs or Supplemental Needs Trust. Assets held in such trusts do not play a role in determining eligibility for benefits and can be used to supplement services that Medicaid and Medicaid Waiver do not cover. It's often a good idea to work with an attorney with a background in estate planning and developmental disabilities to create such a trust.

Additional information can be found online at [sntcenter.org](http://sntcenter.org).

## Legal Guardianship

In the eyes of the law, even a person with a significant developmental, cognitive, or mental health disability is legally permitted to make decisions on his or her own behalf at the age of majority (18 in most states). The only way parents can continue making decisions for their child is to become their legal guardian.

*"Families need to keep in mind that guardianship is not the same as serving as a substitute parent. A guardian is an individual that is truly person-centered and focused on the needs of the individual with disabilities. They will not be required to provide parental types of support".*



**Guardianship** is a court-ordered arrangement in which one person is given the legal authority to make decisions on behalf of another person whom a court has deemed to be "incapacitated." The guardian's decision-making authority extends to all areas specified by the court.

**Limited Guardian:** A limited guardian makes decisions in only some specific areas, such as medical care. Limited guardianship may be appropriate if the person with a disability can make some decisions on his or her own.

**General Guardian:** A general guardian has broad control and decision-making authority over the individual. General guardianship may be appropriate if the person has a significant intellectual disability or mental illness and, as a result, is unable to meaningfully participate in important decisions that affect him or her.

**Conservator:** A conservator manages the finances (income and assets) of a person with a disability. A conservator has no authority to make personal decisions (medical, educational, etc.) for the person whose funds he or she is managing.







## Deciding Whether Guardianship is Necessary

For parents, the decision to seek guardianship can be difficult. You need to protect your son or daughter with autism, but there may be some areas where he or she can make sound decisions. Fortunately, legal guardianship is not an “all or nothing” proposition. It is possible to carve out some areas where your son or daughter can retain important decision-making rights and control of his or her own life.

When considering how much authority you need—and how much independence your son or daughter should retain—you should begin with an assessment of the different areas in which your son or daughter may need your assistance. These areas may include: medical, educational, financial, vocational/adult services, living arrangements, legal, self-care, safety, and communication.

## Obtaining Guardianship

To obtain guardianship, an attorney is not legally required. But you may want to consider hiring an attorney with expertise in this area. Each family is unique in that there are many significant choices and decisions to be made in this process.

## Conservatorship

Conservatorship must be filed in Probate Court of Superior Court, in the courthouse where the proposed individual resides based on zip code. Most courthouses use Judicial Counsel forms and local court-required forms. Conservatorship is a lifelong process. The conservator must comply with the court for lifetime of the individual.

*Resource for above Guardianship information: Special Needs Alliance, [www.specialneedsanswers.com](http://www.specialneedsanswers.com)*

## Housing Advocacy

### Disability Rights in Housing from the United States Department of Housing and Urban Development (HUD)

Regardless of whether individuals with autism live in private or public housing, federal laws such as the [Fair Housing Act](#) provide, among others, the following rights to persons with disabilities:

- **Prohibits discrimination against persons with disabilities.** It is unlawful for a housing provider to refuse to rent or sell to a person simply because of a disability. A housing provider may not impose different application or qualification criteria, rental fees or sales prices, and rental or sales terms or conditions than those required of or provided to persons who are not disabled.
- **Requires housing providers to make reasonable accommodations for persons with disabilities.** A reasonable accommodation is a change in rules, policies, practices, or services so that a person with a disability will have an equal opportunity to use and enjoy a dwelling unit or common space. A housing provider should do everything s/he can to assist, but s/he is not required to make changes that would fundamentally alter the program or create an undue financial and administrative burden. Reasonable accommodations may be necessary at all stages of the housing process, including application, tenancy, or to prevent eviction.
- **Requires housing providers to allow persons with disabilities to make reasonable modifications.** A reasonable modification is a structural modification that is made to allow persons with disabilities the full enjoyment of the housing and related facilities.

For more information about federal housing and residential entitlements for individuals with disabilities, click [here](#).

To learn about the Fair Housing Laws and Presidential Executive Orders, click [here](#).





# Learning the Language of Self-Advocacy

By Samuel Benson

Self-advocacy is one of the most important skills I have learned in my life journey with Asperger's. However, as a child, I did not know what Asperger's was. I was oblivious as to how I affected the people around me because I only attended to my own interests. I did not understand how to communicate myself in a way in which people could understand me. As a society, I do not think we expect our children to be masters in self-advocacy. It was not until I became a teenager that I became aware of the idea of self-advocacy. I remember when I was in school I always had to be right. I berated my teachers and peers when I disagreed with a request or opinion. One of my greatest challenges was that I always took the words and ideas of what people told me literally. I could not see the shades of grey between the words that were being communicated. Even though this resulted in me being ostracized both in the classroom and on the school yard, I still believed that I was RIGHT in terms of the way I perceived the world. For instance, when I was a child, I did not always know how to spatialize what was happening on the playground. I remember I used to love playing handball (now known as "wall-ball"), but I did not comprehend the sequence of how to become involved in this type of activity. I did not always conceive how to approach my peers in order to insert myself into a game that was already in progress. I can remember many times when everyone would get frustrated with me because I did not grasp the concept of turn-taking. I could not figure out the process of "joining in", so I would just throw myself in there and hope for the best; however, people interpreted this kind of behavior as me just simply being "rude", trying to cut the line, or being a nuisance to everyone around me.

At the end of high school and during college, I began reading books about body language and studying non-verbal cues on my own from the literature I would find in bookstores. I wanted to figure out why I was so alienated and why I did not connect with anyone. I believed that learning these skills would potentially allow me to communicate the unique way in which I perceived my own world in an understandable manner. I remember in high school, I finally learned how to become involved in a conversation. I taught myself how to look at people's body stance, determine the angle of their feet as well as the angle of their body posture, approximate the distance that people were standing from each other, and then say "hey, what are you guys talking about", and pray everything would go according to plan. I believe these skills are something many people take for granted. Learning these behavioral rituals was a very complicated process for me. I had to "study" all of these non-verbal cues and expressions from the ground up – but this was what I had to do to become proficient in self-advocacy. As I began transitioning from a school setting into a career position, I did not realize how valuable these tools I had learned would become – whether they were for a job interview, for networking, or for socializing in the workplace. By becoming proficient in non-verbal cues, I learned a new way to manipulate my environment. I was able to redirect the way in which I communicated my thoughts and beliefs in a manner which "mainstream" society could understand.





I would like to say that, as a young adult, I have **NOT** all of a sudden become the world's expert in self-advocacy skills. Far from it! The best way I can describe how I feel when trying to self-advocate is that learning not just what to say, but **HOW** to say something is similar to how I speak Spanish. When I became fluent in Spanish during my early twenties, I also realized I had been speaking another foreign language my entire life. When I speak Spanish, I know different words and I know the basic conjugations, however, I still make mistakes and I am always having to actively think if I am saying the *right* thing. Similarly, even with these mistakes that I make in the world of non-verbal communication, I think I still have become proficient in this "language". I believe I can contribute the most to the dialogue of self-advocacy by acting as a bridge to translate these different languages, the one from mainstream society and the one from the world of autism spectrum disorders. Today, I work with adults at a non-profit organization that helps individuals with developmental challenges. Part of my role involves looking at how to facilitate career growth for these individuals in the workplace. I remember a time when one of my clients told me that he does not say hello or make small talk in the morning because "it serves no purpose." In the world of "Asperger's thought", he is completely correct. Saying hello or talking about the weather for five minutes is not particularly interesting or going to get his job tasks completed, so why bother? So, is this individual's perspective correct or is mainstream society's perspective correct in that being social and friendly is always a must?

I remember another time when I was with some exchange students from the Netherlands at UC Davis. I took them to Best Buy to show them the *greatness* of American chain stores. We walked into the front doors and someone was there to greet us and to ask us how we were doing. The guys turned to me and started asking me why a **STRANGER** was talking to us. They told me how this would never happen where they are from and this type of behavior would be considered strange, or even inappropriate. So, is it appropriate to greet someone when you walk into the store or not? There is no clear cut answer. I want to make the point that the way in which someone with an autism spectrum disorder thinks is not necessarily "wrong", it is just different. Going back to this client at my work, one of the things I have to do is teach him the "grammar" of how to communicate based on the non-verbal and social techniques of mainstream society, and in turn, teach the staff and administrators the constructs of the language that the client uses to communicate. I noticed over time that once I started doing this with the client and the rest of his staff and peers, the co-workers and the client became much more relatable to one another, and the workplace became a more productive and friendly environment between both parties.

Another challenge of having an autism spectrum disorder is that many have had a lifetime of people expecting less of them because of their disability, and I believe it is important to have high and realistic expectations for these individuals. However, this is not an easy feat. In order for this to happen, we first have to educate ourselves about what it means to have autism and understand how to put ourselves in the shoes of this type of person. In turn, a person with an autism spectrum disorder has to learn how to put him or herself in the shoes of someone without an autism spectrum disorder. I cannot say with certainty how this should be done. I do know, however, my experience with learning languages has been one of the greatest gifts to me. What I have also learned is that schools, organizations, and companies will not know how to accommodate individuals like myself if they do not understand the challenges of having disabilities like autism or Asperger's. Accommodating individuals with disabilities does not mean simply fixing a problem by providing a piece of equipment. It means understanding what the individual's challenges are, finding common goals, and setting high expectations.





# Resources

- Self-Advocacy Online  
[www.selfadvocacyonline.org](http://www.selfadvocacyonline.org)
- Wrights Law  
[www.wrightslaw.com](http://www.wrightslaw.com)
- Advocacy Video Series by Hinkle, Fingles & Prior, Attorneys at Law  
[www.youtube.com/user/specialedadvocacy?feature=watch](http://www.youtube.com/user/specialedadvocacy?feature=watch)
- Special Needs Answers  
[www.specialneedsanswers.com](http://www.specialneedsanswers.com)
- Learning Rights Law Center  
[www.learningrights.org](http://www.learningrights.org)
- My Name is David  
[www.youtube.com/watch?v=C\\_O0vRTkaaY](http://www.youtube.com/watch?v=C_O0vRTkaaY)
- *The Everyday Advocate: How to Stand Up for Your Autistic Child*  
by Areva Martin, Esq.
- *The Integrated Self-Advocacy ISA® Curriculum*  
by Valerie Paradiz, published by Autism Asperger Publishing Company
- *Helping Your Child to Help Him/Herself: Beginning Self-Advocacy*  
by Stephen Shore  
[autismasperger.net/writings\\_self\\_advocacy.htm](http://autismasperger.net/writings_self_advocacy.htm)
- *How to Compromise with Your School District Without Compromising Your Child: A Field Guide for Getting Effective Services for Children with Special Needs*  
by Gary Mayerson
- *Getting to Yes: Negotiating Agreement Without Giving In*  
by Roger Fisher, William L. Ury, Bruce Patton
- *A Guide to Special Education Advocacy*  
by Matthew Cohen
- *Wrightslaw: The Special Education Survival Guide: from Emotions to Advocacy, 2nd Edition*  
by Peter W. Wright, Pam Wright, Pamela Darr Wright







Have more questions or need assistance?  
Please contact the Autism Response Team for  
Information, Resources and Tools.

**TOLL FREE: 888-AUTISM2 (288-4762)**

**EN ESPAÑOL: 888-772-9050**

Email: [FAMILYSERVICES@AUTISMSPEAKS.ORG](mailto:FAMILYSERVICES@AUTISMSPEAKS.ORG)

[WWW.AUTISMSPEAKS.ORG](http://WWW.AUTISMSPEAKS.ORG)





Autism Speaks is dedicated to promoting solutions, across the spectrum and throughout the life span, for the needs of individuals with autism and their families. We do this through advocacy and support; increasing understanding and acceptance of people with autism; and advancing research into causes and better interventions for autism spectrum disorder and related conditions.

To find resources, join a fundraising walk or make a donation, go to [www.AutismSpeaks.org](http://www.AutismSpeaks.org).

