

# Chapter 10: Advocacy

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## Levels of Advocacy

### **1. Advocating for children**

The first step in becoming an advocate is learning to advocate for one's own child. Parents must learn about the diagnosis and what it means for their child's development, about the services and supports available to address their child's needs, and about how to work with professionals to ensure that their child's needs are met. These skills are learned by:

- ◆ Reading pertinent articles, books, and web sites.
- ◆ Participating in Individualized Educational Program (IEP) meetings and other service planning meetings.
- ◆ Talking with other parents who are willing to share what they know.
- ◆ Attending training and discussions offered by parent support groups and parent organizations.

### **2. Sharing information with other parents**

The next level of advocacy is sharing information with another parent who needs it. This can be done informally in the hallway at school, in a parent support group, or over the phone. It can also be done more formally by leading a parent support group discussion on a topic or by providing a training session to a group of parents on a particular topic.

### **3. Supporting a parent in a service planning meeting**

This level of advocacy includes a parent choosing to attend an IEP meeting with another parent to teach active parent participation. Learning the process from another adult who is familiar with the IEP process will help the new advocate to get needs addressed by learning to ask the right questions.

### **4. Participating in activities to influence how services are delivered**

At this level parents advocate to change or influence the laws, regulations, and policies that affect the provision of services their child and other children with autism spectrum disorder (ASD) or other disabilities need. At that point, child advocacy becomes systems advocacy.

### **5. Encouraging a child to advocate for himself**

It is important that parents of a child with autism work with the child to be his or her own advocate. Individuals with autism need to be encouraged to share their strengths and unique talents with others. This will allow members of the community to better understand what individuals with ASD can contribute to their communities.

Advocates are needed at all levels. Parent-to-parent support is critical for parents when all they have is a diagnosis and many more questions than answers. No one is more effective at answering those questions than another parent who has been in the same place. The Individuals with Disabilities Education Act (IDEA, 2004) acknowledges the importance of parents providing information to other parents by providing funding to support at least one parent training and information center run by parents in each state. Many parents have served in an advocacy role by helping to create this document to provide information to other parents.

When parents are educated about a family member's issues and the service systems, it is a natural step to take an active role in supporting other parents and in providing input to public agencies and policy makers about effective ways of supporting individuals with ASD. By communicating, parents can help create the schools and communities where the people they love can live, work and play.

## **Where to Advocate**

There are many areas related to aspects of service delivery where parents' voices need to be heard. At the local school district or at the state level, the following are various issues that parents have identified as important.

### ***Education***

- ◆ Increasing the number of educators who understand the complexities of ASD.
- ◆ Placing students with ASD appropriately to best support their needs.
- ◆ Providing accommodations and or modifications tailored to the student's needs (not according to the student's label).
- ◆ Using research-based methods for instruction.
- ◆ Providing social skills training and development.
- ◆ Encouraging the full participation of children with ASD during the school day and in after-school activities.
- ◆ Providing effective transition services to ensure jobs and community living outcomes.
- ◆ Increasing partnerships with families.

### ***Medical***

- ◆ Increasing early screening and diagnosis opportunities.
- ◆ Educating medical personnel who may come in contact with children with ASD.
- ◆ Increasing the availability of specialists knowledgeable about ASD.
- ◆ Encouraging medical personnel to work in partnerships with families.

### ***Social Services***

- ◆ Increasing the number of providers who specialize in the unique needs of individuals with ASD.
- ◆ Making providers more easily accessible.
- ◆ Encouraging providers to work in partnership with families.

## The Importance of Parents Supporting Parents

Parents can be the best resource for providing emotional support and helping another parent learn how to advocate for their child. Many organizations working to improve supports for those with disabilities originated with concerned family members exploring change. In every way possible, online or through parent support groups, the recommendation is for parents to stand with other parents and family members. It is one basic method of becoming involved in systems advocacy. In Washington, parent support is available through organizations such as Washington State Parent to Parent ([www.arcwa.org/parent\\_to\\_parent.htm](http://www.arcwa.org/parent_to_parent.htm)) and Washington State Fathers Network ([www.fathersnetwork.org](http://www.fathersnetwork.org)), Parent to Parent Power - dedicated to serving Asian parents of children with disabilities. ([www.p2ppower.org](http://www.p2ppower.org)), and others.

There are countless decisions to be made in the process of living with ASD. Since such decisions are individualized, families may find themselves choosing different treatment options or paths of education from those of other parents. They might be aligned with the views of a particular organization that is different from what other parents or family members prefer. The situation of each child is different and it would be easy to feel that there is little common ground with others.

It is unrealistic to expect everybody to agree on every choice. It is important to respect each family's choice and also stand with them to support policy changes or legislative changes that will make a difference in the community, the state, and the nation. A sizeable united voice cannot be ignored. Pointers for those interested in systemic advocacy include:

- ◆ Getting involved in efforts that impact the entire ASD community.
- ◆ Being publicly supportive of programs and services that may help any person affected by ASD, even if it does not affect each family directly.
- ◆ Respecting each individual's level of commitment to advocacy however small or large it may be.
- ◆ Giving first priority to being the best advocate possible for children, families, and adults.

Individuals with ASD are entitled to rights and services. Although the statement sounds simple and straightforward, many parents and family members know it can get complicated and be frustrating when trying to work with a system that does not understand a family member's needs. It is imperative that people with experience in ASD issues speak up as every person's experience will be unique. Often times people with a personal agenda urge law makers to make decisions that are not appropriate for the ASD community, such as mandating one specific type of intervention be used with all children with ASD. When there are various opinions and perspectives, the discussion will be rich and hopefully productive. Varied personal experiences will reflect the depth of the topics and a variety of solutions.

Advising a locally elected official on personal views is encouraged and a large part of the democratic process. Citizen participation provides representatives with the information they need from voters on what is important, and what is not working. This process is how decisions are made and answers are found for proposed policies, budgets, and legislation.

## Various Ways to Advocate: Home, School, and Community

- ◆ Join an advocacy organization
- ◆ Advocate for a family member
- ◆ Advocate for other children
- ◆ Call, write, and e-mail legislators
- ◆ Vote every election

- ◆ Call a radio station to explain a position on a particular topic.
- ◆ Write a letter to the editor of the local paper.
- ◆ Hold a town meeting to discuss issues of interest.
- ◆ Attend a school board meeting to discuss concerns.
- ◆ Attend local and state social services board meetings to discuss issues.
- ◆ Join local or state committees that address what you are trying to accomplish.
- ◆ Visit a senator or state representative.
- ◆ Attend a rally at the State Capitol to raise awareness of ASD.

### ***Tips for Talking with Leaders***

- ◆ Always be respectful, courteous and professional.
- ◆ Thank leaders for the work on ASD issues.
- ◆ Be educated on the issues and differing perspectives.
- ◆ Write out and take along a well-thought-out agenda of discussion points and stick to it.
- ◆ Be brief and to the point.
- ◆ Ask for reasonable objectives.
- ◆ Refrain from being negative.
- ◆ Get to know contacts on their staff.
- ◆ Write letters thanking the staff and representatives for time and efforts.
- ◆ Offer to serve as the “autism expert.”

### **Grassroots Advocacy**

“Grassroots” advocacy refers to people working together to write letters, place calls, send e-mails, and visit officials to communicate ideas and opinions to government officials. Most of the time, efforts are concentrated to senators, representatives, and agency personnel. As a constituent, every person has the right to express knowledgeable opinions and advise elected officials about the issues of concern.

In Washington State, Autism Speaks has a government relations person dedicated to advocacy. Through the process of monitoring; insurance coverage for ASD interventions, laws passed in other states, and specific needs of citizens in Washington, Autism Speaks helps citizens create and influence state policies. More information can be found at the Autism Votes web site: [www.autismvotes.org](http://www.autismvotes.org).

It is advised that people start small, perhaps with issues concerning a child or family member. This could be working with a child’s teacher, school district and/or even school board on issues that arise regarding the educational progress or talking about residential group homes.

## Awareness Campaigns

An awareness campaign is slightly different from advocacy work as it is geared toward educating a particular group of people or the general public. A good example of an awareness campaign is the annual April Autism Awareness Month promoted by Autism Speaks, the Autism Society of America (ASA), and the Autism Society of Washington (ASW). Each ASA chapter is encouraged to hold events, obtain proclamations, and distribute literature to the local community to inform them of the issues related to autism.

Local organizations often plan public events like runs or walks, community festivals, or open houses to help community members learn about autism and raise money for research or special projects. If interested in planning a local event, talk with other parents and family members to get their support. Also, contact a state organization like the ASW as they can link a person up with national organizations that may provide materials and guides for planning and staging events.

## Ways to Spread Autism Awareness

Sponsoring a community-wide campaign is a major undertaking. However, there are many other, less time-consuming methods to spread awareness, including the following:

- ◆ Arrange to give a presentation to students at the local public school.
- ◆ Volunteer to educate local first responders (police, firefighters and paramedics) on how to handle individuals with ASD.
- ◆ Take time to educate family and relatives so they can become advocates for a child with ASD, as well.
- ◆ Write a letter to the editor of the local paper during Autism Awareness Month to outline the severity of the problem and what needs to be done.
- ◆ Wear the autism awareness ribbon, autism awareness bracelets or pendants every day.
- ◆ Stick an autism awareness ribbon magnet or bumper sticker on all vehicles.
- ◆ Distribute informational literature from national groups like ASA and Autism Speaks to local doctors, human service agencies, professionals, and therapists, etc.
- ◆ Hold a candidates' forum and invite several candidates to meet with families dealing with autism in their district to hear the stories and learn about the needs.

In 2005, the Washington State Legislature created the Caring for Individuals with Autism Task Force to develop a report for the legislature on services for persons with ASD in the state. The report contained 31 recommendations for improvements in services. Many of these recommendations, such as implementing new supports and service programs, require legislation to bring about change in systems.

It is important for individuals to become aware of what legislation is pending, both at the state and federal level. It is easy to learn about federal issues on the ASA web site at [www.autism-society.org](http://www.autism-society.org). Additionally, Washington state legislation can be accessed on the Autism Society of Washington web site at [www.autismsocietyofwa.org](http://www.autismsocietyofwa.org) and through The Arc of Washington State at [www.arcwa.org](http://www.arcwa.org). These web sites have e-mail “alert” systems that allow sign ups to receive legislation notices and recommendations for how to take action.

Additionally, it is important to have a voice heard by state and federal legislators. Identify the current state legislators by visiting <http://leg.wa.gov>. Click on “Find Your Legislator” and enter your address and zip code. It is easy to find federal legislators through a link on the Washington Legislature web site. Contact legislators and make them aware that a family member is on the spectrum. Describe the challenges faced by individuals with ASD and their families in Washington and the barriers encountered in getting needed services. Remember to always be constructive and considerate. The legislators represent you – and they want to hear from you!

- ◆ Families and professionals should be provided with opportunities to access information about ASD, education, transition, funding, agencies serving older individuals and adults, recreation options, respite, community activities, etc. Families should receive training to access and utilize these services/resources throughout the individual’s passage through school to a job and adult life.
- ◆ Families should be given support to navigate the bureaucracies of education, medicine and other social services. Options could include a service coordinator, case manager, written lists of resources, referrals to local ASD groups, etc.

Prior to the age of eighteen, the individual’s rights as an adult should be explained to both the individual and parent. The individuals’ rights at the age of majority (eighteen years of age) need to be considered and addressed. Issues related to the need for guardianship may be discussed and facilitated by the professional team.

Families should be informed of their legal status throughout their child’s life. This includes the parents’ rights related to the IEP process, as well as the changes that take place at the child’s eighteenth birthday (unless guardianship is obtained through the courts).