

# Advocacy and Disability Awareness

“*‘This is never going to get better,’ I kept hearing myself say under my breath as I talked to professionals about my children’s well-being – educationally, medically, and mentally. Often I got caught up in ‘this isn’t fair’ and ‘what can I do?’ (As if I didn’t already have enough on my plate, I was running kids to nine therapies a week in addition to scheduling the numerous appointments to see my kids’ specialists.)*”

*One day I was watching a TV program and heard someone talk about how one person could make a difference, make a change that could affect many, but that it would take dedication and determination. The next morning I started to make phone calls to local county agencies to find out what committees I could join or how I could give input to people making decisions about services. I wanted to make a difference!*

*I was amazed at how many agencies valued my participation. I felt good knowing that I was going to help make a difference in services, not just in my local community, but at a state level as well. In addition to that, these changes would benefit my own children with ASD.*

Advocacy by parents and family members is essential to ensure that children with ASD have an opportunity to achieve their fullest potential. As important as professionals are in furthering our knowledge of individuals with ASD and how to meet their needs, parents and family members have been critical in their role of educating professionals and policy makers.

As parents, we evolve from the time we first encounter the diagnosis of our child - from needing information and support to becoming educated and providing support and information to others. Because we all talk about what is important to us, we naturally become advocates as we talk with other parents about our experiences.

The opening of this chapter illustrates a parent coming to the realization that what she knew about her children and what she had learned about the service system as she supported her children was knowledge that could make a difference for others.

## Levels of Advocacy

### 1. Advocating for your child

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 websites
- participating in 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 is when a parent chooses to attend an IEP meeting with another parent to help that parent participate fully when she is unfamiliar with the process, or when he feels his concerns are not being addressed.

### 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 ASD or other disabilities need. At that point, child advocacy becomes systems advocacy.

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

It is important that parents of a child with autism work with their child to be his/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.

We need advocates at all levels. Parent-to-parent support is critical for parents when all they have is a diagnosis and a load of questions. 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) 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 their child and about the service system, they are able 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 making their voices heard, 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, here are some 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 children and adults with ASD
- Making providers more easily accessible
- Encouraging providers to work in partnership with families

# The Importance of Parent-to-Parent Support in Advocacy

Parent-to-parent support offers not only emotional support, it also serves as a step in learning to advocate effectively. Many organizations working to improve supports for those with disabilities were originally created by concerned family members. In any way you can, online or through parent support groups, stand with other parents and family members. When you do that, you become involved in systems advocacy.

We make countless decisions in the process of living with ASD. Since such decisions are individualized, you may find yourself choosing different treatment options than other parents. Or you may become involved with an organization that is different from what other parents or family members prefer. Your child may be significantly affected by autism and you may know families who have children that are only mildly affected and, therefore, feel you do not have that much in common.

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 our communities, our state, and our nation.

A large strong united voice cannot be ignored. Here are some pointers for systemic advocacy.

- Get involved in efforts that impact the entire ASD community.
- Be publicly supportive of programs and services that may help any person affected by ASD, even if it does not affect your family directly.
- Respect each individual's level of commitment to advocacy however small or large it may be.
- Give first priority to being the best advocate you can for your child and family. Consider all the demands you may face at the current stage of your journey.

Individuals with ASD are entitled to rights and services. This statement sounds simple and straightforward, but as many parents and family members know, it can get complicated and be frustrating when you are working with a system that does not understand your family member's needs. People with their own agenda are often urging law makers to make decisions that are not appropriate for our ASD community, such as mandating one specific type of intervention be used with all children with ASD. At these times, your voice needs to be heard. You have the personal experience that others may not. Let your locally elected officials know how you feel on certain issues and suggest how they should vote on proposed policies, budgets, and legislation.

## There Are Many Ways You Can Advocate: Home, School, and Community

- Join an advocacy organization
- Advocate for your child
- Advocate for other children
- Call/write/email your legislators
- Vote
- Call a radio station to explain your position on a particular topic
- Write a letter to the editor of your local paper
- Hold a town meeting to discuss issues of concern
- Attend a school board meeting to discuss your concerns
- Attend local/state social services board meetings to discuss your concerns
- Join local or state committees that address what you are trying to accomplish
- Visit your senator
- Attend a rally at the State House to raise awareness of ASD

### Tips for Talking with Leaders

- Always be respectful, courteous and professional.
- Thank them for the job they are doing.
- Educate yourself on the issues.
- Be brief and to the point.
- Ask for reasonable objectives.
- Don't be negative.
- Get to know contacts on their staff.
- Write letters thanking them for their time and efforts.
- Offer to serve as their "autism expert."

## Grassroots Advocacy

“Grassroots” advocacy refers to people working together to write letters, place calls, send emails, 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, you have the right to express your opinion and advise your elected officials about the issues that you are knowledgeable about.

Start small. Begin with your own child. This means working with your child’s teacher, school district and/or even school board on issues that arise regarding your child’s educational progress.

## Awareness Campaigns

An awareness campaign is slightly different from advocacy work because it is geared toward educating a particular group of people or the general public. A good example of an awareness campaign is the annual Autism Awareness Month promoted by the Autism Society of America (ASA) and celebrated every April. 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 and walks, community festivals, or open houses to help community members learn about autism and raise money for research or other projects. If you are interested in planning an event in your town, talk with other parents and family members to get their support. Also contact a state organization like the Autism Society of Ohio. They can link you with national organizations that may provide materials and guides for planning and staging events. Some national organizations are ASA (<http://www.autism-society.org>), and Autism Speaks ([www.autismspeaks.org](http://www.autismspeaks.org)).

## Ways to Spread Autism Awareness

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

- Arrange to give a presentation to students at your local public school.
- Volunteer to educate local first responders (police, firefighters and paramedics) on how to handle individuals with ASD.
- Take time to educate your own family so they can become advocates for your child with ASD, as well.
- Write a letter to the editor of your 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 your vehicles.
- Buy an Ohio license plate featuring the autism awareness ribbon.
- Distribute informational literature from national groups like ASA and Autism Speaks to local doctors, human service agencies, professionals, and therapists, etc.

In 2003, the Ohio state legislature created an Ohio Autism Taskforce to develop a report for the legislature on services for persons with ASD in the state. The report contains 43 recommendations for improvements in services. Many of these recommendations, such as implementing new supports and service programs, will require legislation.

It is important for you to become aware of what legislation is pending, both at the state and federal level. You can learn about federal issues on the ASA website at [www.autism-society.org](http://www.autism-society.org). You can learn about state legislation on the Autism Society of Ohio website at [www.autismohio.org](http://www.autismohio.org). Both websites have email "alert" systems that allow you to sign up to receive legislation notices and recommendations for how to take action.

It is important for you to make your voice heard by your state and federal legislators. You can identify your current state legislators by visiting [house.state.oh.us](http://house.state.oh.us). Click on "Your Representatives" and enter your zipcode. Visit [senate.state.oh.us](http://senate.state.oh.us) and click on "Your Senators" and enter your zipcode. It is also easy to find your federal legislators. Visit [www.house.gov](http://www.house.gov), click on "Write Your Representative" and enter your zipcode. Visit [www.senate.gov](http://www.senate.gov), click on "Senators" and enter your zip code.

Contact your legislators and make them aware that you have a family member with ASD. Describe the challenges faced by individuals with ASD and their families in Ohio and the barriers they encounter in getting needed services. Remember to always be constructive and considerate.

Our legislators represent us – and they want to hear from us. The best way to do so is via post card, letter, or fax. They are bombarded with email so it is not always effective.

You can also hold a “candidates’ forum” and invite several candidates to meet with families dealing with autism in their district to hear their stories and learn about their needs.

Don’t invite legislators in for a complaint session, but for positive dialogue on the issues.

Remember, we want them thinking about how to be a part of the solution.

Finally, when you find candidates who support your positions, support them financially. Private citizens can contribute \$50 per person or \$100 per couple to the candidate of their choice and receive a dollar-for-dollar tax credit! Nothing speaks to our legislators like money and votes.