

CHAPTER 6

Advocacy: Raising Awareness and Influencing Service Delivery

Definition of Advocate:

- To ad-vo-cate: 1. to speak or plead the cause of another
2. to support or promote the interests of another

The above definition of advocacy is plain, simple, and easy to understand. However, the "process" of advocating is not that simple unless you are well educated about your child's disability, knowledgeable about your child's rights especially within the educational system, and firmly believe that that you are your child's natural advocate. No one can be a better advocate for your child than you.

We all have heard the saying, "I had no choice in the matter." Well, this is certainly the case with respect to advocacy. As parents, we have no choice but to advocate for our children. We cannot sit and wait for someone else to do it for us. As parents, we need to develop a sense of urgency that will help set the standards for our child's future.

One choice you do have is the "level" of advocacy you want to take on. You can advocate at the individual level (e.g., for your child only) or at a local or state-wide level. Advocating at a local or state level takes more time and coordination with other advocates for the same disability. You can take on a very important role in your community by getting more actively involved in this manner and create real change for all individuals affected with autism.

You will always receive advice from others around you.....family, doctors, teachers, and other professionals who have your child's best interest at heart. While the advice of others is important, always remember, "*You know your child the best.*" You are living and breathing your child's disorder on a daily basis. As a result, you should feel confident and competent about what you should be advocating for--whether it's during structured meetings with professionals or casual conversations with family members.

Believe not only in your child, but in your ability to advocate at all times!

"Parents are the true educators of their children. Teachers, psychologists, and other support staff are consultants to those parents".
-Nichols Hobbs

How Do I Become a Strong Advocate for My Child?

Become informed –learn what resources exist to help your child

- Join groups who have meetings and newsletters- they have lots of information to share
- Attend trainings-to find out about upcoming training opportunities, visit the KATC website <http://louisville.edu/education/kyautismtraining> or contact your local parent support group
- Visit websites

Know and understand your rights

Contact Protection & Advocacy for free information and assistance
www.kypa.net

Read books such as *From Emotions to Advocacy* by Wrightslaw
www.wrightslaw.com

Read the article, “Beyond IEPs: Eight Ways Parents Can Help Advocate for Children With Autism” by Autism Speaks
www.autismspeaks.org/docs/family_services_docs/BeyondIEP_s.pdf

Learn how to play the role of advocate

- Be prepared
- Write down your thoughts: prepare an agenda and speaking points before a meeting
- Keep your files and records organized
- Know what you want...and be specific
- Build positive, respectful relationships with professionals
- Ask questions about anything you don't understand
- Be a good listener
- Write down details
- Practice beforehand what you're going to say in meetings
- Get professional opinions in writing
- Don't personalize statements made by others...focus on your child and not the personalities of others
- Offer help and support to professionals when you can
- Pick your “battles” wisely
- Realize that sometimes advocacy fails. Know when to stop and try something else
- Thank people for their time

Parents go through many normal feelings when they have child with a disability. There may be anger, denial or depression. Becoming an advocate can help with some of the feelings of powerlessness that you may feel. Even after coming to acceptance we can find ourselves experiencing negative feelings at different times in our child's life.

Know that this is normal and understand that your ability to be an effective advocate can be challenging at these times. You may need to reschedule meetings or make sure you have a strong, supportive advocate to help you.

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 the 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 communicate what is important to us, we naturally become advocates as we talk with other parents about our experiences.

Levels of Advocacy

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. We must be aware of the services and supports available to address our child's needs, and about how to work with professionals to ensure that our child's needs are met. These skills are learned by:

- Learning to ask appropriate questions
- 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

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.

Supporting a parent in a service planning meeting

The third level of advocacy is when a parent chooses to attend an IEP meeting with another parent. This support can help a parent who is unfamiliar with the process or is feeling that concerns are not being fully addressed.

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 needed by their child and other children with ASD or other disabilities. At that point, child advocacy becomes systems advocacy.

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. One such venue for self-advocacy is the IEP meeting. According to the provision under IDEA 1997, the student with a disability should be a member of the IEP Team when the focus is on transition services, which is required when the child reaches age 16. This will allow others 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 lot 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. They are also able to provide 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.

Kentucky Protection and Advocacy

P & A provided information/technical assistance, education, and training on legal rights of persons with disabilities. They also have written materials on a variety of disability issues. They provide some legal counsel based on yearly priorities.

(800) 372-2988 www.kypa.net

The Arc of Kentucky

The Arc of Kentucky holds a Vision of a positive future for individuals with intellectual and developmental disabilities, a future of communities with services and supports that will promote lives of value for Kentuckians with intellectual and developmental disabilities.

(502) 875-5225 or (800) 281-1272 arcofky.org

FIND of Louisville

Community Parent Resource Center (CPRC)

Funded by the Department of Education, provides training and information related to education laws. (502) 594-6813 www.findoflouisville.org

Kentucky SPIN

Parent Training and Information Center (PTI)

Funded by the Department of Education, assists families with concerns related to education.

(502) 937-6894 www.kyspin.com

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
- Providing placements to students with ASD that best support their needs
- Providing accommodations and/or modifications tailored to the student's needs and 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 as well as in after-school activities

- Providing effective transition services to ensure jobs and community living outcomes
- Provide more opportunities for parental involvement in schools
- 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 partnership 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
- Providing government-funded programs that assist families in addressing ASD needs

The Importance of Parent-to-Parent Support in Advocacy

Parent-to-parent support offers not only emotional support, but also serves as a step in learning to advocate effectively. Concerned family members originally created many organizations working to improve supports for those with disabilities. 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. 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 everyone to agree on every choice and it is important to respect each family's decisions. However, there are probably many issues that you agree on, even if at least partially. It is imperative that we seek commonality that will enable us to stand together to support policy and legislative changes that can make a difference in our communities, our state, and our nation. A 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.

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 frustrating when you are working with a system that does not understand your family member's needs. People with their own agendas 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.

Ways You Can Advocate: Home, School, and Community:

- Advocate for your child
- Advocate for other children
- Join an advocacy organization
- 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
- When possible, bring your child or a photo of your child with you.
- 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. You may also contact a state organization like the Kentucky Autism Training Center. They can link you with national organizations that may provide materials and guides for planning and staging events. Some national organizations are the Autism Society of America <http://www.autism-society.org> and Autism Speaks (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 also become advocates for your child with ASD
- 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 awareness pendants every day
- Stick an autism awareness ribbon magnet or bumper sticker on all your vehicles.
- Buy a Kentucky autism awareness license plate

- Distribute informational literature from national groups like ASA and Autism Speaks to local doctors, human service agencies, professionals, therapists, etc.

On March 18, 2005, the Governor signed House Bill 296 into law establishing the Kentucky Commission on Autism Spectrum Disorders. Sponsored by state Rep. Scott Brinkman (Louisville), the legislation charges the agency with the development of a comprehensive statewide plan for an integrated system of training, treatment and services for individuals of all ages with an ASD.

The 22-member commission first met August 22, 2005 and named subcommittees to address the following issues: identification and intervention; services/transition; best practices and training; and funding. The commission is composed of members from key state agencies and nine appointed community members. The appointed members ensure broad representation of Kentucky's citizens concerned with the health and quality of life for individuals with an ASD.

Learn more about the Kentucky Commission for Autism Spectrum Disorders at: [http://chfs.ky.gov/kcdd/HB+296+KY+Commission+on+Autism+Spectrum+Disorders.h](http://chfs.ky.gov/kcdd/HB+296+KY+Commission+on+Autism+Spectrum+Disorders.htm)
[tm](http://chfs.ky.gov/kcdd/HB+296+KY+Commission+on+Autism+Spectrum+Disorders.htm)

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 <http://www.lrc.state.ky.us/Legislators.htm>. 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 Kentucky 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 you might help them with their campaigns or support them financially.