

PFA Tips

Becoming an Advocate

The term advocacy has roots in the legal system, but is used today by individuals and groups working for social change. **Anyone can be an advocate.** When you hear this word, someone who attends your IEP meetings with you on your behalf may jump to mind. Most likely you have been advocating for your child, but never associated this term with your caring efforts. An advocate is simply someone who: is committed to change; is willing and able to publicly share their commitment; and is open to increasing their knowledge and understanding of the issue.

Different titles sharing common goals

Professional Advocates work in the field, including psychiatrists, social workers, psychologists, and education advocates to name a few. **Lay Advocates** are not employed by the systems that are the target of the advocacy, which allows them the opportunity to voice their opinions freely. They can monitor the system from the outside looking in. Lay Advocates can get involved by joining advisory councils and boards of directors; seeking public speaking and education opportunities; participating in letter writing campaigns; and supporting activism.

The rules of advocacy

Sometimes people advocate for themselves (self-advocacy) and sometimes people advocate for others. When advocating for others, always strive to: be a good listener; be supportive; have all the necessary information; and be a good representative.

Advocacy begins at home

You can begin practicing your advocacy skills right at home with your own family. When family members find out about a child's diagnosis, the reaction can be mixed, and sadly might include disbelief, disapproval, criticism, misunderstanding and judgment. Remember, your job as an advocate is to help people understand issues. Share your child's diagnosis and provide your family with good factual information about the

diagnosis to help dispel myths or incorrect perceptions. Encourage reasonable expectations. Provide the same positive reinforcement tactics you use for your children on your family members. And set good boundaries. If a family member cannot accept your child, you may need to pull your strongest advocacy skills and limit the relationship that family member has with your child.

Advocate by modeling

When you stand up for your child's rights, you are unwittingly standing up for the rights of all children with autism. The service you get for your child may then be made available for the next family that comes behind you. And be aware of how you speak to your child in public as others will follow your lead. Are you asking your child to make choices, or are you making all of his decisions for him? If you want others to treat your child with respect, then you must demonstrate by your actions how you want your child treated.

Advocating at school

There are some things to keep in mind before you enter those hallowed hallways. Maintain good records and request everything in writing. Verbal agreements and understandings won't carry any weight when it comes down to implementing the services your child needs. When you attend IEP meetings, do not go alone. Even if you have a great working relationship with the



school, take a friend, a family member, a paid advocate – anyone that can take notes for you and be there for support if things get heated. Speak up with assertiveness, but don't be aggressive. Even if you disagree with what the teachers and administrators are saying, aim to build strong relationships with them. Keep in mind that you want them to have an open line of communication with you.

Advocating for social change in your own back yard

Sometimes advocacy can happen in unexpected places. Communities and groups that you already participate in can become a vehicle for activism. In your community reach out to local support groups, advocacy agencies, faith communities, community associations, and local events. Search our online provider database or scroll through our online calendar of events to get connected. Facebook and other online social networks are another great way to invite "friends" to become fans of Pathfinders for Autism and advocacy groups.

continued on page 2

Becoming and Advocate – cont.Proud Sponsor of
PFA Resource Center**Advocating for systems change**

Don't be intimidated – this is more doable than you may imagine. There are opportunities for you to impact change at the legislature, county council, state agencies, and advisory councils.

Explore ways to participate in public policy and the legislative process, including the Maryland General Assembly, proposed legislation, hearings, and testimony. What can you do?

- Find out when the Board/Committee meets that's discussing a topic or bill of interest to you
- Attend a town hall meeting
- Attend rallies
- Listen, take notes, identify who speaks on what issues
- Make a presentation (public testimony)
- Network
- Write letters to your legislators
- Build relationships
- Share information

For more information on how you can become involved, visit The Arc of Maryland, a statewide public policy advocacy organization committed to dignity, civil rights, quality supports, community inclusion, and the empowerment of individuals with cognitive and developmental disabilities and their families.

Advisory Councils, like each county's Special Education Citizens' Advisory Council (SECAC), link members of the community with providers and policy makers. Community members can find out about joining Advisory Councils by contacting their local elected officials, state agencies, and advocacy networks.

These councils make recommendations on:

- Policies
- Programs
- Evaluations
- Quality Assurance
- Annual Plans
- Budgets

Advocacy is...

- Helping people to help themselves
- Building confidence in others to help them help themselves
- Supporting efforts toward recovery and independence
- Providing necessary resources for appropriate decisions and actions
- Informing people of their rights
- Providing technical assistance and training
- Analyzing a problem and pinpointing areas of responsibility
- Lobbying for necessary laws
- Investigating grievances
- Following up on complaints
- Pursuing legal remedies when other avenues have failed to get results
- Organizing groups for mutual support and action
- Interceding on behalf of people when they are unable to help themselves

Advocacy is NOT...

- Taking over a person's life or situation and making all the decisions
- Reinforcing feelings of helplessness and dependence
- Discouraging people from being activists
- Making excuses for unavailability or inadequacy of services
- Accepting the "status quo" when laws are not implemented

- Ignoring complaints or denying existence of reported problems

The Dos of Advocacy

- DO make it clear who you are and why you are there
- DO request permission from the person to engage in conversation
- DO be honest about your own reactions and feelings
- DO listen carefully
- DO talk about options before attempting to resolve the problem
- DO take notes and try to establish facts
- DO keep all stakeholders informed of all conversations and conclusions

The DON'Ts of Advocacy

- DO NOT make promises you can't keep
- DO NOT force anyone to take a position they do not want
- DO NOT be pressured into backing away from the problem
- DO NOT hesitate to compromise as this will lead to some reasonable conclusion
- DO NOT give false expectations

So the next time your child is melting down at Target and you stand up to the staring and judgmental eyes of strangers, put that giant "S" on your chest and remember you are Super Advocate.

Additional Resources

The Arc Maryland
<http://www.thearcmd.org/>

Pathfinders for Autism Onlie Provider Database
<http://pathfindersforautism.org/providers-services/>

Pathfinders for Autism Calendar of Events
<http://pathfindersforautism.org/calendar/>

Written by Shelly McLaughlin, Director of Safety Programs, Pathfinders for Autism. We thankfully acknowledge Erin Leatherwood at the Mental Health Association of Maryland for her contributions to this article.

© 2010 Pathfinders for Autism