

# Advocate for autism

The word “advocacy” is used in a variety of ways both inside and outside the disabilities community. The *World-English Dictionary* defines advocacy as “active support, especially of a cause.” But what does that mean for us in the autism community, in practice?

Any of us—from professionals to parents and from teachers to individuals—can advocate in a wide range of ways. If you want to work directly with legislators to craft the laws and regulations that benefit the autism community, consider working as a policy advocate. Health-care advocates work to assure access to appropriate medical and wellness care. Or advocate on behalf of your child or sibling with autism by attending IEP meetings and working with educators.

Advocacy can take place on behalf of a group or an individual. Parents may advocate on behalf of their children; policy advocates, on behalf of whole communities; and self-advocates stand up for their needs not only as individuals but also as members of the community.

## Start early to train self-advocates

Ideas for starting to train self-advocates as early as age 10 to 12 (and continuing through age 21) are available in the *Tri-State Transition Slide Guide*. This tool details self-determination, post-secondary education and training, employment, and independent living. Self-advocacy goals include knowing and describing the disability, identifying needs or fears in school and the community, and knowing what an IEP meeting is and participating in it.

A self-advocate might consider these questions:

- How do I make decisions and use community resources?
- How do I talk about my disability and the support I need?
- What are my goals, and what is my plan for reaching them?

The *Tri-State Transition Slide Guide* is scheduled for hand out at a 14-year-old student’s IEP meeting. If you need a copy, ask the educational diagnostician or transition specialist.

## Promoting self-advocacy in health care

A pilot program in Delaware currently applies a new approach to providing comprehensive primary care. Called a patient-centered medical home (PCMH), this new health-care model moves away from the familiar symptom-and-illness structure toward a home base for any child’s medical and non-medical care. The relationship between the child, family, and primary care affords more comfort and convenience as well as optimal health over the child’s life span.

*Why?* Because as a patient-centered model—organized around the patient (or child)—it creates an ongoing partnership with a primary care physician (or doctor) who leads a team of professionals in proactive, preventive, and chronic care management. According to the American Academy of Family Physicians, one of the largest medical organizations nationwide, “a [PCMH] integrates patients as active participants in their own health and well-being” ([www.aafp.org/online/en/home/policy/policies/p/patient\\_centeredmedhome.html](http://www.aafp.org/online/en/home/policy/policies/p/patient_centeredmedhome.html)). In other words, a PCMH promotes self-advocacy in health care.

## How-to guide

### Be a health-care self-advocate

#### Step 1: Make an appointment with your doctor.

If you’re uncomfortable about meeting a new doctor, this is normal. Make the appointment anyway. You want your doctor to know you before a problem arises. Consider your initial appointment as your baseline for your long-term health care. If you feel good today, that’s great. You still need to be screened for possible future health issues. And your doctor knows and has access to the tests that will identify your health-care needs.

#### Step 2: Research health-care options online.

Make sure the research is from a credible source. Here are some sources that may help you get started:

Utah-based Medical Home Portal offers a website that not only helps parents become more effective partners in their children’s health care but also provides a handout for adolescents and young adults in transition. Entitled *Taking Charge of Your Health Care*, the handout focuses on three essential areas:

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- Be your own health-care advocate.
- Take charge of your health-care information.
- Plan for transfer to an adult doctor.

To download a copy of the handout, visit [www.medicalhomeportal.org/link/1102](http://www.medicalhomeportal.org/link/1102).

For more information on patient-centered medical homes, visit the U.S. Department of Health and Human Services webpage, *HRSA, Health Information Technology and Quality Improvement*, at [www.hrsa.gov/healthit/toolbox/Childrenstoolbox/BuildingMedicalHome/whyimportant.html](http://www.hrsa.gov/healthit/toolbox/Childrenstoolbox/BuildingMedicalHome/whyimportant.html).

The University of Minnesota and The Arc maintain a website entitled *Self-Advocacy Online*. There, you can read stories by self-advocates, locate self-advocacy groups in each state, and learn how to get organized, develop relationships, and live a healthy lifestyle. For more, visit [www.selfadvocacyonline.org](http://www.selfadvocacyonline.org).

### **Step 3: Prepare for your initial appointment by listing all your concerns.**

If you have trouble in a new setting or with new people, your list of concerns will help keep you focused.

If you have memory issues, take notes during your appointment, record it, or ask someone to accompany you (to remember what is said). When you leave the doctor's office, you should understand your health risks as well as what you need to do not only to prevent a health issue but also to face a possible health issue in the future.

## **Education advocacy for very young children**

Workers at Child Development Watch (or Child Watch, for short) help families get support for very young children, birth to three years of age, with autism spectrum disorders (ASDs) by writing individualized family service plans. Each IFSP details the services needed not only to help a child's development but also to enhance a family's capacity to help the child's development.

When Child Watch services end at age 3, schools take over. To create a smooth transition, talk to a Child Watch worker as soon as possible.

If a child is already three or older and an ASD is suspected, contact the local elementary school's special education coordinator or teacher, and request a psycho-

educational evaluation. Point out your concerns so the evaluator can be sure to assess them in depth.

**Important:** Always follow a verbal request with a written request!

The initial evaluation must be conducted within 45 school days or 90 calendar days (whichever is less) from the date permission is given. Once determined that a child is eligible for special education, you become an important member of the child's individualized education program (IEP) team.

The Child Watch worker can help you understand the differences between the IFSP and IEP. You may also want training on special education rights. For upcoming training in your county, contact the Parent Information Center (PIC) of Delaware at [www.picofdel.org](http://www.picofdel.org).

For more on special education, read about Title 14 at [www.delcode.delaware.gov/title14](http://www.delcode.delaware.gov/title14).

## **Education is more than academics**

**by Lauren O'Connell Mahler, Esq.  
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If your child gets good grades but struggles socially, behaviorally, emotionally, or physically at school—or perhaps your child can't stay organized with schoolwork—could he or she be eligible for additional educational supports and services? The answer is "Yes."

Education is intended to prepare students to become independent, self-sufficient, job-holding members of society. For students to achieve career success, attend college, or be able to care for themselves, they need more than good grades. Thus, courts have agreed that education extends beyond academic skills. It also includes the social, emotional, and physical skills needed to navigate the real world.

Experts in the medical field have recognized that psychological attributes, such as emotional control, social understanding, organizational skills, motor skills, and other non-academic abilities, are not inborn for all children. The law, likewise, recognizes difficulties in these areas as legitimate disabilities that require educational accommodations if they impact children at school. Thanks to research, we know that children with disabilities can make meaningful progress toward developing non-academic skills if given proper instruction and support.

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Helping People and Families Affected by Autism

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# Advocate for autism (continued)

If your child is struggling with non-academic issues at school and is not receiving special education support, ask your school for a comprehensive educational evaluation—in writing. Make sure that this evaluation includes testing of your child's unique issues. All areas of suspected disability should also be comprehensively evaluated:

- If your child is struggling with behavioral problems, ask that the evaluation include behavioral testing.
- If your child is struggling with social skills, ask that the evaluation examine social function or incorporate autism testing.
- If your child is struggling with organizational or task completion, ask for tests that look at attention deficit hyperactivity disorder (ADHD) and include executive functioning.

Once a child is deemed eligible for special education, his or her individualized education program (IEP) should offer the opportunity to make meaningful progress in each of the areas of need, both academic and non-academic. What kind of special education can help a child who is struggling in non-academic areas?

- For behavioral and emotional problems, a child may benefit from in-school counseling, positive behavioral supports, work with a behavioral specialist to analyze behavior, a functional behavior assessment, a behavior intervention plan, parent training and counseling, and in-school psychological services.
- For deficits in social skills, a child may benefit from participation in a structured social skills group and the chance to practice social language skills with a speech and language therapist.
- For struggles with task completion and organization, a child may benefit from direct instruction in organizational skills, agenda or binder checks, and color-coding of school materials.

For more information, visit the McAndrews Law Offices website at [www.mcandrewslaw.com](http://www.mcandrewslaw.com). Or call (302) 308-4975.



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