Preparing Parents to Advocate for a Child With Autism

Educators have a vital role to play in helping parents develop the skills to become effective advocates for children with autism

By Anne Foster, Debbie Rude, and Caroline Grannan, Phi Delta Kappan

Parents are expected to advocate for their children in a multitude of situations. It begins early with navigating their children’s physical and emotional well-being. They come to rely on their children’s physicians, their family, and the informal network of friends facing similar circumstances to help them steer safely through the early days of parenthood. They read all there is to read on the vast array of parenting subjects, seeking answers on how to avoid making mistakes. When it comes to their children’s education, parents play a key role as first teacher, supporter, and advocate. Parents make choices about how and where their children will be educated, and children thrive best when their parents are closely tied to their educational experience.

But what happens when life throws parents a curve ball? How do they navigate the waters when their child is diagnosed with autism? Specifically, how do they advocate to ensure that their child, like every other child, gets an education that prepares them for their life and future livelihood? And how can schools help them become effective advocates for their children?

For parents living with children diagnosed with autism, advocating for their child presents a new reality in parenthood, often unexpected and with more questions than answers. Once they have passed through the various stages of denial and sadness, questioned the experts, and finally accepted the reality of the challenges their child will face, they have to get busy. Time is of the essence, and advocacy for a child living with autism within the public school system requires that parents have a very specific set of skills.

Public schools and educators have a responsibility to help every child succeed, and this includes children with autism. While communication between teachers and parents is always important, it may take on even more significance for parents of children with autism. Such children whose parents advocate for them have a built-in advantage in schools, but it takes more than this. Educators must
work closely with the student and their family to make sure that everyone is on
the same page and that they are together a strong team for the child.

**Parent Advocates**

Sabra Townsend is a Philadelphia mother of a 14-year-old son who has autism and attends public school. As an advocate and activist for her child and for all children with autism, Townsend has successfully combined her passion for children with autism with the pragmatism required to navigate the public education system and get things done. “People think they know what you’re going through with a child on the autism spectrum. Remember that your child is your child before the autism diagnosis and after. They’re still the same kid,” she said. Her pragmatism is evident when she says that, even in states with ample funding for services, “you still have to be prepared for arguments and battles and advocacy.”

Children with special needs are entitled to certain services as a matter of law but not all school districts provide what’s legally required, Townsend said. Parents need to know how to effectively do Internet research so they can strengthen their hand. They shouldn’t automatically assume that the school is against them. “You have to become an informed advocate for your child,” Townsend said. “It’s the case of the squeaky wheel.”

In 2003, a group of parent volunteers in Philadelphia working to support their children’s education started a group called Autism Sharing and Parenting. With the help of some small grants, this 501(c)(3) nonprofit organization presents practical, hands-on information to parents. They don’t dumb it down, but they do try to explain some of the big “research words.” A play therapist is provided during parent meetings so kids can get more than just child care and parents can focus on meetings.

The Center for Autism and Related Disorders, a national organization that promotes the Applied Behavior Analysis treatment, honored Townsend with its Small Miracles Award this year. Regarding her advocacy, Townsend said, “It’s a full-time job that you’ll never get paid for. Get a file cabinet and keep all your papers organized. Build relationships. When something happens—they already know you. You’re not a new piece of the puzzle.”

She also said with the pragmatism mentioned earlier that hollering and screaming don’t get parents anywhere. “It doesn’t help when they say ‘That mom is crazy,’ and nothing gets done. I want the best services for every child, but I want them to know that I’m going to be asking questions until my child has what he needs,” she said, although she cautions that parents must be sure they’re not so over the top that nobody likes them because that will impede their ability to solve problems in most school districts.

Townsend teaches a workshop called “Everyday Strategies,” where she suggests that participants ask themselves what about their child brings them joy rather than focusing on deficits and challenges. About her own son, she said, “My son can be hilarious. There are amazing things he has taught me. He can do things that other 14-year-olds can’t do.”

**Don’t Get Emotional**

Katy Franklin is a San Francisco mother of a 12-year-old son who has autism and attends a charter school. She was self-employed in her family’s photography business and was able to stop working to devote full-time to working with and advocating for her son. She chairs the San Francisco Unified School District Citizens Advisory Council on Special Education.
Although Franklin believes a child’s special education services shouldn’t depend on the parent’s ability to advocate, she nonetheless believes that parents should learn all that they can about the legal system and the Individualized Education Program (IEP). After her son was diagnosed with autism, for example, she read the entire California Education Code.

To be effective advocates, parents must also be great case managers—managing medical records, school records, evaluations, and history, which means devising a record-keeping system that works for them. Making good notes of everything that happens is essential, she said.

In the Bay Area, Support for Families of Children with Disabilities teaches parents how to advocate with school districts and others. She said parents must rein in their anger and calm down. “You have to almost be a therapist, a doctor, and a lawyer. You have to do this and get on with your life. You have to do this without burning bridges.” Franklin fully understands that while parents sometimes understandably want to write angry six-page letters (and she recently found one she wrote herself when her child was three), what parents really have to do is get schools and teachers on their side.

**Develop a Network for Advocacy**

Like Townsend and Franklin, parents must understand some basic assumptions of advocacy. Though parents are their child’s best advocate, effective advocacy requires a network of personal and professional support. Parent advocates of children with autism should remember that times have changed. Autism is not an educational death sentence for their child or their family, but early intervention is crucial. Although there is no cure for autism, early intervention coupled with parent advocacy will help build confidence in children so they may eventually advocate for themselves as they move beyond the public education system.

Educators will make their work easier—and improve the learning environment for students with autism—if they help parents become effective advocates. Here are some steps that educators can take to guide parents as they navigate the K-12 system.

Provide opportunities for parents to walk in their child’s shoes as he or she manages through the school day. What coping mechanisms are in place for him to successfully manage the obstacles children with autism face? Children living with autism often lack the skills and tools needed to communicate and effectively cope in a traditional classroom. In order to advocate effectively, parents and caregivers must first build a common understanding of autism in conjunction with an understanding of how autism is relevant in a child’s daily life.

For example, how does the child respond to changes in the daily schedule? What effect does a noisy classroom have on the child’s response to changes in the daily schedule? Is the child communicating effectively with his or her peers? Do words have one or multiple meanings? When and under what circumstances does the child “lose it” while in or out of school? How does the child respond to light or physical stimuli? Does the child perform better if he or she is given frequent and deliberate opportunities for physical movement? So, while there is no cure for children diagnosed with autism, parents must develop a deeper understanding and acceptance of their child’s challenges before they can determine strategies to minimize the obstacles autism presents in his or her ability to learn.

Some children’s mild symptoms of autism may not impede their cognitive development. To parents familiar with the less-obvious symptoms, it presents a double-edged sword. To the untrained eye, the child may present very much like a “normal kid” in the classroom. These children are bright, highly compliant, and eager to please teachers, and they have a high need to be accepted by peers. While this sounds pretty normal, psychologists say that these children develop coping skills to hide their
challenges from classmates and teachers. However, if the material becomes complicated (which it certainly will), class size increases, or social issues become more complex, these children struggle. The daily challenges children with autism face in order to survive and thrive in classrooms today are multidimensional and must be met with understanding, compassion, and a clear sense of purpose.

A truly successful model requires advocacy, collaboration, and partnership. Who are the child’s peer and adult “safety nets” at school and in the classroom? What makes these people special to this child? The community of advocates probably won’t be limited to the public school environment. Encourage parents to reach beyond the school to learn more and build alliances with people who specialize in and understand autism. Consider starting an autism parent support group for parents in your school or district. Develop a list of top resources in the local community including speech and language therapists, child psychologists, and special education advocates. Encourage parents to educate immediate and extended family members to build internal support for their child as well. Remind parents to assume nothing. Prepare them to explain autism and communicate how its specific nuances apply to their child. Once they have a deeper appreciation for the challenges surrounding their child, they will be better able to enlist others to support them and their child.

Public schools are under tremendous pressure to deliver a host of general and special education services to a broad range of students along the autism spectrum. Not all students diagnosed with autism will qualify for special education services within a public school. In addition, the data associated with a student’s performance on special education assessments are sometimes determined by agencies outside the school. These agencies were established in the mid-1960s to respond to federal legislation in public education to serve students with special needs. Without these administrative agencies, whole districts would have crumbled under the weight and costs associated with providing these services.

While financial resources for special needs students have always been a challenge for schools, individual districts are facing even tighter general education budgets that limit their ability to deliver quality interventions and resources. Schools and districts can set aside time to educate parents about the budgetary realities early in the game so this group of parents is not surprised by how budget cuts might affect their children. Parents need assistance in recognizing and preparing for the possibility that the district alone won’t meet the child’s needs, although the district can be a major contributor to meeting those needs. The funding situation also gives parents a motivation to work with other parents in making sure schools are adequately funded to meet the learning needs of all children. Equipping parents with a good understanding of how schools are funded for special needs students would aid them in this effort.

Parents of students with autism who qualify under either general or special education must work with building administrators, teachers, and paraprofessionals (specialized aides to assist in classroom environment) to establish a very specific set of educational goals. This is where parent advocacy is crucial. While children benefit from experienced, nurturing, and professional teachers over the years, many teachers haven’t been equipped to handle the nuances that come with children diagnosed with autism. Autism is not something that children outgrow. They simply acquire the strategies to compensate for weaknesses in these areas. Developing sound strategies early on, especially at the elementary education level, will help children with autism as they prepare to transition to the middle and high school level. Teachers are doing what they can with what they know about students in general. But parents must learn how to explain to teachers what makes their children unique. Educators can do this by ensuring that parents understand what is unique about their child, what strategies work best and prepare them to communicate this information to other teachers and supporters. This may mean role-playing with parents so they learn effective ways to express this
information or helping them write down what they want to share with others.

Effective parent advocacy requires a very deliberate strategy—by parents and educators. This strategy requires specific conversation at the beginning of each school year, frequent monitoring, and constant communication between the teaching and professional staff at the schools and parents. Finally, to have the most effective parent advocates possible, parents must understand the resources needed to assist every child’s ability to learn, grow, and contribute to society as they become adults living with autism.

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