

The benefits of a good relationship

We all need good relationships in life. They are the foundations of a fully functioning community. For individuals and families living with autism spectrum disorders (or ASDs, for short), good relationships enable us to work well together. In turn, we can take on overwhelming challenges—and overcome them!

As a nonprofit agency that works to create better lives for people with ASDs, Autism Delaware relies on relationships with people and organizations to meet wide-ranging needs. These relationships allow us to offer recreational outings, family support, social events, advocacy at both the state and local levels, information and referrals, adult services, and clinical services.

In this article, we discuss the benefits that are possible through good relationships—with schools, families, and community partners.

One of the most significant connections any family living with autism can make is with the child's IEP team at school. As the group responsible for the child's individualized education program, the IEP team thrives when a positive working relationship exists between all the members, including the child's parents or guardians.

The principal of the Sussex Consortium, Vivian J. Bush, PhD, has 24 years' experience in the field of psychology and has heard a lot of advice being given to parents. The most important piece is that parents need to be frank with the IEP team.

"What I've seen most often," explains Bush, "is that, by the time parents ask for help, they have established years of negative behavior patterns that take harder work to fix than if the behavior had been addressed when the child was younger. Sometimes, parents do not even realize the measures they go through every day just to keep the peace at home. Then, one day, they are facing a child who is presenting a danger to him- or herself or using his or her strength against the family. Choices become limited. 'How did we get here?' they wonder. 'And how do we fix it?'"

"Families with children with autism have a host of confounding emotions, such as grief, guilt, and anger, all mixed in with love," continues Bush, "so the hardest thing these families ever do is open their doors to strangers and expose their insecurities and weaknesses. These

families may think their lives are not perfect. But whose life is? Accepting life as it is and being completely honest about it may be the only way for anyone to help them—even if they are offered solutions they may find difficult to accept.

"As school professionals," adds Bush, "we know that autism is a 24-hour-a-day, 7-day-a-week job and that schools touch only a small portion. The rest falls on the family. With an empathetic ear, the IEP team can offer support and help. Being honest with the IEP team is hard, but it can be the most critical tool for moving toward a successful outcome."

Experts agree that preparing for each IEP meeting is key. Begin by answering these questions concerning the child or sibling with an ASD:

- What do you want?
- What does the school want?
- What action do you want the school to take?
- How motivated is the school to give you what you want?
- What prevents the school from giving you what you want?
- How can you address the school's concerns and fears?

Note, too, that the questions change focus when the child is about 14. At this time, the issue becomes the transition to adult life. Your goal is to make sure that all the child's needs for education and training are met before aging out of the school system at 21.

"This information is covered in depth in *Wrightslaw: All About IEPs*," notes Autism Delaware Resource Coordinator Heidi Mizell, "and every parent who has a child with autism should have a copy." Written by Peter W.D. Wright, Esq., Pamela D. Wright, MA, MSW, and Sandra W. O'Connor, MEd, this book contains concise answers to frequently asked questions about IEPs.

"To prepare a child with an ASD to meet a life goal," continues Heidi, who is also the mother of an adult son with Asperger's syndrome, "each child requires an education that enhances the child's abilities, addresses the disabilities, and reaches specific goals. Autism Delaware offers support by guiding parents to an understanding of their children's needs. This includes the accommodations and support they need for academic, behavioral, social, and emotional success."

Continued on next page



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Main office:

924 Old Harmony Rd., Suite 201, Newark DE 19713
(302) 224-6020

Southern Delaware office:

16394 Samuel Paynter Blvd., Unit 201, Milton DE 19968
(302) 644-3410

The benefits (continued)

A good relationship with a child's school can continue through the transition process and into adult life with help from Autism Delaware's adult services program. Known as Productive Opportunities for Work & Recreation (or POW&R, for short), the program provides a range of services—community-based vocational services; competitive, supported, and self-employment; and social and recreational opportunities—to individuals with a range of needs.

"To offer all these services," explains Autism Delaware's POW&R director, Katina Demetriou, "we build relationships on a number of fronts, beginning with potential community partners. Each community partner is an organization doing business in the community. It has its own needs, standards, and work culture. Once we fully understand these factors, we work to place the right person in the right job."

Among the many benefits to community partners, Autism Delaware not only matches the organization's needs with a POW&R participant's skills but also teaches the POW&R participant to do the job the way it needs to be done. POW&R assists with operational efficiency and provides ongoing supports for quality assurance, too.

"We expect customer satisfaction," continues Katina, "so a trained staff member accompanies each POW&R participant to work. The staff, having learned the job as well, is able to support the POW&R participant when needed. People with autism sometimes need reinforcement when learning a new process. Or depending on the individual's disability, the new employee may need to modify the work environment for a better fit, like setting up a work area to accommodate sensory needs.

"With the right fit of individual to community partner," adds Katina, "we can create a win-win situation."



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