

This is the first in a series of articles appearing in the *Autism Advocate*, titled “Navigating the System,” on how to help parents, caregivers and individuals on the spectrum learn about and locate the services and supports they need across the lifespan.

After the Diagnosis

BY CARIN YAVORCIK

You may be traveling a different path than you expected.

You wondered during pregnancy if your child would play baseball, if he'd be good at math, whom he would marry and where he would go to college. Now you wonder how to meet your child's needs and who will be there to offer support after you're gone.

You may face feelings of guilt, isolation, confusion and anger.

And on top of a myriad of doctors' visits, technological jargon, labels and a mountain of information to process, you need to learn quickly to navigate a complicated system to figure out what services and treatments your child needs, and how to get them. Where information on autism was once nearly nonexistent, today you can Google the word and get more than 18 million hits. How can you sort good information from misinformation or just plain bad information? Where do you even begin?

Your path may be different than you expected, but the challenges aren't insurmountable. What follows is a collection of suggestions and advice from parents and professionals to help you find your way through the tangle of information that surrounds autism services and supports.

A
B C **First Steps**
The single most consistent piece of advice you'll get is to find other parents

who have been through the process. The services available through any given school system, local and state government are about as varied as people on the spectrum, so it's important to talk to people who have similar challenges to your loved one with autism, and are dealing with them in the same geographical location. You can connect in person, online or over the phone.

“It is important that we help connect new families with a family support system so they can have someone who has been through the maze of services and supports—that can serve as a mentor to help them navigate this new and unfamiliar territory,” explains Jody Fisher, project manager for autism services at the Ohio Department of Mental Retardation and Developmental Disabilities.

The Ohio Center for Autism and Low Incidence took this idea a step further. They asked a group of parents, “When your child was first diagnosed, what information did you need most?” Through the answers, they developed a parent guide to autism spectrum disorders. Though it was

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designed specifically for Ohioans, much of the manual has broader applications. You can find it online at www.ocali.org/pdf_family/Parent_Guide.pdf.

“Once you can connect the dots, you can maneuver through the system so much easier than if you have just little pieces of information,” says Catriona Johnson, whose 15-year-old son Asher was diagnosed with autism in 1995.

“Your first connection should always be with other family members, but the next thing is education—going to workshops, learning more about what your rights are, and finding out about the best practices, new ideas and new evidence-based initiatives on the cutting edge of service delivery.”

Johnson got in touch with the Howard County (Md.) ASA chapter almost immediately after Asher was diagnosed, and says she got her best leads from other families she met there. Within six months, both she and her husband were on the board of directors, and used the opportunity to make the chapter more active, bringing in speakers and hosting workshops.

Another helpful resource in sorting through all the various treatment options can be a developmental pediatrician, says Margarita Fernandez, whose 9-year-old son Stefan was diagnosed with Asperger’s Syndrome three years ago.

“We went to a nutritionist, physical therapist, vision therapist, kinesiologist, occupational therapist, neurologist—you

start going everywhere you think there is room to improve,” she explained. “The developmental pediatrician helped on all these different fronts. As a parent you don’t really know as many details, but he or she can help sort that out.”

However, there may be times when parents are interested in alternative therapies that the developmental pediatrician may be unable or unwilling to assist with. “As a parent you have to figure out what you think is going to work for your child,” Fernandez says. “You feel like you have to try everything—especially if it’s a therapy that is noninvasive or not drug-based—and you constantly have to be checking to see if treatments are making any impact.”

This can be difficult. As working parents, Fernandez says she and her husband looked at practical limitations to treatment—not necessarily just financial limitations, but also limits of proximity or scheduling. If there was something they saw that made an impact on children similar to Stefan, they usually found a way to make it work.



Finding Supports

Finding the financial resources to pay for treatments and services can be one of the most challenging aspects of caring for a loved one with autism.

“For new families, I would encourage them to explore as many avenues as they can to assure they find the necessary resources to meet their child’s health,

educational, and developmental needs,” Fisher advises. “This may include services and supports covered through their family’s health care plan, those provided through state or federal programs, such as Medicaid, as well as those through their local community, like their public school district.”

Bringing several different pots together can sometimes be the best strategy.

“You have to educate yourself about what’s out there and how to fit it together—there’s no place that has one-stop shopping,” explains Johnson, who in addition to being the parent of a child on the spectrum is the assistant director for state and federal relations at the Maryland Developmental Disabilities Administration. “I know a young man with autism in Howard County who’s a great pianist. He was able to get grants from the Peabody Institute and Project Income, a project funded by the Maryland Developmental Disabilities Council, along with funding from the Developmental Disabilities Administration for self-direction, and in January was able to have his first piano recital at the Peabody Institute—and he reached his dream of becoming a concert pianist. That’s three streams of funding he brought together. You have to think, what’s out there that I can use and what can I braid together to help me reach my goals?”

Equally important to finding financial supports is finding emotional ones. Look to natural supports—friends or other loved ones who ask how they can help. Whether it’s a friend, relative, fellow parent, faith community or therapist, the support can make a huge difference.

“Helping parents find ways to stay healthy and happy is key,” says Fisher. “A lot of families become so consumed by taking care of their child’s needs that they put their own needs on the back burner. They do need to provide care for their child, while at the same time remembering to take care of themselves too.”

Having supports outside your immediate family becomes especially important as your child grows older and you begin to think about transition planning.

“In transferring control from a parent to a young adult, a key thing that families can do is help build that circle of support so there are multiple people that the individual can go to if he or she

so interested in it she got a job working in the public policy field. Now, working for the Maryland Developmental Disabilities Administration, her advocacy efforts extend far beyond her personal life.

“The more advocacy that I’ve done, and the more systems I’ve gotten to know, the more my interests have gone beyond my own child,” Johnson says.

fied to meet the needs of the spectrum of kids. How can you put that kind of burden on one teacher?”

Often this kind of advocacy has to happen as children progress through grade levels—there are new teachers, changes in administration, budget cuts. Parents need to stay vigilant and work collaboratively with the school.

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has support needs,” Johnson explains. “Sometimes those support people are part of the service delivery system, but you also need people outside that system with no paycheck involved who are sitting at the table with your loved one. As a family member, that’s the most important thing you can do, so when you’re gone he or she can move on as independently as possible with the support he or she needs.”



Changing the System

There are times when the existing system is not enough to meet your family’s needs. When that happens, change the system, says Johnson.

“Again, it’s about connecting the dots,” she explained. “Once you can connect those, then you have the power to change them.”

Johnson took the Partners in Policymaking course, designed “to teach parents and self-advocates the power of advocacy to change the way people with disabilities are supported, viewed and taught, and how they live and work” (www.partnersinpolicymaking.com). Johnson was

“But every time I advocate for a change in the system, I know my son will benefit too. As you get more and more involved with systems advocacy, it seems like you’re moving farther away from the personal and working to help more and more people, but you’re also building a system that will benefit your loved one.”

You don’t have to take on such a large role to make a difference in systems advocacy. A few phone calls a year in support of important legislation can make a difference, and even just knowing your rights and standing up for them can help.

Fernandez, like many parents, had to stand up for her child’s rights in the school system last year.

“A group of parents and I had to fight with the county to get the proper supports in the classroom,” she explains. The class her son was in was too large and did not include enough assistance to give students the supports they needed.

“We were able to get a promise of having fewer kids this year, but now the class has an incredible variety of individuals, from a child who is nonverbal to kids more like Stefan with Asperger’s. The teacher doesn’t have the support she needs and the curriculum has to be modi-



Walking a Different Path

Ultimately, you have to live within your own reality. From time to time you’ll have to learn to accept the challenges while recognizing the rewards they bring.

“It’s not about wanting to fix people, but to fix communities. I’m at a place now where I wouldn’t change anything about who my son is, even if I got the opportunity,” Johnson says. “But there are a lot of things I would change in our society. I think if people can shift their focus to the external, it can truly improve the lives of people with autism and other disabilities.”

About the Author

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Online Resources

AUTISM RESOURCES

A comprehensive guide to autism resources on the Web:
www.autism-resources.com/

AUTISMSOURCE™

Autism Society of America's online referral database of autism-related services and supports, with more than 25,000 listings of local service providers: www.autismsource.org

NATIONAL DISSEMINATION CENTER FOR CHILDREN WITH DISABILITIES

Has a large selection of information topics on disabilities, as well as contact information for service providers listed by state: www.nichcy.org/

U.S. DEPARTMENT OF EDUCATION, OFFICE OF SPECIAL EDUCATION AND REHABILITATIVE SERVICES

Describes programs and initiatives for students with disabilities, as well as information on the Individuals with Disabilities Education Improvement Act (IDEIA) and No Child Left Behind: www.ed.gov/about/offices/list/osers/index.html

WRIGHTSLAW

Provides in-depth information on special education law and advocacy. Also includes the "Yellow Pages for Kids," a directory of special education service providers: www.wrightslaw.com/

Many parents say they've found the most insights into their child with autism through the observations of others on the autism spectrum. Check out the Web sites of several adults with autism who have chosen to share their experiences.

Stephen Shore: www.autismasperger.net/
Temple Grandin: www.templegrandin.com/
Jerry Newport: www.jerrynewport.com/
Donna Williams: www.donnawilliams.net/

Blogs and listservs offer virtual insights that can supplement mentoring and suggestions you may get from an in-person support group. There are far too many to mention them all, but here are a few good places to start.

Blogs

About.com: Autism: autism.about.com/
Autism Bulletin: autismbulletin.blogspot.com/
Autism Vox: www.autismvox.com

Listservs

AUTISM-AWARENESS-ACTION

Subscribe: autism-awareness-action-subscribe@yahoogroups.com

GFCFKIDS

Subscribe: GFCFKids-subscribe@yahoogroups.com

THE AUTISM LIST FROM ST. JOHN'S UNIVERSITY

kildall.apana.org.au/autism/



blogs

web

listservs

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