As independent as possible

In this issue, Autism Delaware offers some steps that an individual with autism spectrum disorder (ASD) may take to become as independent as possible. With room for parental oversight, checklists are included that the child with ASD can work through while looking at ways to take control of his or her own life. The covered topics include healthcare and driving. We start below with an overview of supported decision-making.

The roadmap is the same

In The Sun’s recent interview with Jonathan Martinis, JD, the nationally recognized legal expert on disabilities and policy advocate begins by describing some cultural differences between the neurotypical and disabilities communities: “In the neurotypical world, we build on our strengths and overcome our weaknesses by relying on the advice or support of experts. So, if you struggle with math and filing your income taxes, you go to a certified public accountant (CPA) or download TurboTax®. Many of us consider ourselves smart for making this decision. But when an individual with a disability struggles with a task, he or she is judged and labeled for the weakness.

“Why?” asks Martinis. “We all need help making decisions and support to reach our goals. So, we all need someone to help us figure out what’s in our way and help us through. This process is a plan that can lead to self-reliance and independence.

“We hold people with disabilities to a different standard, and that culture needs to change. People need to be seen as people. The roadmap is the same; the only question is the degree of help needed” states Martinis. As the senior director for law and policy at Syracuse University’s Burton Blatt Institute and coproject director of the National Resource Center for Supported Decision-Making, Martinis recommends supported decision-making (or SDM, for short).

“Basically,” explains Martinis, “SDM involves getting the information you need in a way you can understand so you can make a decision.” An example of SDM is asking your doctor what she means when you don’t understand the medical jargon. “Just saying ‘May I have this in plain English please?’ is SDM. We’re able to manage our healthcare because we understand and can do what the doctor says.” This process, says Martinis, is taken away from some people without their
Looking back thankfully

In December, I finished my third and final year as president of the Autism Delaware Board of Directors. I have been truly honored to serve in this leadership role because Autism Delaware is a phenomenal organization. Our mission may sound simple—to help people and families affected by autism spectrum disorder (ASD)—but we embrace all people affected by ASD and our vision concerns their opportunities to learn, grow, and live full lives as included and valued members of their communities.

Over the past three years, I’ve witnessed incredible growth and accomplishments on so many fronts:

- Autism Delaware’s family services team has supported a record number of families.
- Our adult employment program (known familiarly as POW&R) has seen phenomenal growth.
- Autism Delaware’s advocacy effort has seen significant accomplishments. Most notable is the signing of the Alex Eldreth Autism Education Act as well as the long overdue rate increase for direct support professionals.

For all these accomplishments, so many people deserve our thanks, especially the passionate and dedicated Autism Delaware staff that quietly fulfills the organization’s mission day in and day out. I see the staff’s DNA as a double helix of caring and service. It’s a wonderful thing to see and why the organization is so successful.

To our many volunteers, a deeply heartfelt thank-you for donating your time and energy to Autism Delaware. We are successful because of your effort.

A big thank-you also to my fellow members on the board. Our many talents and various backgrounds make us a diverse group—with one important thing in common: passion for supporting Autism Delaware. I will continue to serve as a board member in 2019.

Finally, our agency is fiscally sound with a solid strategic plan in place to address the endless journey of our families affected by ASD. If you are not yet involved in this effort, I encourage you to join us. I assure you, your experience will be fulfilling and rewarding.

Pete Bradley
President
Autism Delaware
Board of Directors

Katina Demetriou, director
katina.demetriou@delautism.org

Melissa Martin, assistant director
melissa.martin@delautism.org

Kim Rosebaum, vocational administrative assistant
kim.rosebaum@delautism.org
Bus: 302.224.6020 Ext. 214
The roadmap is the same Continued from p. 1

consent, even if they have less restricting cognition issues: “The number of people with disabilities in guardianship tripled in the last 25 years. And 90 percent of them lost all their rights—despite the growth in technology and the number of available supportive programs.

“Science has proved that life can get worse when you lose your right to make choices. Forty years of study have determined that the more self-determination a person has and the more effectively the person is empowered to make choices, the better his or her life is. Self-determination equals a better life.

“Parents, I know your goal for your child is happiness, independence, and security,” assures Martinis. “I’m just offering some options to try if you’re coming up against a block of some kind; SDM may give you ways around the block. It all boils down to making a plan to reach a goal and determining what’s in the way and who can help. For people with disabilities, SDM can be a best practice because it leads to informed choice and offers some opportunities without prejudging the individual or taking away rights.”

An in-depth explanation of SDM can be found in The Right to Make Choices: Introduction to Supported Decision-Making. Written by Martinis, this publication can be downloaded from the Missouri Developmental Disabilities Council website at moddcouncil.org. Included in the publication are the steps to take to learn and support an individual’s decision-making preferences, methods, and voice. Briefly, these steps are as follows:

• **Listen, and think:** Talk with the person. What are his or her interests and goals? What kind of decisions does the person make now, and how? What kind of decisions does the person want to make but has trouble with?

• **Identify opportunities and challenges:** Ask what kind of support the person needs to make decisions and reach his or her goals? What challenges does he or she face?

• **Find friends:** Learn about and contact people, agencies, and organizations that can provide the supports the person needs to overcome his or her challenges.

• **Coordinate support:** Work with the person and his or her supporters to develop a plan for who will provide the help the person needs and how it will be provided.

• **Memorialize effort:** Create a written record of your plan. Written plans can help you stay organized and ensure appropriate follow-up.

Get your roadmap here!

“As a parent with a child with disabilities,” says legal expert and policy advocate Jonathan Martinis, JD, “you can be so overwhelmed—you almost have to be a medical professional, education specialist, legal expert, and so many other things. You need a roadmap.”

On pages 4–6 in this newsletter are two roadmaps for parents who want to help their children become as independent as possible. Both include a parental overview and a checklist for a loved one with ASD:

- The piece on managing your own healthcare was submitted by Cory Ellen Nourie, MSS, MLSP, the transition social work coordinator for Nemours/Alfred I. duPont Hospital for Children.
- The driving checklist was researched and written by long-time Sun contributor Jen Nardo, who is also the parent of two sons, one with autism spectrum disorder (ASD).

Another guide that may serve as a roadmap is Supported Decision-Making Teams: Setting the Wheels in Motion, by Martinis and Suzanne M. Francisco, an educational advocate who has three children with disabilities and limited verbal abilities. According to Martinis, this guide has been cited as best practice because it is simple for parents to use while offering ways to find help and a worksheet to help move through the conversation with your child. Find this guide on the National Resource Center for Supported Decision-Making website, supporteddecisionmaking.org.

SDM in Delaware

When former Del. Gov. Jack Markell signed Senate Bill 230 into law in 2016, supported decision-making (SDM) became an option for people who can make their own decisions but need some help because of a physical or cognitive disability.

A legal form known as the supported decision-making agreement can be completed by the individual with disabilities and his or her appointed support person. A copy of this agreement as well as more information can be found at https://www.dhss.delaware.gov/dhss/dsaapd/supported_decision_making.html.
Parents

Has the time come for your child to move out of pediatric-focused healthcare?

If your child already sees a family healthcare provider, a change of physician or nurse practitioner may not be needed. For some people with autism spectrum disorder (ASD), this move might simply mean changing the dynamic in the doctor's office: instead of you answering all the doctor’s questions, let your child answer and work on his or her own healthcare plan with the doctor.

But if your child is still seeing a pediatrician, ask at what age your child will be expected to move to adult healthcare. Some pediatricians follow their patients well into their 20s, while others may have to stop treatment at 18 or 21. Even if your child gets to stay with the pediatrician a little longer, your child’s goal is to be seen and treated as an adult.

With your help, this page is intended to guide your child through the steps that come with adulting his or her own healthcare.

Adulting your own healthcare

The following are some goals for becoming more in charge of your own healthcare. With guidance from your parents, you can pinpoint your strengths and find out where you need help to become as self-reliant and independent as possible. As you move through this process, please ask parents or friends for assistance as necessary.

- Carry your state identification or driver’s license with you at all times. If you do not already have ID, get one at the Delaware Division of Motor Vehicles. There, you can apply for a federally acceptable ID as well as a driver's license. For details, visit https://www.dmv.de.gov/documentguide/index.shtml.

- Also, carry your health insurance card with you at all times. You may need to ask your parent to hand over their copy, or you can request your own card from your health insurance company. Having both your ID and health insurance information is necessary when you go to any doctor’s appointment. Take your ID and insurance card out of your wallet, and hand them to the front desk person who checks you in. If you have never checked yourself in before, the next time your parent does it for you, pay attention to what is done. Better yet, ask your parent to guide you through the process.

- If you take medications, learn how to refill the prescriptions. Start by looking at the number of remaining refills. The number is on the bottom of the label. If you are out of refills, call the doctor’s office, and be ready to share your pharmacy’s name and phone number. Most larger pharmacies have an app to order refills, so you may not even need to speak with anyone. The app allows you to scan the barcode on your medicine bottle to order the refill. If you do not have a cell phone or your pharmacy does not have an app, ask your parents to show you how to call the pharmacy for a refill.

- Start to take your medicine on your own. If you have a hard time remembering, look for an app, pillbox system, or timer to remind yourself when to take your medication.

To set up this new system, consider getting support from someone you trust; in turn, you may discover you’re gradually fading the support of others you've been depending on.

- Know your medical history. The goal is to tell your doctor how you have been feeling over time. This is why doctors and nurses ask as many questions as they do. This process is the kind of thing that takes practice. Go over some of your medical history with your parents ahead of time, and think about writing it all down and keeping it in your wallet or cell phone so you can retrieve it when you need it. Also, consider inviting someone to go with you to your appointments. And ask if you can record the doctor’s comments on your cell phone for future reference.

- Have some basic medical information on you at all times. Some people get a bracelet or necklace to wear that lists an emergency phone number as well as any relevant diagnoses, such as allergies and autism. In the event of an emergency, someone could look at this necklace or bracelet and figure out how to help you. Medical alert or ID bracelets come in different materials, such as metal, silicone, paracord, and leather. Do a search to find a style you would be comfortable wearing. Your cell phone may also have a health app that allows you to store some medical information.

Finally, relax and enjoy your adulting experience. It took you 18 years or more to get to this point in your life, and you are not expected to do all of these steps overnight. Adulting your healthcare is a transition process in which you build skills over time. Eventually, you will be able to look back on these days with pride and know how much you have accomplished.
Behind the wheel with autism

The following checklist features only some of the process for getting a driver’s license in Delaware. Here, you can get an idea about the amount of information you need to know and where to start to get some help.

The Division of Motor Vehicles (DMV) considers you an adult at 18, even if you are still in school. If you are a public school student, read the section below—“If you’re under 18” or “If you’re over 18”—that applies to you. For homeschooled teens or those in private schools, go to “If you’re over 18.”

If you’re under 18—As a student in the public school system, you can take driver education in high school. This course includes road instruction and a written test.

When you pass the course, the instructor will hand out a blue certificate, which means you are eligible for a driving permit called a graduated license. It is considered a permit until you turn 17 and have met two six-month requirements: (1) During the first six months, a licensed driver (at least 25 years of age or older) must accompany you in the vehicle for a mandated number of hours and conditions. (2) During the second six months, you cannot drive by yourself between 10:00 PM and 6:00 AM, except for school, work, or religious activity.

When you complete these requirements, your graduated license will become your legal driver’s license.

If you’re over 18—The first step is to pass a written test to get a learner’s permit. Go to the Delaware DMV and ask for a permit test fact sheet, driver’s handbook, and an app for a practice test. To get your permit, you must answer at least 24 of the 30 questions correctly. For more information, visit https://driving-tests.org/delaware/de-dmv-test-exam-mode.

For complete information on getting a driver’s license, visit the DMV website at https://www.dmv.de.gov/services/driver_services/driver_svcs.shtml.

If you decide driving is not for you, get help using DART First State at https://www.dartfirststate.com.

To learn how to drive safely, a child with autism is entitled to driver education according to Title 14, Section 540, of the Delaware Administrative Code. If your child is a Delaware public school student, driver education can be added to your child’s individualized education program (IEP); specific goals can also be added to boost your child’s driving skills.

On this page is a checklist for your child. It contains a few issues that a teen with autism may face when learning how to drive and is intended to guide the future driver through a self-evaluation process. This checklist also offers some suggestions for turning possible weaknesses into strengths.

Parents

Letting any teen behind the wheel can be scary, but a study reported on the HealthDay website in June 2018 noted “that kids with autism who aren’t intellectually disabled are probably capable of driving a car safely, though they may need more practice time before they get their license” (https://consumer.healthday.com/cognitive-health-information-26/autism-news-51/many-young-people-with-autism-can-become-safe-drivers-study-734919.html).

The next part of the worksheet may help you evaluate your potential for driving and offer some help if you need it.

Continued in the middle column on p. 6
Behind the wheel with autism

Continued from p. 5

Are you ready to drive?
As a new driver, you need to be physically ready to handle the task. The Autism Speaks website provides a checklist of crucial driving skills, including physical coordination and fine and gross motor skills (https://www.autismspeaks.org/expert-opinion/teen-autism-reluctant-drive-should-parent-push-0). For more information, visit https://www.autismspeaks.org.

The Teen Driver Source on the Children’s Hospital of Philadelphia (CHOP) website takes the readiness question a step further: “...first schedule a doctor's appointment to address any concerns, such as communication or cognition issues. [You] may also want to seek the advice of a behavior therapist, an occupational therapist who specializes in driving, or a driver rehabilitation specialist who has training in working with individuals with special needs” (https://www.teendriversource.org/learning-to-drive/driving-with-special-needs/autism-spectrum-disorders-and-driving). For more information, visit https://www.teendriversource.org.

What's the vocabulary of the road?
Like any skill set, driving comes with its own vocabulary. For an introduction to this vocabulary, read readily available information, such as a brochure from a car dealership, an auto mechanic’s manual, or the driving test booklet supplied by the Delaware DMV.

When you understand the language, take the DMV’s sample test online. According to its website, this test offers “an example of the test format and a few questions that you may be asked when taking the driver’s license examination at the DMV or through a driver's education course” (https://www.dmv.de.gov/sampledlexam/sampledlexam.ejs?command=SampleDLExamHome).

An online driving quiz and more information are available at www.dmv.de.gov. Similarly, CHOP offers a practice test at https://www.teendriversource.org. This site also lists the questions you need to answer before starting driver education and guides you through the learning-to-drive process. Skills are broken down into individual steps, and you can practice as often as necessary.

To monitor your progress according to DMV requirements, download the Road Ready app. It will track driving hours and conditions, such as nighttime driving and weather. For details, visit https://www.roadreadyapp.com.
Having a marvelous time learning behavior strategies

I had a marvelous time as a participant at the Outside the Box Annual Conference 2018. It was a great source of knowledge for me as a mother who just recently started a blog about my life experiences called Unboundedmamma. I will be sharing my conference experience on this website.

I have three children in total. My two sons are on the autism spectrum and have developmental difficulties from being nonverbal; my daughter is neurotypical. The conference provided essential tools for dealing with the everyday issues I face with not only my children with special needs but all my children.

The onsite staff provided great activities to keep the children captivated. Plus, everyone felt a part of the conference. No role was more important than another because everyone worked together. It was incredible!

My favorite workshop was Behavior Strategies for Families. Here, I learned the following core strategy for a successful behavior method:

- For a strategy to succeed, start with the “meat and potatoes”—Meet your family’s basic needs.
- Prepare for expectations that involve the entire family.
- Keep your family values while acknowledging your lack of control even with the best behavior plan; trusted companions can intervene and shift to make adjustments.
- You can’t be the only one involved in the behavior strategies.
- Have requirements for the child. What are you willing to negotiate for the child?
- Your strategy is not all or nothing; balance is paramount.
- Setting reasonable goals is vital to successful behavior management strategies.
- Using a visual schedule and token boards, find the motivators and stick with them; include everyone in the family. (Do not limit to only siblings).
- Plan to help your child with his or her strengths and weaknesses.
- Be able to recognize where you are emotionally; as caregivers, all families should be able to do this.

I want to extend a thank-you to everyone who worked diligently to make this year’s conference a success. I am very excited for next year’s conference!

—Mònique Bullock

Stipends available on first-come, first-served basis

Each year, Autism Delaware’s fundraising effort supports parents who want to attend an autism workshop or conference. Reimbursing a parent for as much as $250, a first-come, first-served stipend is available for related costs, such as travel expenses, registration, hotel, and childcare while attending the workshop. To apply, please complete and submit the conference stipend application, which can be found at AutismDelaware.org/About/Scholarships.

Once you’ve received confirmation, be prepared to write a summary of your experience at the workshop or conference, and submit it with your receipts.
What is Smart Cookie Day?

One day every April, autism advocates from across the state gather in the Delaware General Assembly to share their issues and concerns with their elected officials. It’s called Smart Cookie Day because freshly baked cookies are donated for our state senators and representatives to enjoy while we ask support for much-needed legislation. This annual advocacy is a grassroots effort led by Autism Delaware. As an independent 501(c)(3) nonprofit, we rely on individual volunteers to spend some of their precious time and energy advocating for an ideal autism community.

Please join us! Send an email of interest to Sarah.Young@delautism.org. Or call her at (302) 224-6020, ext. 204.

Day camp offers challenge-by-choice approach

Pictured here are just some of the youth who enjoyed Autism Delaware’s 2018 summer day camp held at the Children’s Beach House in Lewes. The local day camp is appreciated by youth and families affected by autism who are not interested in an overnight camp.

Offering the usual range of activities for summer camp, this day program applies the challenge-by-choice approach. In other words, children are encouraged—but never forced—to try new activities. The goal is to guide each child in building self-esteem and enhancing communication and socialization skills.

Around March, visit AutismDelaware.org for details on how to enroll your child in the 2019 day camp.

Did you know?

You can pay for Autism Delaware’s day camp with respite funds from the Delaware Division of Developmental Disabilities Services (DDDS). To get these funds, you need to apply and your child needs to be eligible and approved.

For more information, call DDDS’s Automated Assistance Line (AAL):

In New Castle County, call (302) 577-7171.
In Kent County, call (302) 739-8299.
In Sussex County, call (302) 856-5386.
Direct Support Professionals (DSPs) Day
Honoring their dedication and service

Supporting young men and women with autism both at their jobs and in the community is the daily work of Autism Delaware’s direct support professionals. Through the agency’s community-based employment program known as Productive Opportunities for Work and Recreation (or POW&R, for short), these DSPs support each POW&R participant in his or her choice of vocational service and social and wellness activity.

“The staff wears a variety of hats—caregiver, cheerleader, mentor, supporter, teacher, and opportunity-maker,” emphasizes POW&R director Katina Demetriou. “DSPs show up with a can-do attitude to help each POW&R participant make progress every day.”

Celebrating Direct Support Professionals Day, the festivities began with a keynote address by U.S. Representative Lisa Blunt Rochester (D-Del.) and moved on to awards and acknowledgments for the DSPs, including three who work in Autism Delaware’s POW&R program.

The Community Excellence Award was bestowed by the Ability Network of Delaware (AND) and presented to Alexandra Isitmezoglu, who works out of Autism Delaware’s Lewes office.

Chosen out of more than 50 candidates from various agencies across the state, Isitmezoglu was acknowledged as an outstanding example of what a DSP means to the individual he or she serves as well as the positive impact a DSP can have on an individual’s life. The honor also highlighted Isitmezoglu’s exceptional level of tact and diplomacy as she supports her POW&R participant with dignity and respect.

Nominated for AND’s Star Award were DSP Vickie Fischer and DSP Rosemary Rivera. “This award,” notes Demetriou, “is intended for a person who is a shining example for others to follow. Both Vickie and Rosemary fulfill the demands of their work with the highest level of integrity and demonstrate a strong sense of personal commitment to client satisfaction. They also set a positive example for the individuals they support. They are just plain awesome.”

For more information, go to Autism Delaware.org/Get Help/POW&R.

Autism Delaware’s POW&R program provides state-of-the-art training for its new direct support professionals. If you’re interested in a career as a DSP, send your résumé to Resumes.Power@delautism.org.
Delaware Governor John Carney holds up House Bill (HB) 292 after signing it into law on August 29, 2018. Renamed the Alex Eldreth Autism Education Act, the law stands as testimony to the grassroots effort directed by the former Autism Delaware policy and community outreach director.

This law funds a three-year pilot project intended to make training and coaching available to all Delaware teachers who educate students with autism in their classrooms. It also guarantees critical updates to the state program that serves Delaware students with an educational classification of autism, the Delaware Autism Program (or DAP, for short).

“As a model of service delivery, DAP was considered ahead of its time, but with an 895-percent increase in the number of Delaware school children given an educational classification of autism, the program is unable to provide the level of services and support it once did,” wrote Eldreth in June 2015. Two years later, the percentage was even higher: For the 2017–18 school year, 2,109 students were given an educational classification of autism—compared to 152 in 1991.


Eldreth’s oversight of the grassroots effort focused on the families affected by autism. He supported each autism advocate in a range of activities, from letter writing to telling personal stories to legislators on Autism Delaware’s Smart Cookie Day. Some of the many individuals who advocated over the years were parents Melissa Stansell, Marcy Kempner, Kathy DeNight, Michelle Mathew, Cory Gilden, Jennifer Cinnelli-Miller, and autism advocate Kyle Bryan. Also advocating was University of Delaware Center for Disabilities Studies staff Annalisa Ekbladh, who continued the effort after joining Autism Delaware’s staff and then assumed the lead in passing HB292 after Eldreth died in 2017.

Let your voice be heard

Autism Delaware provides plenty of opportunity to voice your concerns as a parent or caregiver of an individual with autism spectrum disorder (ASD). As an autism advocate, you can choose from a range of tasks that support our grassroots effort without overwhelming you. Plus, we’ll support your effort!

For more information, contact Autism Delaware’s policy and program coordinator, Sarah Young:

- Phone number—(302) 224-6020, ext. 204
- Email—Sarah.Young@delautism.org
Every year, Autism Delaware’s annual volunteer celebration and awards night highlights the outstanding work of dedicated volunteers and autism advocates. This year’s much-deserved red carpet treatment took place in October at Dover Downs Hotel & Casino.

“We take this opportunity every year to acknowledge our volunteers’ unbelievable support,” notes Autism Delaware executive director Brian Hall. “These are the folks who show up, rain or shine, and work to make a success of our fundraisers and family support programs. Without them, Autism Delaware would look very, very different.

“This year,” continues Hall, “we added two new awards to celebrate autism advocates who have gone above and beyond the proverbial call of duty. The Margaret Rose Henry award honors the long-time effort of retired-Delaware State Senator Margaret Rose Henry, and the Alex Eldreth award remembers the lifelong advocacy of Alex Eldreth, who served as Autism Delaware’s policy and community outreach director until his death in 2017.

“To celebrate our twentieth anniversary as an autism agency in Delaware, we also handed out the first-ever Autism Delaware Founders Award.”

Other award winners included
• Outdoor sports store Cabela’s, which received the Noelle Perry Smith Employer of the Year Award.
• Beverage distributor NKS Distributors, Inc., which was named Outstanding Community Partner.
• Delaware Department of Natural Resources and Environmental Control project and data analytical specialist Heather Helmer, who was given the Jason Anderson Outstanding Employee Award.
• Old State Elementary School student Faith Aaron, who received the Rising Star Advocacy Award.

Autism Delaware board member Roger Pearce and his daughter Hope were given the first-ever Alex Eldreth Advocate for Autism Award.

Attorney Frances Ratner received the first-ever Autism Delaware Founders Award.

POW&R Kent County coordinator Joe Balinski received Autism Delaware’s Volunteer of the Year Award.

Delaware State Representative Earl G. Jaques, Jr., was given the Margaret Rose Henry Award for Distinguished Public Service.

Become an Autism Delaware volunteer
Volunteers support every area of Autism Delaware’s grassroots effort. During autism awareness month, for example, volunteers may man information tables, fundraise for Autism Delaware, support the statewide Walk for Autism, or advocate on Smart Cookie Day—depending on their abilities and time. Anyone interested in volunteering should fill out an application at AutismDelaware.org/Change the World/Volunteer.
Helping People and Families Affected by Autism

2019 Walk for Autism

Sign up now!
Saturday, April 6
Cape Henlopen State Park
Lewes

Saturday, April 13
Fox Point State Park
Wilmington

For more Information
Visit AutismDelaware.org/
Change the World.

Or contact Autism Delaware’s
events manager at:
Deanna.Principe@delautism.org

AutismDelaware.org