



THE SUN

SUMMER 2024

The quarterly newsletter for people on the spectrum, their families, and the professionals who support them:

We at *The Sun* strive to be the leading resource for expertise, advocacy, and raising awareness as well as for supporting acceptance and inclusion in Delaware.

What is transition?

Basically, a transition is a change in routine that can range from getting up in the morning to graduating from high school.

This issue's cover story explains the transition planning process used by Delaware schools. And inside, two parents suggest ways to support an autistic child through a transition.

Coverage of transition will continue in the autumn issue due out in October. In it will be information about assessment tools used by the Delaware Department of Education's Autism Resources workgroup and by the local school-based training and guidance firm, ABC Consultants, LLC.

Transition planning: Moving successfully through school

by Kathi Stephan, MEd, Education Associate, Exceptional Children Resources

Transition is a comprehensive and coordinated set of activities designed to prepare students with disabilities for the shift from high school to post-secondary life. In Delaware, this process starts when students turn 14 and continues until they exit the school system. (Even though the process formally begins at 14, early preparation begins the first day of preschool.) The goal of transition planning is to equip young adults with the skills, knowledge, and experiences they need to achieve their post-secondary goals and lead fulfilling, independent lives.

The framework for transition planning was developed by George Tilson, EdD. A longtime transition consultant for the Delaware Department of Education, Tilson developed the conceptual framework around the key principles for any student navigating the educational system. (See the graphic on p. 3 for one example, the conceptual framework for achieving independent living.)

We continue to add and develop this framework using feedback from the statewide multi-agency Transition Cadre that meets on the third Thursday of the month throughout the school year. The purpose and scope of the framework help all stakeholders visualize how all

students should be preparing early and throughout their school careers. Students, families, and school personnel should take certain additional steps to ensure successful outcomes. These steps will lead to a student's meaningful engagement in employment, education and training, independent living, advocacy, recreation, and community contributions.

The core principles include self-determination, a person-centered approach, and having high expectations, adult allies, champions, and supporters as well as cross agency collaboration for follow-along services if eligible.

Early career exploration and assessment are also heavily emphasized. With a student's early exposure to what is possible comes the ability to visualize what post-school goals are possible in the future. To this end, school and community-based assessments aid the student's individualized education program (IEP) team in determining his or her strengths, preferences, interests, and needs.

Five key areas of focus in transition planning

#1 Education and training

It is imperative that students have access to inclusive classrooms from

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AutismDelaware.org

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Take time for yourselves, caregivers!

Having a loved one on the autism spectrum brings both exquisite joy and overwhelming struggle into our lives. Yes, we all care for our children out of love. And we support each other by listening and sharing words of encouragement: "You got this!"

But for me, in all honesty, there are seasons when the struggles overtake the joys. I know many parents, siblings, and caregivers who also experience these struggles, but hide them, putting on a happy face to show the world that they are strong when, in reality, they are dog-tired. That tired-to-the-bone tired.

Do you know about the very real physical and emotional demands that come with constantly caring for someone near and dear to you, day in and day out, with no time for yourself? These demands can lead to frustration, anger, exhaustion, stress, and a feeling of loneliness and burnout. I speak from experience.

So, here is my word of encouragement for all you dog-tired parents, siblings, grandparents, guardians, and support professionals: Take time for yourselves. I'm sure you have heard this advice before, so it may sound trite—but even the sainted Mother Teresa, founder of the Order of Missionaries of Charity, un-

derstood the value of taking time for yourself. Referring to what she called "compassion fatigue," she planned for the nuns in her order to take an entire year off for every five years of service.

Obviously, no way could we take that much time off. The point is, we need to take at least a little time for ourselves. If not, the continuous stress will lead to burnout—and we find ourselves getting short-tempered with our loved ones.

Now that you are considering the benefits of taking some time for yourself, let's make sure you feel good about leaving your loved one.

Respite care is an avenue you may want to consider. For those who are new to the autism community, respite care will cover your child while you get a much-needed break. The coverage can be for a couple hours or a much-needed vacation.

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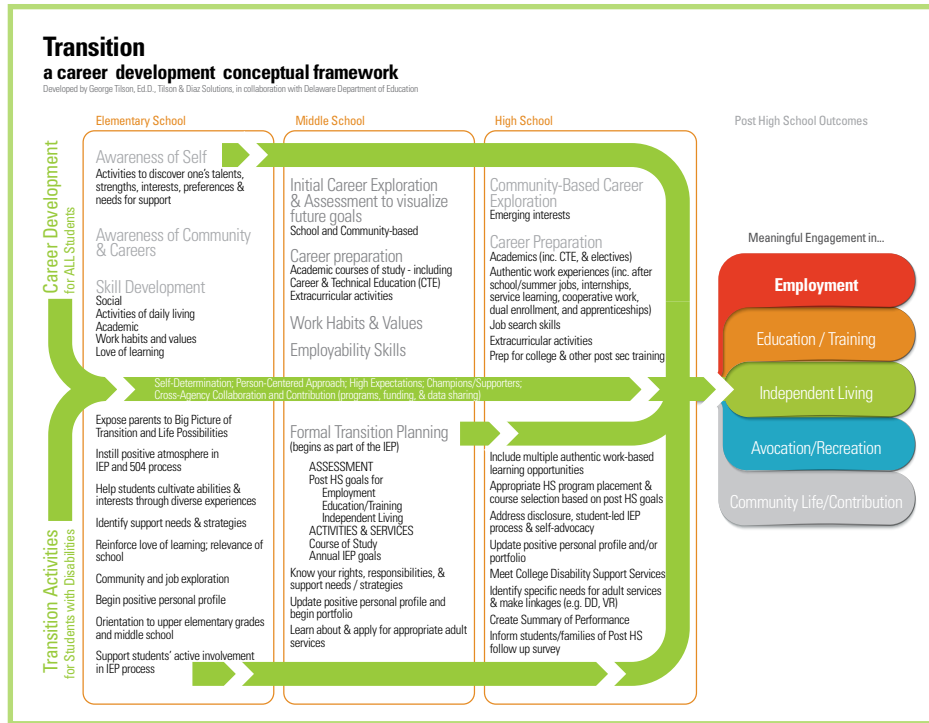


Rodger Pearce
President
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the start. As students reach middle school and high school, participation in exploratory pathways and career technical education (CTE) will assist with future employment interests and post-school credentials. Extracurricular activities provide an inclusive opportunity to practice social skills and executive-functioning skills and to develop relationships and passions outside the classroom.



#3 Independent living
Independent living encompasses any skill a person may need to be fully capable of living an independent and fulfilling life. This area of focus may include health management, transportation training, financial literacy, social skill development, and explicit teaching of executive-functioning skills.

#2 Employment

Whether the pre-vocational and vocational skills are practiced in a classroom or a community participating in the student's work-based learning, these skills contribute to work readiness skills and employability. Employability skills (or soft skills) are essential abilities that enable individuals to perform effectively in the workplace. These skills include verbal and written communication, teamwork, problem solving, critical thinking, time management, and organization.

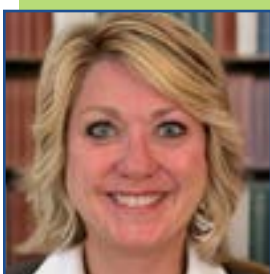
Also crucial are self-management, professionalism, leadership, customer service, networking, continuous learning, and attention to detail. These skills will assist young adults on the spectrum not only in getting a job but also in maintaining employment and career advancement—and employers value these skills highly,

#4 and #5 Recreational planning for meaningful engagement and participation in community activities and services

Planning for these areas can be included in post-school goals under independent living because it's where inclusive integration in one's community comes into play. You may know this area of focus by the proverb "It takes a village": how an individual can find natural supports that assist him or her in achieving a full and meaningful life.

As you follow the conceptual framework, multiple stages frame career development for students. These stages begin in pre-kindergarten and elementary school with awareness of self, community, and careers plus strengthening a love of learning. The middle school stage continues building the conceptual framework with skill development, community-based career exploration, and

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Kathleen "Kathi" Stephan, MEd, has experience as a transition coordinator for the John S. Charlton School, as district transition coordinator for the Capital School District, and as associate principal for the Kent County Community School. Currently, the mother of three is an education associate with the secondary and transition programs in the Delaware Department of Education's Exceptional Children Resources workgroup and works closely with Autism Resources director Mary Whitfield, EdD, BCBA.

7 tips to help you and your child through any transition process

by **Karen L. Tuohy
and Carla Koss (Ed.)**

transition team suggests something new that you can't quite wrap your mind around, take time to think about it. Whether you need a day or a week to mull it over, tell the team: "I need to think about it."

Most importantly, never spring the change in routine or location on your loved one on the spectrum, because it will not go well. Instead, tell your child that a change will take place, when it will occur, and what will happen. Because you have thought in depth about the change, you will feel confident about what you tell your child.

And if your child needs a walk-through to understand the change, be sure to take time for this, too—and tell the team.

Tip #2: Build routines for daily transitions. The point here is consistency and structure. In other words, to create a process that can be followed every day.

Tip #1: Plan ahead. This tip is essential because it will give you the time you need to make appropriate decisions on behalf of your child. When you create a plan around a transition, you envision how you and your child will move forward and consider the steps both of you will take.

As you know, most people respond well to change when they have enough time to make a decision that works for them. So, if your child's



Clip Art

For example, to prepare for the first day in a new school year, do a walk-through for going to bed on time the night before, waking up on time, and getting ready to leave the house. You might consider a walk-through of your child's class schedule for the first day as well.

Tip #3: Use songs. Did you know that music can decrease your child's anxiety and even promote relaxation? Songs can be effective tools to help carry out a routine and ease the transition.

Tip #4: Always engage with your child's transition team. The team may include educators, vocational rehabilitation counselors, and service providers. Altogether, you will develop your child's individualized education program (IEP) and, when your child reaches middle school, an individualized plan for employment (IPE).

Never dismiss a suggestion made by the transition team simply because it's something you never considered. You may be surprised at how effective this suggestion is for your child.

And never demand that your suggestion be the only one that counts. Just like you, the transition

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With 31 years' experience in Delaware's Red Clay School District, Karen L. Tuohy is currently a 4th-grade special-education teacher at Heritage Elementary School. An honored Autism DelawareSM volunteer, she has supported the agency's annual fundraisers for 25 years and managed the Wednesday family bowling night for 15 years. Karen is also the mother of two adult children on the spectrum.

7 tips to help you and your child through any transition process Continued from page 4

team is there to help your child successfully navigate a public education. If you feel a particular suggestion is wrong, state politely what you feel is best for your child; be gently persuasive instead of abrasive. The old saying is true: You do catch more flies with honey than vinegar.

Tip #5: Provide your child's transition team with all the relevant information you have concerning medical, social, financial, and guardianship issues. Never withhold information, because the more the transition team knows about your child's behaviors and likes and dislikes, the smoother the transition will go. Remember: The information you do not share can also influence how others see your child.

Tip #6: Support self-determination and self-advocacy in your child's transitions. The goal is to empower your child by teaching him or her how to voice personal wants and needs. If your child wants to communicate his or her preferences during the IEP or IPE meetings, be sure to share this with the team—and add a place at the table.

Tip #7: Share all relevant information with teachers, job facilitators, and service providers. With effective communication, everyone will get to know your child for the loving and capable individual he or she is.



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The Autism DelawareSM family support staff is trained to help parents through the IEP process—and so much more!

For more information, visit the Autism Delaware [website](#).

Or make an appointment by calling (302) 224-6020, ext. 219.

How does a parent help a child through a transition?

With information, communication, and connection

by Cory Gilden, PhD, MS, MEd

Every child is unique, and so is every family, which can make the autism journey isolating and challenging at times. Fortunately, we now have more modes of communication and access to information than ever before. Parents can get information and connect with families and professionals for help along the way through podcasts, websites, social media groups, conferences, books, webinars, seminars, social clubs, social events, and more. Because the autism journey is long and challenging, and because you never know which resources will help complete your autism picture, and because everyday life is busy enough without feeling like more is required of you than you have time for, parents can benefit from reviewing as many sources in as many formats as possible to find what they need.

I've found conferences to be a great way to get a lot of different information in one place, but they can be expensive and inconvenient to attend if they're not close to where you live. Luckily, in these post-pandemic times, many conferences are now being offered in hybrid models. With both in-person and virtual options, and even completely online options, conferences are accessible to a wider audience.

I recently attended sessions of *Autism Parenting Magazine's* four-day virtual Autism Parenting Summit that took place in May (www.autismparentingsummit.com). I could either attend the sessions at the time they were scheduled and have access up to 24 hours later or opt to pay the \$40 fee to have unlimited access to the recorded sessions.

The summit featured a diverse range of speakers, from the well-known Dr. Temple Grandin to medical doctors, therapists, and other experts, and even social media influencers with lived experience plus parent-advocates. There was an even wider offering of session topics, ranging from mental health to picky eating, behavioral interventions, and more.

Given my 15-year-old son's current 10th-grade status, I was most interested in attending three sessions:



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- “The Difficulties of Transitioning to Adulthood”—because my son is facing the transition into the real world soon.
- “Autism and Bullying”—because, although my son has never complained about bullying, I am always concerned about how he and I will handle it if it arises.
- “The Effect of Mold on Brain Inflammation in Autism”—because I am always interested in how the environment can trigger biological and behavioral reactions in children on the spectrum.

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How does a parent help a child through a transition? Continued from page 6

“The Difficulties of Transitioning to Adulthood” was a question-and-answer session with Thomas Henley, an advocate and autism consultant (www.thomashenley.co.uk), public speaker, podcaster, and instagrammer (@thomashenleyuk). Henley made the important point that a lot of tasks (like cooking, maintaining finances, socializing, and dating) are harder on a young adult because these tasks are no longer structured or planned out for them. Instead, the young adult has to initiate and plan them. Henley also spoke about how navigating the social scene can be lonely and isolating, so it’s important to join clubs or take up an activity with built-in social opportunities. (Henley took up Taekwondo.) He noted that independence is not a state that you achieve but an ongoing process of learning and adapting that everyone experiences on a sliding scale. To help build skills for independence, Henley recommends pushing kids out of their comfort zones when possible, connecting adults with autism who can relate to each others’ experiences and who can offer guidance through their lived experiences, and using tools like apps and calendars with timers to help set up routines.

“Autism and Bullying” was another Q&A session. This one featured Alicia Trautwein, a parent, autism awareness and education advocate, blogger, writer, and motivational speaker (www.themomkind.com). Trautwein emphasized the importance of having multiple ways of helping your child communicate his or her feelings. Apps and tools, such as social stories and emotion cards, were suggested as well as routinely checking in with specific questions. For example, instead of asking “How was your day?” an open-ended question will help your child open up about how he or she is feeling. In turn, you can offer emotional support as well as detect any bullying.

“The Effect of Mold on Brain Inflammation in Autism” was a presentation given by Theoharis C. Theoharides, PhD, MD, FAACAP. With a proficiency in research or practice in the field of allergy

and immunology, Theoharides is director of the Center of Excellence on Neuroinflammation Research at Nova Southeastern University (www.nova.edu/nim/research-studies/theoharides-bio) and has published hundreds of articles and a few books, many on the topic of inflammation. In his summit session, he provided scientific evidence that mold contributes to mast cell activation and brain inflammation in people with autism, which contributes to their brain fog, allergies, and behaviors. According to Theoharides, clinical trials using antioxidants and anti-inflammatory molecules have shown benefits that are statistically significant.

Theoharides shared much more technical information from his publications throughout the past 10 years. To learn more, search for his work on Google Scholar (www.scholar.google.com), on PubMed (www.pubmed.ncbi.nlm.nih.gov), on the Autism Research Institute website (www.autism.org), or at mastcellmaster.com.

In sum, the speakers of these three sessions came from the United Kingdom, Missouri, and Florida, but I was able to learn from their experiences and knowledge from the comfort of my house in Delaware. These virtual conferences, along with social media following and sharing, podcasts, and other new ways of collaborating, were simply not happening 10 years ago. So, the next time you are struggling through a tough day of parenting and the world is feeling small, consider expanding your reach with these new ways to get information, communication, and connection: Listen to a podcast while driving to work, and pick up some new perspectives. Mix in and “like” some autism-oriented social media pages to your feed and feel less alone. Or sign up for newsletters from some national, state, or research organizations to keep on the cutting edge of research and policy. While each autism journey is unique, methods are available for everyone to progress toward a better quality of life for themselves and their loved ones on the spectrum.

The current research and evaluation manager for the National Leadership Consortium on Developmental Disabilities, Cory Gilden, PhD, MS, MEd, is a former teacher, longtime autism advocate, and graduate of Partners in Policymaking, a program that teaches parents of children with developmental disabilities how to advocate for their children in school, how to talk to lawmakers, and how to push for appropriate health care needs.



The Bunny Train adds a second car

One of Autism Delaware's many popular programs, the Bunny Train boasted record attendance this year. With 250 children and their families taking a ride on the Wilmington and Western Railroad—as well as having fun with the Bunny and Alex, the Autism Delaware bear—this year's program needed an extra car.

"We enjoyed record attendance this year, so we rented every car the railroad had available," assures Autism Delaware development manager Kris Grant.



Programs

This list comprises the Autism Delaware programs for July through September, which had been scheduled by *The Sun's* publication date.

For the up-to-date list, visit <https://www.autismdelaware.org/events/>.

Grandparent coffee hour
(for grandparents who are not primary caregivers)
July 17. 6:00 PM. Free. Virtual via Zoom.
Contact: Heidi Mizell at Heidi.Mizell@autismdelaware.org.

Parent coffee hour
(for parents and guardians)
July 17, August 21, and September 18.
7:00 PM. Free. Virtual via Zoom.
Contact: Heidi Mizell at Heidi.Mizell@autismdelaware.org.

Sussex bowling night
Mondays. 6:00–8:00 PM.
Millsboro Lanes, 213 Mitchell St., Millsboro.
Free shoe rental. \$4 per game.

Weekly family bowling night
Wednesdays. 5:30–7:30 PM.
Bowlerama, 3031 New Castle Ave, New Castle.
Free shoe rental. \$4 per game.

A day at the Blue Rocks
July 28. 12:30–5:00 PM. Frawley Stadium, Wilmington.
\$20 per ticket.
Contact: Susan Campbell at (302) 224-6020, ext. 228, or susan.campbell@autismdelaware.org.

Beach picnic
August 11. 10:00 AM–12:00 PM. Cape Henlopen State Park, Main Beach Pavilion. \$5 per ticket. Tickets on sale starting July 1.
Contact: Susan Campbell at (302) 224-6020, ext. 228, or susan.campbell@autismdelaware.org.



The Drive for Autism

Support for more clients needing adult services

With proud papa Artie Kempner holding the speech for his son, Ethan Kempner welcomed the golfers and volunteers present in the Fieldstone Golf Club on April 29. After noting that 2024 is his fifteenth year as opening speaker for the Drive for Autism, Ethan thanked everyone for continuing to support Autism Delaware's adult services program known familiarly as POW&RSM.

The seed money from the first golf tournament formed the foundation for the program, and the funds raised at the annual event support the growing number of individuals who rely on adult services.

"Today, 170 adult clients are served by Autism Delaware's POW&R program," said Ethan—repeating it to emphasize the value of the golfers' and volunteers' continued support.

"Thanks to this event and all of you here today, I am leading my very best life," added Ethan.

DelAWAREness has now raised more than \$300,000 for Autism Delaware programs and services

Many thanks to Todd Muñoz's dedicated team and all the dancers and contributors to the 2024 DelAWAREness.

Now a new member of Autism Delaware's board of directors, Muñoz started DelAWAREness in response to his little brother's autism diagnosis. As the co-owner of Beat Ad-dikts, Muñoz combined his love of dance and his love for his brother by bringing together organizations to raise awareness and funds through dance.

Held during National Autism Awareness Month, DelAWAREness raised \$40,000 its first year—and, since its first year, has raised \$300,000 for Autism Delaware programs and services.

Top photo: Scene from Harry Potter dance program. Bottom photo: All dancers on stage for grand finale.



Walk for Autism presented by Delaware City Refining Company Our largest community fundraiser—again!



The 2024 Walk for Autism enjoyed a surge in attendance not seen since 2019. More than 1,500 people on the Walk's Delaware City leg joined U.S. Senator Chris Coons and Delaware State Senator Nicole Poore on a very windy April 13. And Delaware State Senator Russ Huxtable enjoyed the company of approximately 500 people on the Walk's Milton leg on April 20.

"I love seeing the number of individuals and families able to come out and enjoy themselves and their community," smiles Autism Delaware's director of development, Dan Getman. "In the year leading up to this event, we worked tirelessly to assure everyone's safety and well-being as well as to provide an enjoyable and rewarding experience.

"A first this year," adds Getman, "our grand marshals featured two sets of twins: in Delaware City, Avi and Dria [pictured at right] and in Milton, Andon and Arya Dohring [pictured below]. If you didn't get a chance to meet our ambassadors of good will, their moms share a little bit about them here."

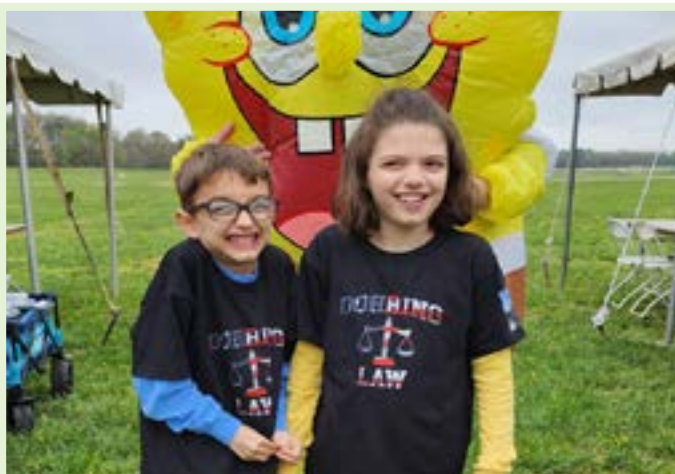
"Every day," says Avi and Dria's mom, Kyla Honey, "my daughters show me they're capable, that they can do anything they put their minds to.



"It gets better—it truly does. It's just all about how you look at it.

"I let them blossom at their own speed while pushing them to be their best selves. Five years ago, after hearing they would never do so many things—and watching them do it all now—is what made this journey more special than anything."

"Andon and Arya have been attending Autism Delaware's Walk for Autism since they were four years old," says the 9-year-old twins' mom, Carly Juno, "and they attend as many Autism Delaware events as they can.



"They also participate in sports through both Special Olympics Delaware [SODE] and Top Soccer. Andon has participated—and received gold medals—in basketball, track & field, bowling, and long-distance running through SODE. Arya has participated in soccer and was a gold medal winner in bowling for SODE.

"They both love going to school, going to professional sports events, and being with their family."



Why is Smart Cookie Day essential to the autism community?

Because it's one day a year when individuals and families get to stand eye to eye with their elected officials and share personal stories of life affected by autism: Not only is the process deeply personal, but it's also essential to adequately support Delaware's autism community. Supporting this effort, Autism Delaware stands ready to explain to state representatives and senators why legislation needs to be introduced, affirmed, and passed as well as to ask the governor to sign the legislation into law.

This year, 75 autism advocates registered to take part in Smart Cookie Day on March 27. Escorting them to their legislators' offices in Dover were members of the Delaware Alliance for Non-Profit Advancement (DANA). Together, the autism advocates and the DANA escorts met with nine legislators who shared a glad willingness to meet with their constituents.

"It was committee day," notes Autism Delaware compliance officer Sarah McGuire, who organized

this year's Smart Cookie Day event, "so some legislators were difficult to pin down, but their staffs were very helpful in getting us connected around meetings that went over schedule. We are lucky to have legislators committed to Delawareans and want to hear from them."

Why is the event called Smart Cookie Day?

Because autism advocates deliver cookies to their representatives and senators to, one, thank them for writing, supporting, and passing needed legislation and, two, to call them "smart cookies" for supporting specific issues.

ShopRite donated 200 cookies for this year's event, and a participant in Autism Delaware's adult services program and his direct support professional (DSP) individually packaged the cookies. In addition to the cookies, each legislator received a copy of Autism Delaware's policy priorities and a "thank you" postcard highlighting all of the agency's adult services' participants and their DSPs.

Smart Cookie Day guest of honor and speaker: Karen Mackie

The parent of a young adult in Autism Delaware's adult services program, a longtime autism advocate, and a former Autism Delaware family support provider, Karen Mackie shared her challenging experience with services as well as how changes in Delaware's state programs and services have supported her son Jake. Mackie also made a call to action to Governor John Carney to continue working toward improved supports and services for autistic people in our state.



How do I join the Autism Delaware community?

Being an autism advocate on Smart Cookie Day is only one way to be engaged in the Autism Delaware community. You could also donate some of your time and talent as a volunteer or support autism-friendly social and recreational events throughout the year.

For more information, click [here](#).



Take time for yourselves, caregivers **Continued from p. 2**

You may say “There is no way I’m going to leave my child with a stranger.” Be assured: Respite care can be provided in your home by a trusted family member or friend.

Did you know that you can hire, train, and supervise your own personal care attendants, including family and friends, and that they can be paid to provide the care? For the eligibility requirements, click [here](#).

Now that your child will be well cared for, schedule some time for yourself. If this thought is still overwhelming, I encourage you to think small: maybe a

day of fishing by yourself or getting together with friends in a stained-glass class. Maybe it’s a nice chat with a friend in a tearoom or playing a round of golf—or taking only an hour on the driving range. Plan to do whatever is fun for you.

Remember: Your intent is to take time for yourself. Therefore, you have to plan for it, or you may never do it. In fact, just planning this time off may feel like a breath of fresh air for you.

And may I be the first to say, “You got this!”

Transition planning: Moving successfully through school **Continued from page 3**

exploration of emerging interests. High school begins career preparation, authentic work experiences (including after-school jobs, internships, and so on), and preparation for college or other post-secondary training opportunities. Post-high school outcomes continue to revolve around employment, education and training, and independent living.

Important steps along the transition framework always include ongoing assessments, such as the [Positive Personal Profile](#) outlined by George Tilson. A key element in transition planning, this profile highlights a student’s strengths, interests, preferences, and support needs and is used to guide the development of individualized post-high school goals (Tilson, G. 2017. *Transition: A Career Development Conceptual Framework*. Delaware Department of Education: p. 10).

In addition, a portfolio that highlights strengths, interests, credentials, and experiences should begin to be developed. Adult services agencies should be identified and applied to as early as possible. Delaware Developmental Disabilities Services (DDDS) provides funding for follow-along services if the individual is eligible, and the Division of Vocational Rehabilitation (DVR) provides additional support around [employment](#), [transportation](#), and so on.

Tips for the parents of school children

Keeping the five focus areas at the forefront of transition planning is essential to creating a vision of what is possible in post-school life. I recommend the following:

- Stay informed and updated on the components and importance of the transition process. Become involved by actively taking part in the IEP and transition planning meetings.
- Click to sign up for [Delaware Transition Cadre](#) info and times.
- Does the plan on the transition page of the IEP reflect your child’s interests, preferences, and strengths? Continue to advocate to ensure that it does. If able, your child should be leading the IEP meetings and self-advocating for his or her own needs.
- Encourage independence by supporting your child in developing the skills needed in adulthood.
- Work with the IEP team to seek available resources and services that will support you and your child as you move through each transition.
- Contact the [Parent Information Center](#) of Delaware and [Autism Delaware](#) for valuable information and people to walk you through the process.

If you have any questions, email me at Kathleen.Stephan@doe.k12.de.us.

Get more info

The Delaware Department of Education (DOE) provides easy access to info on individualized educational programs (IEPs) at <https://www.doe.k12.de.us/Page/2335>.

Plan for Success: A Delaware DOE website—<https://delawarestudentsuccess.org/>

DeLAWARE DisABILITY HUB: Governor’s Advisory Council for Exceptional Citizens’ Transition into Adulthood—<https://deldhub.gacec.delaware.gov/>

[Emerging Educational Consulting](#) offers college planning services to help students and their parents determine if the transition to college is appropriate at this time.