# AUTISM SPECTRUM NEWS YOUR TRUSTED SOURCE OF SCIENCE-BASED AUTISM EDUCATION,

FALL 2024

INFORMATION, ADVOCACY, AND COMMUNITY RESOURCES

VOL. 17 NO. 2

# **Supporting and Empowering Autistic Adults**

# Strategies for Autistic Adults to Achieve Greater Independence and Well-Being

By Maria Vella, MS, BCBA, Kate Foley, RBT, Andrea Pagan, RBT, Brandon Sierchio, MA, BCBA, and Howard Savin, PhD First Children's Services

he transition from childhood to adulthood can be a scary and difficult life experience for most people. It can be even more challenging for those diagnosed with autism and their families. This phase of life brings a blend of excitement and uncertainty, and the road to achieving greater independence can be complex. Autism service providers play an integral role by offering strategies to foster self-care and autonomy. It is widely known that as autistic individuals become adults and age out of children's services, the supports that were once in place through insurance and school services come to a sudden end. It is paramount that autism service providers, school administration, related service providers, and families work together to bridge the gap with a transition plan to adulthood.



Transitioning into adulthood is an exciting and challenging period. Autism service providers can support and empower young autistic adults' transition into adulthood by increasing independence. One way for service providers to increase independence is by teaching self-management skills. Self-management is essential to becoming more independent (Li et al., 2023.) This skill can assist autistic adults to have more control in identifying and pursuing their own goals. It is important that every individual adopts professional and personal goals that are meaningful to them. Some of these goals may consist of career, relationship, leisure, spiritual, financial, hygiene, and overall life goals. Self-monitoring is one component of self-management in which individuals observe and keep track of their own behaviors. Autism service providers can start to incorporate self-monitoring goals by collaborating with autistic adults to determine what behaviors are important to the individual to monitor. After selecting a behavior to monitor, a visual tool such as a checklist can be utilized as a measurement to visually support the frequency that targeted behaviors occurred.

Self-monitoring can also assist autistic adults in identifying their strengths, which could help them choose a career path. Selecting a career can be especially challenging for adults with autism. It is estimated that 85% of the autistic adult population in the United States is unemployed. It is also estimated that 50% of autistic adults in their 20s have never worked a paying job, even with having the skill set for the job (Palumbo, 2021). It is important that family

see Independence on page 16

# Advocating for Empowerment: Navigating End-of-Life Care for the Aging Autistic Population

By Amanda L. Duffy, MEd, BCBA, LBS, Kristina Gasiewski, MOTR/L, MEd, BCBA, and Lara Redcay, MEd, BCBA Melmark Pennsylvania

hile history began documenting autism in children in the early 1900s, it was not until later in the century that autism became recognized as a distinct circumstance. The first generation of children diagnosed with autism is just now moving into older age. With aging brings social, physical, and cognitive health issues as well as the potential challenges of being autistic. Today's interdisciplinary teams are among the earliest professionals supporting this age group, and as a field, we must commit to setting precedents that can be built upon for generations to come.

The following is the preliminary work and experience of an interdisciplinary team consisting of a behavior analyst, nursing, speech pathologist, occupational therapist, physical therapist, and operational leadership personnel working in an intermediate care facility. Through our experience, it has been critical to have early conversa-



tions around end-of-life plans before it becomes too late and the ability to provide compassionate care is compromised. As anyone faces the end of their life, the need to plan for the distant or even near future is often put off or ignored across populations. Often, the pressure and urgency of daily needs leave little energy or resources to plan outside of the present.

The number of adults with intellectual and developmental disabilities over 60 is estimated to grow from about 641,860 as of 2000 to 1.2 million in 2030 (Garcia-Dominguez et al., 2020). In B.F. Skinner's 1983 lecture, which later led to the novel *Enjoy Old Age*, he referred to aging as a "special problem, [that is not particularly new], to which little attention has been given." Decades later, this remains truer than ever, especially for populations with learning differences and those who are differently abled. Because autism is often specifically accompanied by difficulty in communication and social reciprocity, the completion of assessments and delivering needed services can be a challenging undertaking for all involved in the individuals' care.

We are beginning to identify the differences in the aging experience of our autistic population. Adults with intellectual disabilities are shown to exhibit higher rates of epilepsy, psychosis, hypothyroidism, asthma, diabetes, and heart failure (Cooper et al., 2018). As a field, we need to identify and prioritize long-term care considerations for the people we support, especially for those unable to vocalize their wishes for the end of their lives. It's easier to start having conversations about a "good death" for someone while the person is healthy. Michael Baron, a founder of the National

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Spring 2025 Issue **Improving Physical and Emotional Wellness** Deadline: March 5, 2025

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Fall 2025 Issue **Fostering Safety and Stability During Difficult Situations** Deadline: August 27, 2025



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- Christopher Banks, President and CEO Autism Society of America

Read the Press Release

# Vote the Spectrum: An Unprecedented Opportunity for *All* Voices to be Heard

#### By Denise D. Resnik Founder & President/CEO First Place® AZ

he U.S. Surgeon General, considered "the nation's doctor," is charged with the overall health of the nation by providing Americans with the best scientific information available on how to reduce the risk of illness and injury. Historically, this has included issuing warnings on the dangers of substance abuse, disease, and potentially hazardous personal lifestyle choices. However, current Surgeon General Dr. Vivek Murthy has shifted the focus in recent years to social concerns, including the mental health crisis and increasing rates of loneliness and isolation, which disproportionately impact the disability community. What can we do to solve these broad, complex, and often sensitive issues?

Dr. Murthy challenges us to transition from a world powered by fear and anger to one led by love, kindness, generosity, and service. Instead of hiding behind the veil of social media, he encourages candid conversations with our neighbors and unlikely acquaintances to push toward civil solutions. Communities thrive on commonalities as much as diverse ideas, perspectives, and experiences.



autism and/or intellectual/developmen-

tal disabilities (A/I/DD) include access

to housing, education, employment, and

healthcare. They span the political spec-

trum - and are not issues to be divided into

party lines. They involve the community

at large and can only be addressed through

the charitable nonprofit First Place AZ -

through its Global Leadership Institute

- launched Vote the Spectrum<sup>SM</sup>, a non-

To drive awareness and spur action,

collaborative action.

Autism will not stop my child from voting. It will inform his vote.

If you have autism or any other disability, it's important to know your rights. Depending on your guardianship, those rights may include voting. Learn more at votethespectrum.org.

partisan voter registration and education initiative developed to promote civic engagement and local and national collaboration. A corresponding promotional toolkit informed by valued collaborators who also participate in a series of "Spark the Spectrum" accessible voting workshops is also available to continue increasing awareness.

The following inspiring videos were created to promote this growing initiative. More information is also available at votethespectrum.org/videos. • We the Spectrum featuring adults with autism and their family members

- A More Perfect Union offering relevant messages from prominent state leaders
- Life, Liberty and the Pursuit of a Healthy Community representing diverse collaborators with shared interests
- Democracy Doesn't Work Unless We Work at It - a title that speaks for itself!
- Powerful words from Richard Stengel, political analyst, former Under Secretary of State, and former managing editor of TIME

Vote the Spectrum is supported by the 1993 Voter Registration Act, enacted during a remarkable decade that included the passage of the 1990 Americans with Disabilities Act (ADA) and the 1990 Individuals with Disabilities Education Act (IDEA), renamed from the 1975 Education for Handicapped Children (EHC) Act and amended to improve transitions to post-secondary life.

With more than 1.1 million U.S. children with autism transitioning to adulthood and voting age! - over the next 10 years,

see Vote the Spectrum on page 38



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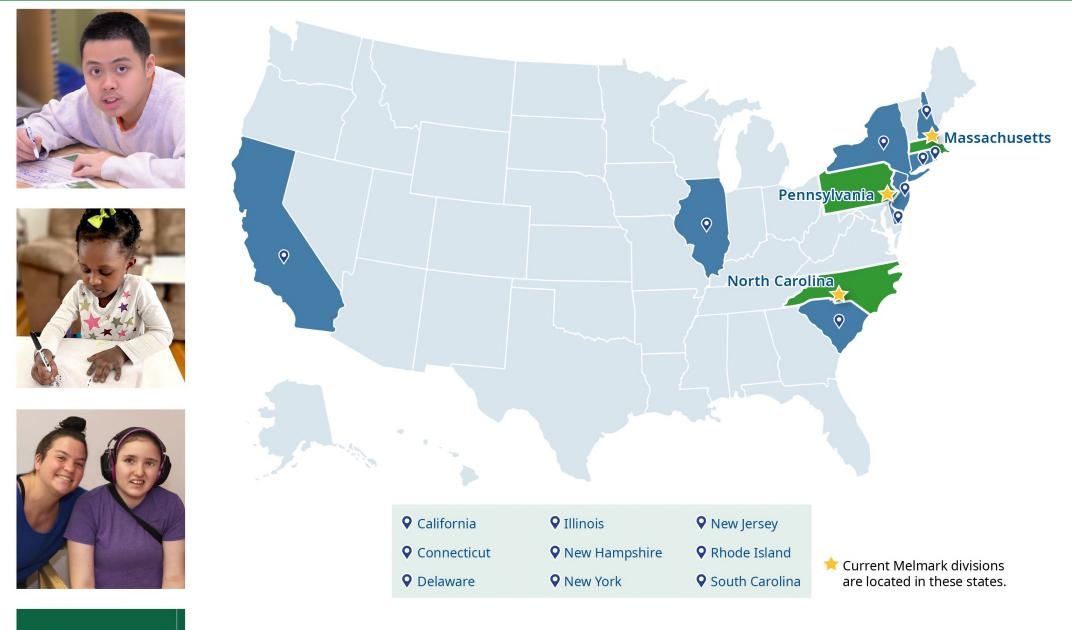
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# The Daniel Jordan Fiddle Foundation Announces 6th Adult Autism-Focused Endowment Fund Establishing the Nation's First-Ever Post-Doctoral Fellowship for Direct Care Service Providers

By Linda J. Walder Founder and Executive Director The Daniel Jordan Fiddle Foundation

he Daniel Jordan Fiddle Foundation (DJFF), the nation's first not-for-profit organization to exclusively focus on adult autism, has launched a ground-breaking endowment fund at the Medical University of South Carolina College of Health Professions (MUSC-CHP) adding to DJFF's existing endowed program initiatives at Brown University, Yale University, Rutgers University, Arizona State University, and the University of Miami's Center for Autism and Related Disabilities (CARD), all focused on areas relating to adult autism.

With an initial gift of \$52,500, The Daniel Jordan Fiddle Foundation Adult Autism Post-Professional Doctoral Capstone Project for Direct Care Service Providers has been established at the Medical University of South Carolina College of Health Professions. This endowment will identify The Daniel Jordan Fiddle Foundation Direct Care Service Provider Fellow, who will be selected annually by MUSC-CHP from a qualified pool of post-doctorate candidates with expertise in



### The MUSC-CHP team with Linda J. Walder and Dr. Ava Jayne Fiddle at the check presentation ceremony on September 11, 2024 in memory of Danny Fiddle's birthday

adult autism and a professional interest in advancing the field of direct care service for the diverse population of autistic adults. The DIFE and average fund will support

The DJFF endowment fund will support the Fellow's Post-Doctoral Capstone work, with the goal of designing and implementing an impactful project that immediately affects the field of adult autism. The project will define the issues and challenges relating to direct care service for adults with autism and will propose implementable guidelines and solutions to address them.

In alignment with The Daniel Jordan Fiddle Foundation's mission, the MUSC

endowment will provide an opportunity for an experienced professional who has a deep passion for the issues facing adults with autism to create a Doctoral Capstone Project that can immediately be translated into practice.

Founded by Linda J. Walder, a pioneer in the adult autism arena, The Daniel Jordan Fiddle Foundation has blazed trails to develop, fund, and advocate for programs and public policy related to all aspects of adult life, such as jobs, housing, creative expression through the arts, community/ social life, health and wellness, and importantly resources and support for the family members of adults. DJFF is named in honor and memory of Linda's son Danny, who was diagnosed with Autism Spectrum Disorder (ASD).

The DJFF-endowed program funds have opened new doors with the establishment of *in perpetuity* adult-autism-focused collaborations with the nation's leading researchers and practitioners at renowned universities. They are addressing the critical issues in adult autism and advancing the creation of new research, vital support systems, and replicable programs benefiting autistic adults.

see Endowment on page 37

# THIS IS WHAT SUCCESS LOOKS LIKE



# THIS IS WHAT AN ADULT WITH AUTISM LOOKS LIKE!

Adults with autism are diversely individual, and all are entitled as a matter of human rights to have opportunities to live their best lives.

The Daniel Jordan Fiddle Foundation Adult Autism Endowed Funds are trailblazing research, housing, jobs, public policy, family support, artistic expression and community life for adults with autism worldwide today, and for generations to come. Learn more about **The Daniel Jordan Fiddle Foundation Endowed Funds** at Yale University, Brown University, Rutgers University, Arizona State University, and the University of Miami by visiting our website **www.djfiddlefoundation.org**. Stay inspired by our Daniel Jordan Fiddle Foundation Leaders in Adult Autism, signature programs and international leadership.

To make a donation, please visit bit.ly/30B59fx THE DANIEL JORDAN FIDDLE FOUNDATION FOR ADULT AUTISM TRAILBLAZING SINCE 2002

# The Importance of Personalized Support and Care for Autistic Adults

By Laurlen Coker Coordinator of Adult Day Services The Summit Center

eople with autism have the potential for growth at every stage of life. When supporting someone with autism, know that every moment and interaction can make a difference in their well-being and independence if you understand how they learn.

Many of the people who receive support at the Summit Center are navigating significant challenges related to their autism. They may experience difficulty with communication, self-help skills, or sensory processing, and yet they push themselves to accomplish their goals and try new things. It brings me joy.

Working in a community-based day habilitation program, I interact with people not just as a professional but very much on a personal level as well. Providing tailored support and accommodations is critical to enjoying a full life.

There is a common belief that autistic people reach their potential upon graduating from high school. That is certainly not true. Like everyone, they continue to learn well into adulthood and oftentimes experience milestones and breakthroughs while adults. Recently, a gentleman learned sign language and became proficient enough to let his program supervisor know that he en-



A smiling young man at The Summit Center's Day Program Photo Credit: The Summit Center

#### joys his favorite lunches!

We pride ourselves on our program S.T.E.P.S. (Success Through Engagement and Positive Supports). S.T.E.P.S. centers around activities that we organize based on people's interests. This could include bowling, going to the zoo, gardening, or participating in volunteer services. Helping them feel comfortable among their peers and taking part in familiar activities is always paramount.

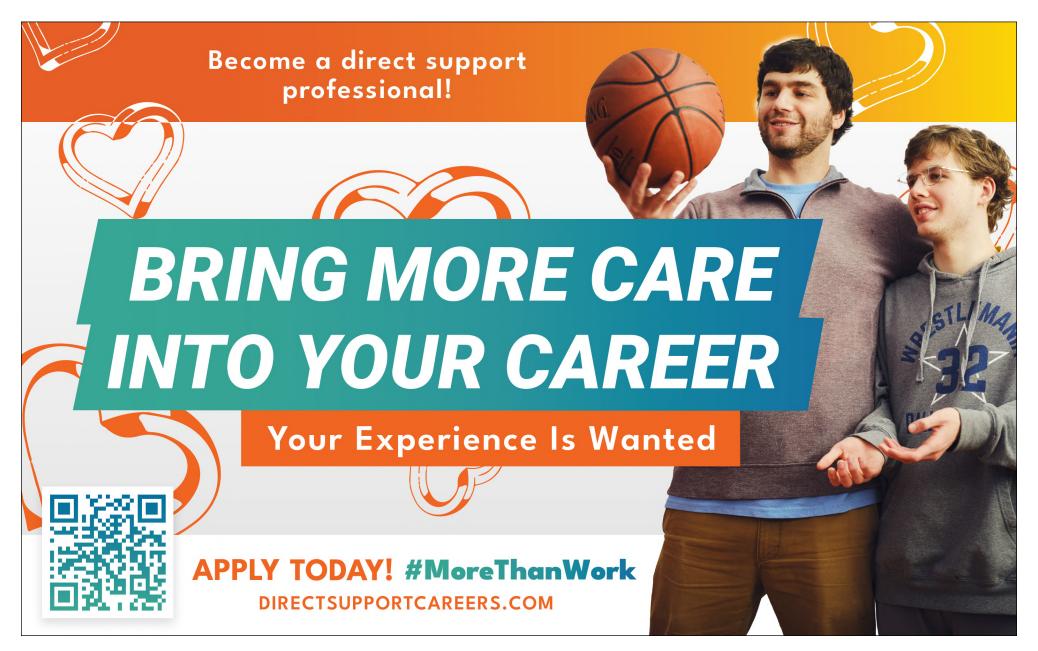
This holistic support and care for autistic adults can be provided in various ways while being personalized as much as possible. A few strategies that I have found particularly impactful are:

- Breaking down skills into very small steps
- Giving opportunities for practicing a task or skill in several settings and scenarios
- Understanding sensory needs (hypersensitivity vs. hyposensitivity) around lights, sounds and smells

Every day, I see firsthand how our passionate and dedicated staff helps empower autistic people. The recent launch of the #MoreThanWork Direct Support Professional (DSP) recruitment campaign exemplifies the importance and value of direct support as a career path, which is very encouraging. This comprehensive statewide campaign highlights the essential role DSPs play in the lives of people with developmental disabilities while promoting the tremendous value and meaningful impact a DSP career can provide. This campaign is a call to action that will directly help the people we support and further develop future leaders in our field.

The autistic spectrum is not linear. It has multiple facets that manifest in people in countless ways. There's a reason for the saying, "If you've met one person with autism, you've met one person with autism." Every individual is impacted by their own

see Personalized Support on page 16





# Shaping the future of ASD care

Guided by our values and motivated by our capacity to care, Catalight is leading the industry with outcomes-driven treatment plans that recognize that one size does not fit all and that affordability is the key to expanding access. As a not-for-profit, success for us is helping our clients and their families find confidence, independence and wellbeing. We are looking for partners on our path.

Join our journey.

catalight.org

# Charting New Paths to Wellbeing: Catalight's Compass Behavioral Program Launched This Month



By Doreen Samelson, EdD, MSCP Chief Clinical Officer Catalight

n an industry where a one-size-fitsall approach to treatment is too often the norm, Catalight's new Compass Behavioral program teaches neurodivergent teens and young adults life skills that are important to them and their idea of future success. The innovative treatment option truly places the client in the driver's seat by giving them the ability to guide their own journey toward greater wellbeing and into adulthood.

Compass Behavioral, or Compass B for short, is a life coaching experience designed with flexibility and personal choice built into its core. For many neurodivergent individuals, particularly those with autism who do not have significant intellectual disabilities, traditional approaches can feel restrictive or ill-suited to their unique needs. Compass B is different. It was created on the principle that individuals thrive when they are empowered to set and pursue their own goals.

As part of Catalight's innovative suite of treatment modalities, Compass B provides clients with a manual with tips on how to improve executive functioning and social skills. From the manual, the client chooses goals to focus on with the help of a licensed clinician, who they usually meet with for an hour a week for three to six months.

As a non-profit, Catalight primarily supports children with intellectual and developmental disabilities. We created Compass B after receiving referrals for a number of autistic individuals who didn't need the rigorous structure of applied behavioral analysis or psychotherapy. They just needed some coaching to learn new skills that they wanted to learn.

We started Compass B in April 2023 as a pilot within our network of providers and clients. More than 200 participants provided valuable feedback that helped refine the program. What started as a concept aimed at filling a gap in services evolved into a proven model for individualized, client-centered care. In presenting the program findings at various conferences, we heard from many BCBAs interested in learning how they can provide Compass B to their clients.

In response, this month, we launched web-based training via Catalight Classroom for practitioners beyond our network who would like to learn Compass B. With this expansion, more people will now have access to this transformative approach.

In focusing on what truly matters to them, clients work with behavioral health experts on skills including self-advocacy, social abilities, making new friends, understanding social cues, understanding emotions, task initiation, flexible thinking, self-awareness, and even getting better sleep. The self-directed approach is not about altering who someone is but about helping them achieve what they want for themselves.

Imagine a young adult preparing for their first job interview. Unlike many neurotypical youth and young adults, most autistic young people don't have summer jobs or intern experience. Through Compass B's newest section about job hunting, they can work with their coach to develop specific skills tailored to the task, like effective communication and self-presentation, all while maintaining their own sense of identity and autonomy. The program also addresses crucial life skills, from planning and organization to self-management, in a personalized way that's practical to everyday scenarios.

While the program is short, the lessons are everlasting and important for any young adult launching themselves into the real world. Clients are taught to be self-reflective, intrinsic thinkers – better understanding their behaviors and the behaviors of others in order to identify cause and effect in the future, thus further learning what to do and not to do in particular situations. In a short time, they, in essence, learn to become their own coach.

As clients work on their chosen skills, the overarching goal is to see significant improvements in their overall wellbeing. It's not just about hitting targets or achieving

# **Prospect Meadow Farm: Empowering Autistic Adults Through** Vocational Training, Employment, and Community Building

By Amy Timmins VP of Community Relations ServiceNet

ocated in the Pioneer Valley of western Massachusetts, ServiceNet's Prospect Meadow Farms provides vocational training and employment for more than 100 differently-abled adults aged 22 to 70, 20% of whom are on the autism spectrum.

The original farm, located on 11 acres in Hatfield, was founded by ServiceNet in 2010 as a therapeutic program to connect people with animals and nature. Prospect Meadow has since evolved into a busy social enterprise spanning a total of 100 acres at three locations: two in Hatfield and one across the Berkshire mountains in Pittsfield. These farms have become the largest producer of log-grown shiitake mushrooms in western Mass, and their fresh eggs and produce are carried by several area markets, including Prospect Meadow's farm store.

Farmhands are all paid at least minimum wage (\$15/hour) and have opportunities to advance to senior farmhand, peer mentor, or job coach as they gain experience and confidence on the job. Several have also moved on to the farm's culinary training program and working at the farm's Rooster Café in Northampton, while others have



Planting time at Prospect Meadow Farm West in Hatfield, MA

gone on to community employment. And some have started their own private ventures—from beekeeping to book illustration—using skills and insights gained at Prospect Meadow.

"Everyone comes here with their own interests and abilities," said Shawn Robinson, founding director of Prospect Meadow Farm and ServiceNet's Vice President of Vocational Services. "And each of our vocational support plans is specifically tailored to their needs. These plans might include skill development related to animal care, landscaping, carpentry, food services, or retail operations, and usually include some sort of combination." While farmhands have many work-

While farmhands have many workgroups to choose from, each set of tasks has inherent routines, which can be especially beneficial for individuals on the autism spectrum, according to Robinson. "Having clear, predictable tasks that are listed on a visual posted schedule can help people understand their daily tasks, which also helps reduce anxiety," he noted. "At the same time, our program's structure, which has farmhands rotating between various workstations to meet seasonal and other needs of the farm, enables people to increase their ability to be flexible."

Another beauty of working at Prospect Meadow is that it offers individuals on the autism spectrum spacious outdoor environments in which to spend most of their day. For many farmhands who had previously worked in noisy production or commercial settings, being outdoors offers newfound relief from sensory overload. There are also a variety of quiet indoor workspaces and relaxation areas at each of the farms, and further modifications are made as needed, including noise-canceling headphones.

Because farmwork requires both gross and fine motor activities, it helps farmhands develop important physical skills. And the demanding exercise involved can serve to relieve tension and restore balance - whether people are planting, harvesting, or caring for the chickens, llamas, and goats.

Jim Seltzer, a retired psychologist, mushroom farming hobbyist, and longtime volunteer and friend of the farm, started Prospect Meadow's log-grown shiitake mushroom operation in 2014 after he noticed that the hard work of drilling, inoculating, and hauling logs was soothing for farmhands on the autism spectrum. "While some of these individuals could become quickly frustrated with repetitive detail work, they were eager to handle power tools that required their physical strength and intense focus, and to move and stack the heavy logs into place," Seltzer recalled. "It felt like such a positive, natural fit right from the start. And after beginning with just a few mushroom logs, we now have more than 5,000 between the three farms."

As farmhands work alongside their peers, job coaches, counselors, supervisors, and volunteers like Seltzer, they have multiple opportunities to sharpen their verbal and non-verbal communication and improve interpersonal skills. Prospect Meadow Farm staff also create a variety of supervised, structured opportunities for social interaction and offer small group activities and peer mentorship programs to provide social support and help farmhands foster friendships.

"We are all in this venture together," noted Robinson. "Each farm requires careful planning, lots of hard work, and handling setbacks that may be caused by storms, downed trees, hard freezes, or foxes, coyotes, and other predators attacking the livestock. None of us can do this alone, and to be an effective team, people need to communicate clearly, support and care about each other, go with the flow of what needs to be done, and have a personal stake in the outcomes."

Farm families are another key part of this team equation—whether serving as their adult family member's guardian or simply being a supportive presence in their lives. Program leaders and staff keep families informed about the vocational training process and provide helpful tools and strategies to ensure a home environment that supports farmhands' learning and growth. They also plan family picnics and other social gatherings to promote involvement in the farm and offer opportunities for families to connect with one another.

Connection is a core theme running through every aspect of life at the farm: from connection to self and work and purpose to connection with fellow workers and leaders, family, and community. On the latter, farmhands may, by turns, staff the booth at area farmers' markets or deliver eggs and produce to area grocers, work in the farm store serving customers, or participate in the culinary program and café. And because the farms each offer daily late morning tours to visitors, farmhands become well-versed in telling the story of the farm and their work there.

"Farmhands are involved in every tour we conduct," explained Robinson.

### see Project Meadow on page 16

ServiceNet's Prospect Meadow Farm will be co-hosting the Care Farming Network's Inaugural National Conference at the University of Massachusetts in Amherst, January 13-15, 2025.

This event will be filled with farmer-to-farmer learning, inspiring speakers, hands-on workshops, and insightful panel presentations.

For more information, go to carefarmingnetwork.org/2025-conference.



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# Fostering Independence for Young Adults with Autism and Low Vision

By Ernst VanBergeijk, PhD, MSW and Alexandra LaVoie, MSOT Transition Center at the **Perkins School for the Blind** 

anBergeijk and LaVoie (2024 April & January) established in previous issues of Autism Spectrum News that "autism is the most commonly reported co-existing developmental disorder in children with blindness and other severe visual impairment." They highlighted the need for a proper differential diagnosis by practitioners who are well-versed in Cerebral/Cortical Impairment (CVI), which is brain-based visual impairment and the leading cause of blindness in children. CVI is often misdiagnosed because autism and CVI have overlapping features (Van-Bergeijk and LaVoie, 2024, April). Having a child with both a visual impairment and an autism spectrum disorder can be overwhelming for any parent, and even seasoned special educators struggle to develop goals for the future that include the critical skills needed to live as independently as possible. To prepare for life after high school, parents should work together with the school team and students to establish a shared roadmap that reflects the students' strengths, recognizes areas where support will be needed, and includes social connectedness and community participation.



A young man practices accessing public transportation to travel

Looking Forward, But Working Backwards

Looking forward but working backward refers to a concept VanBergeijk and Cavanagh (2024) explored when referring to residential options for individuals on the autism spectrum. The concept involves developing a shared goal or endpoint that a team of special educators and parents embrace for the student. This goal or vision should be lofty and embody the best

#### possible outcome for the student as they reach young adulthood. Typically, as a part of the Individualized Education Plan (IEP) process, the team identifies goals that revolve around transitioning to the world of work, post-secondary education, and living in the community. The goal is usually set at age 14 and the transition plan is enacted by the time the student is 16 years old. VanBergeijk and Cavanagh (2024) argue that the planning for the student's future should begin early in the child's life. Family involvement is key as special educators have a good sense of the academic skills necessary to transition to post-secondary education but do not live with the child to experience their daily routines, strengths, and areas of growth at home and in the community. Also, there is often a tendency to focus on deficits and what the student is not able to do currently. This can lead to a cycle of underestimated potential for young adults with disabilities. Ongoing communication is critical as parents and educators work together with the student to identify strengths and incorporate ambitious goals into the transition plan. Aim high. Dream big.

#### What Does Independent Living Look Like for a Young Adult on the Autism Spectrum?

This will be different depending upon the environment in which they will transition and the student's individual interests and goals. We had the privilege of educating a student on the autism spectrum who was non-verbal until he was in the third grade. He ran away from his teachers and school regularly as a young child. His parents and special education team had big dreams for him. The focus was not only on academic skills acquisition but also on the Expanded Core Curriculum, which includes self-advocacy, vocational skills, independent living skills, and social skills. His transition plan included that he attend a Comprehensive Transition and Post-secondary (CTP) program at a college near his home. When he graduated from his CTP, members from his elementary school IEP team attended his graduation. He was the class representative and delivered the commencement address. Today, he lives independently in his own apartment with some drop-in supports. He works as a personal shopper for a national grocery store chain. He regularly boards a train into the city to meet friends for dinner, to see a movie, and to attend Broadway plays. He works out multiple times a week and participates in 5K runs, which raise funds for autism-related causes. Our former student also travels internationally with peers through specialized programs such as Embark Inclusive Travel, Inc.<sup>TM</sup> He has been to Europe, Central America, and Asia with his peers. By all measures, our student has a good quality of life and has exceeded the expectations of his educators and parents. It is critical that school teams work with young adults to build the practical skills necessary to navigate real-world challenges and foster independence.

How Can Parents and Educators Prepare Young Adults with Autism and Low Vision to Live as Independently as Possible?

Parents and special educators will need to imagine the student as a young adult navigating through the world. Independent living skills are a series of highly complex building blocks across a variety of domains. These domains include personal hygiene, cooking, cleaning, grocery shopping, budgeting, banking, and managing medical appointments and medications. Organizational skills, first aid skills, traveling to and from work, appointments, and social events also need to be taught explicitly. Developing self-advocacy skills is particularly important as it enables young adults with disabilities to navigate challenges, access resources, and participate fully in their communities. Students need explicit instruction to build the critical self-determination skills needed to apply for a job, advocate appropriate accommodations, and manage their own environment as independently as possible. These skills encompass goal-setting, problem-solving, self-advocacy, and decision-making, all of which contribute to greater independence and confidence.

Financial literacy is essential to living independently in the community and consists of several domains, including earning, spending, saving, and borrowing. These are all higher-level skills that are composed of early building blocks. The IEP for younger children should include the skill of recognizing numbers, simple mathematical operations (e.g., addition, subtraction, multiplication, and division, etc.), and may need to reflect reasonable accommodation of using a calculator in later years. Recognizing denominations of coins and bills will also be important to learning financial literacy. Students who are blind or have low vision may need to learn strategies to recognize coins by size, fold bills of different denominations, and organize them into their wallets. There is also a range of currency readers and applications available that parents can explore with their children.

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# **Empowering and Supporting Women with Autism Spectrum Disorders**

#### By Jill Krata, PhD, CLC Evolve Autism and Family Coaching

omen with autism spectrum disorders present with a complex social and behavioral profile that can differ from men. It is important to understand some of the diagnostic differences between women and men so that we can help empower women not only to address their individual needs but also to help create a more just, inclusive, and equitable society for all. These differences can present themselves in how they both experience the world, as well as how they are perceived by others. Women with autism may experience societal pressures to conform to social norms, leading to increased anxiety and a higher likelihood of being misunderstood or overlooked in various settings. By providing tailored support and resources, we can empower these women to recognize their strengths, build self-confidence, and advocate for their needs. Ultimately enabling them to thrive in a world that often marginalizes their experiences while providing them with a better quality of life.

Women with autism are often underdiagnosed or diagnosed later in life compared to men. This is partly because symptoms of autism in women can be more subtle or masked by social conditioning or "camouflaging" (Milner, McIntosh, Covert & Happé, 2019). This is a technique where women disguise their autistic traits to fit in socially, and they either mimic or learn socially acceptable behavior to fit in with the neurotypical world. Long-term studies have shown that while women with autism are successful at camouflaging, they report feeling constant exhaustion and a lack of a sense of identity (Bargiela, Steward & Mandy, 2016), which has been linked to an increase in self-reported stress and anxiety in comparison to men who do not camouflage (Cage & Troxell-Whitman, 2019; Hull et al., 2017). Another diagnostic difference between women and men with autism is that women report fewer social and communication difficulties than men (Lai et al., 2011; 2015) and are more able to demonstrate reciprocal conversation. Women are also more motivated to initiate friendships than men on the spectrum are. The repetitive behaviors that females with autism adopt also appear less unusual, focusing on topics like those of their neurotypical peers (Gould & Ashton-Smith, 2011). These repetitive interests are in areas that are more socially acceptable or appear to be more "typical," such as animals, movies, or fashion. As a result, their interests may not be recognized as a sign of autism.

Supporting women with autism helps to challenge stereotypes and misconceptions about autism, particularly the notion that autism primarily affects males. This can lead to greater societal acceptance and inclusion, reducing stigma and creating more opportunities for women with autism to participate fully in all aspects of life. Historically, autism has been viewed through a male-centric lens, leading to the misconception that it primarily affects boys



and men. Supporting women with autism brings attention to how autism manifests differently in females while helping to challenge the stereotype that autism is a "male condition" (Wisniewski, nd).

Research has shown that women with autism are at a higher risk of mental health issues, such as anxiety, depression, and burnout (Lai et al., 2019; Yau, Anderson & Smith, 2023). This is often due to the stress of masking their autism and coping with societal expectations and overall feeling misunderstood. Empowering women and providing them with appropriate support can significantly improve their mental health and overall wellbeing. Providing specialized access to mental health resources and creating environments where women can openly discuss and address these challenges is vital. It is essential to offer access to mental health professionals who understand the unique challenges faced by women on the spectrum, where regular mental health check-ins and personalized therapy sessions can help manage these challenges.

Another area that has empowered and supported women with autism in forming their identity is social media (Bargiela, Steward & Mandy, 2016). Social media has provided women with autism the ability to connect with other women on the spectrum, and they are able to form connections and identities based on their special interests rather than traditional societal norms for women (Harmens, Sedgewick & Hobson, 2022). Social media platforms provide a space where women with autism can share their experiences, connect with others, and find a sense of community. Online communities, forums, and groups on platforms like Facebook, Instagram, and X can help break down feelings of isolation by creating networks of individuals with similar challenges and strengths. Research has indicated that social media provides several benefits for women with autism, particularly in terms of communication, connection, and self-expression. This was evident by a study performed at the A.J. Drexel University Autism Institute (https://drexel.edu/autisminstitute/), which concluded that many women with autism prefer online communication because it offers more control over their interactions. It helps them to engage in conversations at their own pace and helps to reduce anxiety, typically associated with face-to-face interactions and the unpredictability of in-person conversations (Koteyko, 2023; McGhee-Hassrick, 2021). Additionally, social media was noted to help women with autism form more meaningful social connections, maintain relationships, and pursue special interests more frequently. Overall, social media serves as a double-edged sword for women with autism while offering valuable spaces for connection and advocacy while also presenting challenges such as difficulties interpreting social cues online and the potential for social media to exacerbate anxiety. While social media provides many benefits, it is essential to acknowledge the potential challenges, such as online harassment or misunderstandings related to the interpretation of social cues. However, with the right support, many women with autism find social media to be a powerful tool for feeling connected and supported.

Supporting women on the spectrum requires a multifaceted approach that addresses their needs and challenges. While social media and mental health services are vital, they alone are not enough. Tailored social programs, inclusive social communities, and encouraging self-expression can also be effective in empowering women with autism. These programs focus on fostering social skills and self-advocacy and building supportive communities where women can express themselves and be surrounded by other women who are going through similar challenges. There are several organizations that specifically focus on these issues, for example, the Autistic Women and Nonbinary Network (AWN), the Association for Autism and Neurodiversity (AANE), and Felicity House in New York City. These organizations combined offer women with autism mentorship and tailored programs to offer emotional support, advice, and guidance

see Supporting Women on page 42



If you are interested in working together or have any questions, please email: DrJill@evolveautismandfamilycoaching.com

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# The Value of Facilitating Social Groups for Autistic Adults in a Community Mental Health Setting

### By Kenneth Mann, PsyD

Director WJCS Outpatient Services for People with Developmental Disabilities

Providing comprehensive and meaningful therapeutic services for autistic adult clients in a community mental health center requires offering a range of therapeutic groups within which a client can work to reach their potential in a way that might not be possible via individual therapy sessions alone.

For many of the autistic clients that we work with at Westchester Jewish Community Services (WJCS) in Westchester County, NY, there is a limitation in having them work exclusively in a 1:1 mode. A core challenge for our clients is the habilitation and application of skills related to socialization, as well as navigating the complexities of interpersonal relationships across settings in their daily lives. In a group setting, whether structured or unstructured, there is an opportunity for those issues to emerge and become part of the work.

One client, for example, in a virtual, structured social skills group for young adults, consistently asked probing and personal questions of his peers. Although the questions were in some way related to the curriculum, the fact that the client



was getting too personal ultimately became off-putting to his peers. He was surprised when his peers began to respond to him curtly. He wanted to improve his relationships with his peers in the group, and we worked on his concentrating on talking about himself and asking one general question that was not too personal. We identified the acronym TAY (Talk About Yourself). As the facilitator, I was able to send him a chat message stating "TAY," which he was able to take as a prompt and, thereby, modify his behavior in the here and now. He also was able to ask his peers if a question was too personal before "officially" asking it. We all worked together to identify what was and was not too personal to ask. In this way, his peers also benefitted from considering what could be asked in a group forum and what was inappropriate. In a breakthrough moment in the group, he stated: "I know this question is not too personal," and then proceeded to present a general, relevant, and appropriate question for us all to consider.

One of the less structured social skills groups we offer for ASD clients is a weekly in-person lunch group. The discussions in the group focus on issues related to family dynamics, vocational training, and reactions to political events. We delve into these topics while having a meal together. One of the participants has a moderate level of misophonia, and he told me, in an individual session after having tried the group, that he would not be able to tolerate the sensory input, particularly because he perceived that some of his peers were "sloppy eaters." This group usually begins with a check-in, and he agreed to bring this up at the beginning of the next group meeting with my support and guidance to see if this approach would make a difference. We practiced first how he could politely and directly point out to a peer when he was uncomfortable with the way that they were chewing. His peers were kind and responsive, and they worked to accommodate him. As a result, he soon felt validated and recognized, which allowed him to tolerate an improved, albeit not perfect, sensory environment. Another limitation in working exclusively in a 1:1 format is that clients do not experience the force and power of affirmation. This is achieved by being validated by a group of like-minded people whom the individual has come to like and respect. We know that, as professionals, we can tell students, children, clients, or friends a pearl of wisdom that we are confident could be helpful, and we feel either ignored or minimized when they do not see us as sages. However, when a peer says the same exact thing, it seems to have a greater impact, as it is often experienced with less defense.

Sometimes, ASD clients struggle with

activation, and the next step is there and ready to be seized, but inertia prevails and the individual struggles to work through. I have observed clients in a group setting activate each other in a way that I had not been able to via individual sessions. For example, I had been urging a client to consider a volunteer position at a local not-forprofit organization, but he was not scheduling the required intake appointment. Yet, a conversation in the group on the benefits of volunteering in the community, especially in the context of preparing for competitive paid employment, was enough to encourage him to make the call. He continued to use the group as a place to process his experience as he began his volunteering in that organization.

Sometimes, it can be surprising just how isolated some of the adult ASD clients are. Their only interaction with other people during the week is the group they attend. In most cases, it is our therapeutic goal to change that. However, without even considering the skill-building opportunities in the group, leaving the house and attending a group with peers is, itself, of enormous therapeutic value. Conversely, one client who does have social connections at school and in the community explained to me that one of the positive aspects of attending a group is that there are no groups in which he participates formally or informally that are comprised exclusively of neurodivergent peers. Attending our group provides a sense of community and safety that does not characterize his other interactions. From the most isolated to those who might already exist successfully in a myriad of groups, a group experience with neurodivergent peers has value (Chan, Doran & Galobardi, 2002).

In our more structured groups, skills that relate to coping and emotional regulation are directly presented, practiced, and applied. A group appraisal of these skills and how they can be implemented provides an opportunity for problem-solving that becomes richer than individual therapy as multiple unique perspectives and experiences can be considered. Our department has just begun our first DBT group exclusively for a neurodivergent population, and in just several sessions, the participants are working together to think about how interpersonal effectiveness skills could enhance their relationships both in their lives as well as within the group itself.

I am working with several young adult ASD clients who compare themselves to what their perception of the norm is in terms of social, vocational, and/or educational achievements and, as a result, are self-critical and vulnerable to depressive ideation. Another advantage of having these clients participate in a group forum is that the idea of moving at one's own pace is legitimized. There is social reinforcement and validation for moving forward in a way that is reasonable for a client. Clients have also effectively used these discussion opportunities to define for themselves what moving forward means to them and how to communicate this to significant people in their lives. This has been an essential aspect of

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# Artificial Intelligence in Education: Benefits and Risks for Neurodivergent Students

#### By Tara C. Fappiano Advocate and Mediator

rtificial Intelligence (AI), seemingly all of a sudden, has permeated our world. New advances in technologies have the potential to assist students inside and outside the classroom and increase the potential for independence and success. AI can be used by educators to support students. It can be used by students to enhance communication skills. It can help with independence, planning, and organization. However, there are also risks with AI - some related to the content creation itself, and others come from a lack of understanding of a new technology. Those risks can be mitigated with education, clear guidelines, and appropriate policies. Ultimately, AI can and should be an effective tool to support the success of neurodivergent students.

AI has existed in our common experience for some time now. Most of us are familiar with common uses such as mapping locations through a GPS or mobile app, the voices of Siri and Alexa helping us to set timers and alarms, or telling us who wrote a song we may have forgotten. More recently, AI is turning up in new places, sometimes without our even knowing it. AI technologies are estimated to create a value of \$13 trillion by 2030 but also displace some 800 million jobs in that same timeframe (Hutson et al., 2022). In educational settings, there is a broad spectrum of responses to the availability of AI. AI has the potential to positively impact learning outcomes, but many view it with ambivalence or even open hostility (Hutson et al., 2022). A report from 2018 cites such positives as better learning outcomes, increased access to education, increased retention, lowering the cost of education, and less time to complete schooling (Klutka, 2018).

In the classroom, AI can be used to create adaptive learning experiences, personalizing learning to support the needs of individuals based on their learning styles, interests, and limitations. The potential for students to overcome learning obstacles is significant, allowing for content difficulty and delivery to be adjusted in real time (Rajaratnam, 2024). All of this can be considered an assistive use of AI.

AI's biggest promise is its generative use, or the ability to create content with certain prompts. AI can be used to write essays, create art, and answer writing prompts. It can generate an email or letter when provided with minimal information. For a student who might have difficulty communicating verbally or in detail, asking AI to write an email to a teacher to get clarity on an assignment or address a particular challenge offers that student support. For some students, learning challenges themselves can be paralyzing or foster procrastination. Having a reliable tool that lessens that challenge can be quite beneficial.

However, the line between assistive and generative uses of AI is not always clear to the user or to the reader. Content generated by AI tools like ChatGPT, Claude,



Google Gemini, and Microsoft Copilot do not cite the primary sources upon which they rely. Those tools merely scour the information available on the internet and summarize it without any regard to the source, age, credibility, or reliability of the information. Yet some web browsers have embedded AI in such a way that it is not even clear if it is being used. The risks for students, therefore, are many. The learning that comes from the process of research and writing is lost. The content itself might be flawed or completely wrong. There is a lack of research and analytical skill-building. However, there might be a benefit to using AI as the first step in a research/writing project. It can be used to generate an outline which, in turn, can be the step-by-step guide to the research to be done from there.

Much of the skepticism, and even hostility, toward the use of AI in education stems from these risks. The use of anti-plagiarism software is commonplace in educational institutions (Hutson, 2022). The most used software is Turnitin. But, there has been a discussion centered around the reliability of the product in the first place (Fowler, 2023), which has caused a rise in academic dishonesty conflicts between students and educators.

In addition, the use of such technologies without appropriate education to students, then adjusting policies to respond to suspected improper use of AI, may create a barrier to accessible education for neurodivergent students. It is common for educational institutions to have policies in place that address "plagiarism" or "cheating." The common definitions of both are understood and usually defined in academic integrity policies. The discipline for violating those policies can be severe, including failing grades, failing classes, and dismissal from the school. These consequences are particularly devastating in higher education, where every credit comes at an increasingly high financial cost or the time to earn those credits is limited to the four years students might be able to live away from home. Adding classes or having to make up credits can be costly and time-prohibitive. A dismissal can have particularly devastating results, impacting a student's future career prospects irreparably.

The potential for misunderstanding lead-

ing to these types of situations is currently high but can and must be mitigated proactively. Apart from professional development in AI for educators, educators must gain an understanding of their students' perception of AI (Feedback Fruits). One suggestion is the use of pre-course surveys to gain knowledge about how students are using AI already, as well as their questions, misconceptions, and expectations for AI use (Feedback Fruits).

Defining the norms and boundaries around the use of AI must also be a top pri-

ority for educators (Feedback Fruits)-in short, crafting clear and appropriate policies to reflect the capabilities and potential misuse of AI, but which are not draconian in their application. As with almost everything in education, sound policies should begin in the classroom. There should be clear written ground rules for what is an acceptable use of AI, what is not, and what to do if the distinction is not clear. There should be clear processes in place for constructive conversations around suspected misuse of AI to fully investigate the circumstances before conclusions are reached. The definitions of cheating, academic dishonesty, and plagiarism should be examined and discussed in the context of AI. The disciplinary measures for violating those policies should also be examined and adjusted to allow for transparency and accountability for students who knowingly violate policies, but also to allow for education and support for those who do not.

Assistive uses of AI, however, have a tremendous potential to improve academic success for neurodivergent students, as well as to assist them in gaining independence and supporting daily living and social skills. AI can be used to create digital calendars, to do lists, and set reminders and alarms to get those tasks done. It can be

see AI in Education on page 59



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#### Personalized Support from page 9

unique combination of language skills, social awareness, sensory processing, and thinking and repetitive behaviors.

Understanding one's support needs, setting boundaries, and asking for help are critical skills that every person with autism should develop while learning how to advocate for themselves.

Today, I am as optimistic as I have ever been in my direct support career. Initiatives and investments like #MoreThanWork provide necessary growth and development across regional and statewide workforces, which ultimately and most importantly

what it means to them, and its impact. Ev-

ery person on our farms understands that

Prospect Meadow is a vital contributor to

the local food economy, and this is a huge

point of pride for all of us. Who better than

have a positive effect on New Yorkers with developmental disabilities. I applaud these efforts and encourage continued investment in this field. After all, everything we do is to make lives better. We cannot forget that.

Laurlen Coker is Coordinator of Adult Day Services at The Summit Center. The

the farmhands to tell this story?"

Amy Timmins is Vice President of Community Relations for ServiceNet, a large non-profit mental health and human serSummit Center is Western New York's leading provider of evidence-based educational, behavioral health, adult, and community programs to more than 1.000 children and adults each year with developmental, social, and behavioral challenges. Learn more about the organization at www.thesummitcenter.org.

vices organization helping people through-

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#### Project Meadow from page 11

"Whether we're hosting a small group of neighbors or a U.S. Congressional Representative, they are the experts on their work,

#### Independence from page 1

members, service providers, and adults with autism work together to bring awareness of and address this workplace discrimination.

A key element to supporting and empowering autistic adults includes mental self-care. Traditionally, teaching autistic individuals how to care for their bodies is one of the first things we teach: wash your hands, brush your teeth, and dress yourself. These are clearly valuable skills necessary for achieving independence throughout the lifespan. However, mental self-care is frequently neglected, perhaps due to communication barriers and behavioral and/or cognitive challenges.

Imagine if self-care routines for the mind-body connection were integrated into adolescence rather than a reaction to a symptom later in life. Using a holistic approach could involve teaching autistic individuals to manage both their physical

and mental well-being from an early age. What if ASD providers included the mindbody connection as part of a daily living routine as an antecedent strategy rather than a consequence strategy? It would look something like this...Wash your hands. Practice breathing techniques. Brush your teeth. Stretch your body. Get dressed. Eat healthy food. Go to school. Spend time with friends. Get fresh air. Take a shower. Listen to calming sounds/music. Consume positive social media. Eat well. Incorporating the mind-body connection as part of a daily routine can act as a proactive strategy rather than a response to emotional dysregulation only when it becomes problematic.

Family members, caregivers, and educators can model these habits and incorporate them into regular activities. Techniques such as mirroring healthy behaviors, using videos and peer models to demonstrate practices like breathing exercises

"Life-Changing Outcomes

and stretching can be useful and effective. By embedding mental health practices into early daily living skills, we equip autistic individuals with tools for long-term well-being. Just as we teach good hygiene and nutrition, integrating mental self-care from a young age promotes overall health and independence. The key is to address both physical and mental self-care together, ensuring a well-rounded approach to personal development. Supporting autistic adults through life

transitions is crucial for ensuring their well-being and success (Higgins, 2020). As they navigate different stages of adulthood, parents and guardians play a pivotal role in facilitating smooth transitions (Smith et al., 2021). This support often involves understanding and leveraging various systems and services designed to assist autistic individuals (Johnson, 2019). One key aspect is the Fiddle Foundation, an organization dedicated to empowering autistic adults (Fiddle Foundation, n.d.). It provides resources, advocacy, and a supportive community, which can be invaluable during transitions such as moving from school to employment or independent living (Fiddle Foundation, n.d.). Their programs often include skill-building workshops, mentorship, and guidance on accessing necessary services (Fiddle Foundation, n.d.). Guardianship is another critical consideration. As autistic adults reach adulthood, determining the need for guardianship or supported decision-making is essential (White et al., 2022). Parents may need to explore legal avenues to ensure their child's rights are protected and that they have the support needed for making significant decisions (White et al., 2022). This process can vary by jurisdiction, so it's important to seek advice from legal professionals specializing in guardianship and disability law (Black et al., 2023). DDD services (Division of Developmental Disabilities) offer vital support for autistic individuals, particularly in areas like employment services, residential support, and daily living assistance (Division of Developmental Disabilities, 2023). Parents can help by navigating the application processes, ensuring that their child receives the appropriate level of support and is aware of the services available (Division of Developmental Disabilities, 2023). The DDD's resources can significantly impact an autistic adult's ability to live independently and integrate into the community (Division of Developmental Disabilities, 2023). Finally, understanding the benefits of Social Security is crucial. Programs like Supplemental Security Income (SSI) or Social Security Disability

Insurance (SSDI) can provide financial support to autistic adults (Social Security Administration, 2024). Parents can assist with the application process, ensure that their child's needs are well-documented, and understand the ongoing requirements for maintaining benefits (Social Security Administration, 2024). Overall, a proactive approach by parents in utilizing these resources is essential for supporting autistic adults through their transitions (Higgins, 2020; Smith et al., 2021). Fiddle Foundation, guardianship options, DDD services, and Social Security-can greatly enhance the quality of life for autistic adults during major transitions.

For more information, visit firstchildrenservices.com.

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**AUTISM SPECTRUM NEWS ~ FALL 2024** 

# A Collaborative Approach: **Addressing Food Insecurity and Empowering Adults with Disabilities**

By Lori Lerner, LMSW, RYT-200 hr **Coordinator of Family and Wellness** Services for the UnderServed (S:US)

ew York City is experiencing unprecedented levels of food insecurity, with hunger impacting over 1.2 million New Yorkers in 2022.<sup>1</sup> Visits to New York City food pantries and soup kitchens were up 75% in 2022 compared to pre-pandemic levels.<sup>2</sup> Inflation costs soared along with the COVID-19 pandemic, labor shortages, and global supply chain issues. In the 2022 Annual Survey of the people we serve at Services for the UnderServed (S:US), 43% of respondents reported that they need help accessing a food bank, meal delivery, or grocery delivery. This large percentage was at the forefront of our minds at S:US as a large nonprofit organization based in New York City supporting people with disabilities, people living in poverty, and people facing homelessness. We employ a dedicated staff of 1,800, many of whom face the same challenges or support loved ones with these hardships.

With a passion for helping alleviate food insecurity and by embodying S:US' commitment to advancing social justice and health equity in underserved neigh-



Adults with I/DD and ASD served by S:US and AHRC NYC stocking the community fridge with fresh food and pantry items.

borhoods, S:US' leadership staff in Developmental Disabilities Services and Community Food Security - Jajaida Gonzalez, Johanna Cepin, and Michael Hollis launched the Community Fridge program in 2022. Today, there are five community fridges located outside S:US supportive housing and group homes for people with intellectual/developmental disabilities (I/ DD) in Brooklyn and the Bronx. These

boroughs were chosen because they are where people experience the highest food insecurity rates in New York City (19.7% in the Bronx and 15.5% in Brooklyn).<sup>1</sup> As S:US President and CEO Perry Perlmutter shared at the recent opening of our fifth fridge, "We are committed to supporting the Bronx community by ensuring that evervone has access to fresh, nutritious food. This fridge is more than just a place to pick

up groceries; it's a symbol of our ongoing dedication to fostering health, dignity, and hope for all."

Last year, S:US Chief Program Officer Monica Santos and S:US Vice President of Day Habilitation Services Jajaida Gonzalez presented "Mutual Aid: Community Fridges Fostering Community Via Direct Giving" at the New York Alliance for Inclusion and Innovation's Annual Conference. Their presentation highlighted the importance of addressing complex issues like food security in our communities. The Community Fridge program is operated by adults with I/DD and/or Autism (ASD) who attend S:US' Day Habilitation programs. As stewards, with support from staff, they clean and maintain the fridges on a weekly basis. Not only are they gaining transferable work skills, but they are also experiencing joy in helping to serve their communities.

Darinka Vlahek, Adult Day Services Director at AHRC NYC, and her colleagues attended the mutual aid presentation. They were impressed with the fridge program and had a desire to collaborate to help cultivate food security in the Bronx and support the people in their programs to build skills. The seeds of collaboration were planted to grow the support provided

see Food Insecurity on page 40

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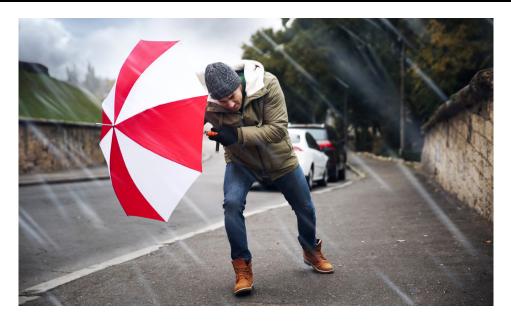
# Amid Increasingly Extreme Weather, Autistic Individuals Left Particularly Vulnerable to Climate Change Effects

#### By Emily Blumberg Freelance Writer

herman Gillums Jr., the Federal **Emergency Management Agency** Director of Disability Integration and Coordination, remembers the event that made him realize emergency responses needed to be more autism-inclusive. In the throes of Hurricane Ian the fifth strongest storm to ever strike the United States — he found a mother living out of her car with her two autistic sons in the backseat. When he asked her why she didn't go to a shelter, she said she worried they would be treated as troublemakers rather than autistic adults. On top of that, she hoped the quiet, enclosed environment of a car would minimize her sons' sensory overload.

"I just felt like this was something the Office of Disability Integration and Coordination had to address," Sherman said. "Autism wasn't really visible to me until that moment, and I want to help other people have that epiphany like I did."

In 2020, the Centers for Disease Control and Prevention found 1 in 36 Americans is diagnosed with autism, a disorder characterized by social communication challenges and restricted, repetitive behaviors (Maenner et al., 2023). The United



Nations Department of Economic and Social Affairs reported that people with disabilities — including autism — are two to four times more likely to die or be injured during natural disasters (United Nations, 2016). As rising temperatures and sea levels make extreme weather events like Ian increasingly common and intense, Sherman says he has committed to developing autism-specific support systems for natural disaster situations.

"People with autism include our family

members, friends, co-workers, neighbors, and community members. It is in our collective best interest to better understand how autism affects all aspects of living, especially during times of crisis," Sherman said. "Understanding the unique aspects of their lived experiences will help us better ensure their safety and recovery when impacted by any number of major disasters, from extreme heat to hurricanes."

When Hurricane Sandy hit New York in 2012, Cassie Bradshaw not only had to

take care of herself but also the seven autistic adults living in the residential home she manages. Forced to evacuate from their beachfront house in Long Beach, Cassie and what she refers to as "the guys" spent four nights sleeping on cots in the Brookville Center for Child Services gymnasium. As Bradshaw and other staff members stockpiled canned food and necessary medications, "the guys" and their classmates performed shows and played basketball in the auditorium.

"One of the guys would literally point to the door every now and then because he wanted to go home," Cassie said. "I would show him pictures of little things, like trees down in the road and highways closed, to explain why we couldn't go home. I didn't tell him our house probably wasn't there anymore."

Hoping to improve the experiences of people like Cassie and "the guys," Sherman and his Office of Disability Integration and Coordination collaborate with local disaster responders to promote autism acceptance and understanding. One of these responders, Jerry Turning, is a retired New Jersey police officer who began holding autism first responder training sessions after his son was diagnosed in 2007. Jerry's Blue Bridge Autism Training provides emergency

see Extreme Weather on page 41

# A Maze of Red Tape: My Experience with Benefits and Bureaucracy

#### By Remy St. Gallen Freelance Artist Studio St. Gallen

hough I was diagnosed as autistic in my infancy and can remember as far back as when I was four years old, I never realized I was different until the second grade, when I was shuffled between special and regular education, when I made the fateful decision to become fully integrated into the latter, in my attempts to become a "normal" person. Throughout my grade-school years, I never fully embraced being autistic, even during the months before I graduated. When I was offered to go on Social Security due to my disability, I was reluctant at first before ultimately accepting, a decision I didn't regret, although it would easily become a pandora's box years later.

I mostly used the money I received from Supplemental Security Income (SSI) to pay for community and undergraduate college, along with various scholarships I received. Although I graduated in December 2008 with my bachelor's degree and an excellent GPA of 3.93 in computer information systems, the job offers didn't roll in at all, despite my constant applications to various positions. I eventually discovered Social Security's Ticket to Work program, which, after a lengthy process that involved background and reference checks, helped me



land my first part-time job for a firm that worked with the local military base, slightly in my field, but very far from high paying.

That job only lasted for two months, after which I was promised another position with the same company on the military base working for the provost marshal's office, but I did not receive it until the following year. This occupation lasted only a year due to my high error rate in submitting reports. Between my first and second paid jobs, I had relearned to drive, as not being able to do so had been a major deterrent in having to turn down a position with my old community college in the middle of 2009, and I did not want to burden my parents with the constant need to bus me to and from work.

Around this time, I lacked experience with mass job posting sites and relied on applying to positions directly through company websites. I submitted applications for several positions in my town's school district and netted my third position as a substitute teacher, which, too, lasted around two months. The next and final job I would have for several years was with an education platform's call center, which lasted longer than the others I had held, and during my tenure, I discovered that my parents constantly needed to submit my wages to Social Security so they could determine how much to reduce my payments and whether I needed to pay back some of the money I had received from the government.

After I was terminated from that job, I began a seven-year hiatus where I held no form of paid employment and lived off my Social Security money while living with my parents and keeping up to date with my various medical obligations through a combination of Medicare, Medicaid, and Tricare for Life, the last of which I received since my father had been in the military. In 2019, I made the decision to reenter the workforce, applying for several jobs online and ultimately receiving a customer service representative position at my town's call center, which at that time became the job I held longest before stress and the onset of the coronavirus pandemic pressured me to resign.

Again, my parents needed to submit my earnings to the Social Security Administration, where they needed to endure the constant waiting game and runaround of snail mail correspondence in which they reduced my monthly payments and even necessitated me to pay much of it back. After I left the call center, I worked at home for an inbound support specialist position

# **Building a Healthcare Transition Program** for Autistic Patients Entering Adulthood

By Carrin E. Schottler-Thal, MD Medical Director Albany Medical Center

he rise in the diagnoses of autism spectrum disorder in youth will mean a rise in the number of adolescents transitioning to adult medical care. 50,000 youth with autism are estimated to enter adulthood each year (Rast et al., 2020) with varying degrees of communication skills, adaptive functioning skills, and social skills. Many autistic patients also carry other mental health and physical diagnoses. Developing a comprehensive transition plan is essential to any healthcare provider taking care of this population.

Despite the need for transition programs for autistic adolescents, a recent analysis (Zablotsky et al., 2020) of The National Survey of Children's Health (NSCH) has found that only 1 in 4 youth with ASD had actively worked with their doctor to understand future changes in their healthcare. This is significantly less than youth with other mental, behavioral, or developmental disorders. Currently, adults with autism report multiple barriers to receiving adequate healthcare, making the need for transition programs critically important. Doherty et al. (2021) reported that the greatest barriers



to receiving healthcare for autistic adults were uncertainty about whether symptoms warranted a medical visit, difficulty making appointments by telephone, not feeling understood, difficulty communicating with their doctor, and waiting room environments. Unfortunately, providers also report many barriers when designing and implementing adequate autism transition programs. Harris et al. (2020) reported provider barriers as inadequate time, provider preferences, and difficulty in collaboration with adult providers. For this reason, a clear framework for an autism transition program that considers medical, personal/social, and educational/vocational needs is needed.

When considering the medical needs of an autistic young adult, transition programs need to consider the increased rates of ADHD, depression, anxiety, seizures, and obesity in this population. Providers who are comfortable managing these issues will be essential in the transition team. Other specialists, as well as allied healthcare professionals, will also be needed in the transition team because many of these issues are not all managed by the primary care provider. Preventative care services such as counseling, nutrition, and fitness services will also have to be included.

Individual patient needs will also need to be addressed. The transition program should focus on building health literacy skills, including effective communication, with their medical team. Individual patients will also need to gain knowledge of their medical conditions and medications. The program should also address reproductive health and risk-taking behaviors of all patients regardless of intellectual ability. The program should also help patients with various communication abilities practice strategies for making and attending appointments. Text-friendly services, as well as provider comfort using communication devices, will be of utmost importance. Autism-friendly pharmacies that allow for texting or picture-based medication re-ordering services will need to be part of the transition plan as well.

When considering the social and personal needs of the patient, transition programs should support patients in improving their

see Transition Program on page 41

# **Supporting Autistic Individuals in Driver Education: A Systematic Approach**

By Heidi Hillman PhD, BCBA-D, LMHC and Rebekah White Eastern Washington University

earning to drive is a significant milestone, symbolizing greater independence and autonomy. Driving independently offers freedom, builds confidence, and encourages self-reliance, empowering individuals to make their own decisions (Cheak-Zamora, Tait, & Coleman, 2022). Additionally, independent driving reduces reliance on public transportation, which is particularly beneficial in areas with limited transit options. Moreover, for autistic individuals, driving can be a safer alternative to public transportation by minimizing the number of transitions and sensory issues (Lubin & Feeley, 2016). However, learning to drive presents unique challenges for autistic individuals since it often involves anxiety, difficulty mastering complex driving skills, sensory sensitivities, unexpected changes, and struggles with applying theoretical knowledge to practical situations (Sheppard, Loon, & Ropar, 2023; Wilson, Lee, Vaz, Vindin, & Cordier, 2018).

Despite these obstacles, many autistics aspire to obtain a driver's license. Yet traditional driver's education programs, required by many states before granting a license, typically follow a one-size-



fits-all approach that may not meet the specific needs of autistic learners. Understanding how autism affects the process of learning to drive is vital for providing effective support and accommodations. We examine the challenges autistic drivers face, the importance of customized instruction, and strategies for promoting safe and confident driving. By addressing the unique needs of autistic learners, we can create empowering pathways to driving independence.

#### The Gap in Research and Driver's Ed Programs

Despite extensive research focusing on driving challenges autistic individuals experience and developing strategies for safe driving (e.g., Lindsay, 2017; Silvi, Scott-Parker, & Jones, 2018), there is a lack of driver's education programs designed for autistic individuals.

To address this gap, we conducted a nationwide search of driver education

programs offering driving services for autistic individuals. Our search yielded 18 programs across 18 states, but after evaluating the programs based on their website and excluding programs that did not focus on driver's education leading to a driver's license, only six met our criteria. The six programs included Adaptive Experts (serving Minnesota, Wisconsin, Iowa, North Dakota, and South Dakota), Driving MBA (Arizona), NeuroHub (Florida), Strive for Independence (Illinois), Driving for Exceptional Learners (Iowa), and Wheel to Drive (Michigan). The remaining 12 programs focused on rehabilitation for licensed drivers or driving safety assessments.

Our findings highlight the scarcity of driver's education programs tailored for autistic individuals, underscoring the need for effective programs for autistic individuals. Given the limited research on tailoring driver's education to autistic individuals, we propose a systematic approach to adapting traditional driver's education programs to better meet the unique needs of autistic learners.

> Driver's Education Program for Autistic Individuals

For autistic drivers, the goal of driver education is to expose them to a new environment in a gradual, methodical, and

# A Simple Guide to Wealth Building for Autistic Folks

By Danielle Aubin, LCSW Autistic Private Practice Therapist My Autistic Therapist

realize it might seem odd that a therapist is writing an article about money, but I'll have you know finance has been one of my autistic special interests for over ten years. Over the years, I've read and listened to countless books and podcast episodes on finances. I would never preach one "right" way to do finances, but I will share what I have gleaned over the years and what has worked well for me as an AuDHD'er, mom, and business owner.

#### Understand What Money Is

The first thing you must understand is what money is. Money is a powerful tool that can be used to buy you freedom if you understand how to invest it. In order to invest money, you need to earn more than what you spend. After you figure out how to earn more than you spend, you will need to learn what to do with the excess. Learning how to manage money is a psychological game. In fact, according to the business insider (Weisenthal, 2014), dead people tend to outperform live people when it comes to investing. The moral of that story: don't mess around too much with your investments; set it and forget it. Anything else requires a lot of research and guessing.



#### Learning Your Money Story

I grew up in a family where my parents didn't know how to invest money, so they never did. When my father inherited \$10k after his mother passed away, he invested in penny stocks (basically stocks that are very cheap and volatile), and he lost it all in a matter of days. Our family and backgrounds heavily influence how we feel about money. I highly recommend the podcast I Will Teach You To Be Rich by Ramit Sethi (Sethi, 2021). Ramit has a great way of coaxing his guests into divulging their psychological hang-ups and inherited money stories. It's really important to learn what yours is and how it impacts how you handle money.

#### Autism and Money

In addition to the money stories we inherited from our parents, we also can absorb money stories from the larger autism community. We can hear disheartening statistics such as "....50-75% of the 5.6 million

autistic adults in the U.S. are unemployed or underemployed. Nearly 50% of 25-yearolds with autism have never held a paying job..." (Palumbo, 2021). This can be demotivating, to say the least. We cannot argue with these statistics; they are true, but that doesn't mean we can't learn about money and how to manage the money we make. While the majority of autistic people are unemployed/underemployed, there are many of us who are employed or even in high-paying jobs and need to find ways to protect ourselves via investing so that we can hedge against burnout and the potential need to retire earlier than our peers.

### A Simple Way to Invest

After studying finances for over ten years as my special interest, I have settled on one money philosophy, and that philosophy can be summed up as simplicity. I don't try to make fancy investments or predict things. I just take all of my extra money (acknowledging privilege here) and buy broad-based index funds. Index funds are essentially a slice of all of the stocks on the market. So, my investment portfolio just goes up and down with the stock market. And if you have ever looked at how the stock market has performed over the past 100+ years, you will see that it is a long game, but ultimately, it has always

see Wealth Building on page 43

# Navigating the Later Stages of Life with Autism and Aging

#### By Johanna R. Murphy, MFA Director of Development Evolve Coaching

omething that we as a community have yet to fully turn our attention to is the question of "how do we help our autistic elders thrive and live in dignity as they age?"

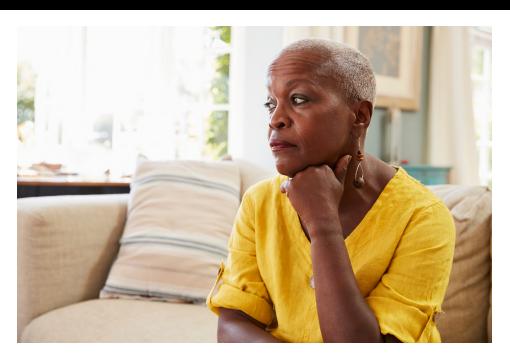
As a late-diagnosed autistic woman, I am a pretty good example of what growing up and growing old without any particular support looks like. Nearly all of the late-diagnosed women that I know are in similar shape: two mistakes away from dire poverty and facing escalating health issues while our earning power is declining.

The numbers back me up: according to the Social Security Administration," 17.3 percent of nonmarried elderly women (widowed, divorced, or never married) are living in poverty today." And *that* figure doesn't take disability into account.

According to *American Progress*, in March of this year, "In 2022, 26.2 percent of disabled women lived in poverty compared with 10.7 percent of nondisabled women and 21.6 percent of disabled men."

That 26.2% is a vast increase over the already appalling 17.3% for unmarried women. I am an unmarried disabled woman in my 50s, and I am mildly concerned.

I'm only speaking for myself, but I know that my story echoes that of so many other



adult autistic women my age. We struggled. We struggle. Our late diagnosis gave the struggle a name and a framework but did not lessen the struggle materially or socially. It's only by talking about so many of the things that embarrass me, that have similarly embarrassed others, that we can draw attention to the areas where we and younger late-diagnosed women will need more intentional support.

Growing up in the wild and wooly 70s, my autism and ADHD were never diag-

nosed. Similarly, growing up in the 1930s and 40s, my parents' neurodiversity, now blazingly apparent, also went undiagnosed. The thing about growing up in a cluster of ND folks is that your neurodiversity doesn't necessarily stand out. Mine stood out only due to my failure to be good at being a girlthat was the focus of "fixing me" at school and at home. Things would be fine if I were just more demure, more mindful....

I wasn't, and none of those things helped. What that strategy did was guarantee that I would feel awkward and burdened with shame about simply existing, both around my family and everyone else, to this day. I moved away from home as soon as possible despite not having any resources or knowing much about how the world outside of school worked. For example, I literally did not know that *people paid money for their utilities*. However, if I hadn't left home then, I never would have made the leap.

I had no idea of how to advocate for myself, or what was just treatment, or what behavior I shouldn't tolerate. My mother was so infuriated that I didn't plan to move back home after college that she punished me by taking the little bit of money I had squirreled away from my last student loan disbursement, hoping to prevent me from going by taking away the means I had acquired to set myself up. I felt that I deserved such treatment because I was disappointing and disobeying my mother, and as someone who was just inherently wrong, I had no right to expect better. It took me years and a lot of grief to pay that small loan off, and I never really stabilized from that precarity until my 30s, which in turn made me feel even more ashamed and awkward.

I never lost the sense of shame that was laced through everything, the never-receding feeling of not deserving to be where I was, that I shouldn't be there. I never recovered from the sense that I should hide

# The Complete Autistic Travel Guide

### By Karl Wittig, PE Aspies for Social Success (AFSS)

ravel, whether for necessity or pleasure, is an important part of human existence and opens the door to a variety of new experiences. For many, it also presents opportunities for excitement and adventure, as well as a welcome change from the boredom of daily life. To the autistic person, however, this can constitute a disruption of regular routines, which may be uncomfortable and even result in anxiety. Also, the reasons for and value of recreational or educational travel, not to mention how the experience is processed, can be very different for an autistic than they are for a typical person. In particular, the intense and restricted specialized interests of an autistic person can greatly affect all of these. Sensory sensitivities and discomfort with unfamiliar environments and situations can have a great effect as well.

I discuss these issues in large part from the perspective of my own travel experiences, which consisted of various European trips along with some domestic (U.S.) travel. This was done both during my career while working as an engineer for a Europe-based electronics company and later when attending numerous autism conferences.



#### Preparing for Travel

Going on a trip constitutes a disruption of regular daily routines and usually requires at least some preparation. As such, it is best to be as well-equipped for such in advance as possible. This is very wellknown to prominent autistics like Temple Grandin and Stephen Shore, both of whom travel the world extensively and frequently, and both of whom have described the challenges that this presents to them and how they have dealt with such. Even though I do not travel nearly as often (perhaps once or twice a year), I have, over time, devised (independently) my own methods of being prepared for any trip that might arise. As it happens, these are much like the ones that they had been using! Clearly, the autistic mind often works in similar ways for otherwise different individuals.

A major part of preparing for travel involves packing bags or luggage. This requires determining what one needs to bring and estimating how much of each item. Some time ago, I realized that having a dedicated drawer for my travel paraphernalia would be of great help. This includes small containers (nowadays TSA-approved sizes) for toiletries (toothpaste, mouthwash, shampoo, etc.), as well as my toothbrush, comb, hair trimmer, and other personal items. A daily dispenser for medications, vitamins, etc., is also a must and has to be filled before departure (making certain that there is enough for every dose needed during the trip, plus some extras). The needed number of each clothing item is determined by the duration of the trip and how often they must be changed, plus extras in case they are needed. Dedicated plastic bags for some items (e.g., socks, underwear) have also been recommended. Blank forms for necessary arrangements (e.g., holding of mail by the Post Office) should also be placed here; this serves as a reminder that they need to be filled out and submitted before departure. Also, any bills that come due during the trip should be paid in advance, if possible. A checklist of all necessary items and preparations can also be of help. The important point is that by systematizing the process of preparation, it becomes more straightforward and creates less anxiety for autistics who otherwise might find the experience very stressful.

see Travel Guide on page 46

# **Cultural Autism Studies at Yale: A Revolution**

#### By Dawn Prince-Hughes, PhD Co-Chair Cultural Autism Studies at Yale (CASY)

have always been sensitive to cultures around me, especially those that remain largely silent or unseen. As a child, I would spend hours watching how crawdads moved together, what dances turtles did when they communicated, and what joy interactive playing brought to jumping spiders - every facet of culture was part of a greater diamond within me.

I define culture differently than I was taught through university textbooks. In fact, I find that it's difficult to define culture at all because it is so dynamic and alive in every moment, and each tiny culture links to larger and larger cultures around it and moves through it. As an autistic person with a relational way of being, the environment is not separate from any living thing, nor is any living thing separate from any other living thing.

Culture then becomes a point of view through movement, constantly innovated, embodied, and shared... a living organ designed to keep a larger energetic body of relationships connected. It is holographic in nature, in that every single facet reflects every other facet in the universe, ad infinitum - an inconceivably complex and interwoven net of gems that each reflect every other.

In traditional anthropology, a researcher



goes into a group of people much different than themselves and tries to put the things that they experience, the things shared with them (willingly or unwillingly) in a box. By definition, anthropology isolates and removes culture from context. As with so many things about neuronormative culture, this approach to learning about other shared ways of being - this reductionist way, this colonizing way of looking at things - never resonated with me. Culture is a mirror. And we are mirrors of culture. After many years of working as an autistic anthropologist over my career, uncovering unnoticed or under-valued cultures, it was natural that I would gravitate toward an ethnography of my own people, putting all of these thoughts and experiences to work.

An "ethnography" is a formalized acknowledgment, exploration, and recording of the unique shared patterns that give a group of social beings sustained and meaningful cohesion. Ethnographies are generally considered the primary tool of cultural anthropology, and I pondered for some time exactly what an ethnography would look like from an expansive framework.

Synchronicity itself is a part of autistic culture. I met Dr. Roger Jou of the Yale Child Study Center when I was asked to come and speak about my work with gorillas a couple of years ago. He listened with interest to my evolving ideas about the importance of acknowledging and exploring the burgeoning autistic culture (recently exploding with the assistance of technology). We worked together to win a grant from the Connecticut Council for Developmental Disabilities so that I could begin to explore autism as a cultural phenomenon through the autistic social program that he had already established.

> Why Is an Autistic Ethnography Important?

Because the shared lived experience of being deeply understood, participating in a shared framework that supports its participants in contributing to the greater good, offering an expanded identity that is a valued part of security, validation, and safety is the ancient birthright of every social being. Moving far beyond utility, acknowledging, documenting, and preserving autistic culture is the right thing to do in and

# Navigating Sex as an Autistic Adult

#### By Britt Boylan Student, Naropa University

t has long been thought that autistic adults desire sex at a lower rate than the general population, and recent research has shown this to be an incorrect assumption seeded with infantilization (Weir et al., 2021). Although autistic adults often need accommodations to be made regarding sensory differences or a need for structure, there is still space for them to have fulfilling sex lives. There is also a lack of adequate sex education provided to autistic adults that considers the increased rates of sexual victimization that can occur throughout their lifespan (Weir et al., 2021). This article aims to discuss ways in which autistic adults can advocate for their sexual needs as well as empower them to be authentic and take up the space they deserve.

Infantilization is the act of treating or responding to an adult in a way that would be appropriate for a child (Stevenson et al., 2011). This is a phenomenon ever present in the autistic community. Studies have shown that when non-autistic (henceforth, allistic) people are asked what comes to mind when they think of an autistic person, they often describe a child (Stevenson et al., 2011). This is also true for many organizations that are aimed at "helping" autistic people. Often, the verbiage found on



these websites is centered around autistic children and neglects to acknowledge that autistic children eventually grow into autistic adults (Stevenson et al., 2011). This is crucial to consider when discussing how autistic people choose to approach sex. Infantilization has gotten in the way of proper sex education being provided to autistic individuals and contributed to the significant inconsideration that many autistic people are a part of the 2SLGBTQIA+ community (Weir et al., 2021). Neuronormative expectations placed on autistic people regarding gender, sexuality, and sex have impeded an open conversation about how autistic adults can navigate sex (Wise, 2023). This can show up in autistic people entering cisheteronormative monogamous relationships because this is what is deemed as "societally acceptable," not considering that these relationship structures were not designed with autism in mind (Wise, 2023). Autistic people may question societal norms at a higher rate than allistic people, which is hypothesized to be one reason many autistic people are queer, gender-expansive, and/or polyamorous (Weir et al., 2021). These are all pieces of proper sex education for autistic people that are lacking in the healthcare space (Weir et al., 2021).

#### Accommodations for Sex

Each autistic person will have unique needs, support needs, and traits present, so when considering how to accommodate oneself within the context of sex, it is important to start with what one's needs are. The autism spectrum can be viewed as a circle, where each individual can define where they fall in various categories such as language, sensory, executive function, perception, and motor skills (Bradshaw et al., 2021). Spending time considering areas where an autistic individual may have higher or lesser needs can lead them to narrowing down accommodations they may need during sex.

Autism comes with a variety of sensory differences and needs that will vary from person to person, so how can one take these into consideration during sex? Touch that feels overstimulating outside of a sexual context may feel pleasurable within a sexual context, so experimenting with this alone or with a trusted partner

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# Autistic Resilience: Overcoming Adversity Through Self-Care and Strengths

By Lisa Morgan, MSW, MEd Lisa Morgan Consulting LLC

could say 'Adversity' was my middle name, but I'd be lying... it's Rae. Still, like so many other autistic people, adversity has been part of my life for as long as I can remember.

Research has validated that claim by saying autistic people have an increased risk of experiencing adverse events, trauma, interpersonal violence, and the results of those experiences, such as PTSD, anxiety, and thwarted belonging (Lobregt-van Buuren et al., 2021; Bhargav & Swords, 2022).

Autistic people have been bullied in school, at work, and even at home (Humphrey & Hebron, 2015; Praslova et al., n.d.). They've been rejected, ostracized, discriminated against, and have felt the utter unfairness of prejudice. Most have had numerous friendships that have ended without warning or reason. They have been misunderstood, invalidated, and unintentionally harmed by well-meaning support people and professionals, although we need to remember that unintentional harm is still harm.

Why, after decades of living with adversity, do autistic people keep going? How do I, and many other autistic people, become resilient, knowing each new day will most likely bring some kind of adversity? Where does the resilience come from?



The Resilience Theory was developed to understand and describe people who have gone through difficult, traumatic experiences and then thrive as they move toward health, healing, and happiness (Van Breda, 2018). They are determined to find a way to take care of themselves so they feel safe, joyful, and productive. They have the ability to not only overcome negative experiences but also become stronger because of them (Ledesma, 2014).

I know many autistic people who have a background of trauma live with PTSD, and yet they are resilient. They keep moving forward, doing great things in their jobs, homes, communities, and even around the world. I believe there are three distinct areas that help autistic people to be resilient in spite of the adverse experiences they have endured. They all fall into the overall category of self-care.

The first one is a sense of awe and wonderment. Autistic people, with their fascination with facts, attention to detail, and creative curiosity, can use the sense of awe and wonder to take care of themselves. In order to be awestruck, one has to be able to focus on something interesting in great detail until everything else falls away (The Awe of the Autistic Mind, n.d.). The idea is to get to a place where the overwhelm, the sensory stimulation, the countless thoughts, and the anxiety – are displaced by a sense of wonder and awe, even if it's just for a little while. It could be a flower, especially the flowers that have grown up straight and tall within a crack in a rock or cement. It could be the immensity of a tall building, the sound and sight of waves crashing onto the shore, a song, the vast blue sky, or a meaningful poem.

The second is creating an inner world. Autistic people have rich inner worlds. Many autistic people can lose themselves in a place they create in their minds that feels safe, joyful, and perfect for them. Over 200 autistic people were surveyed, and 90% of them reported an inner world they used for self-care (Exploring the Inner Worlds of Autistic Minds, 2021). Autistic people who use their inner worlds create the types of places that make them content. They can have more than one inner world; they can create characters, design their world exactly how they want it, and then escape into it for self-care.

And the third is the ability to recognize and use their unique strengths. Autism is typically looked upon as a deficit-based neurological developmental disorder, but it's so much more than that. Autistic people can use their unique ways of being as strengths. For instance, focused passions

# What Neurodiversity Means to This Late-Identified Autistic Adult

#### **By Sam Farmer**

Neurodiversity Community Self-Advocate, Writer, Author, and Public Speaker

Lived the first 40 years of my life as an autistic individual who didn't know it yet. In a sense, lost because I lacked a complete picture of who I was. Confused because I faced too many questions as to why I was contending with challenges that were foreign to just about all of my peers, which I simply could not answer. Masking as a people pleaser because I thought doing so would address my fear of confrontational situations and help me "fit in" better than I otherwise would. Down on myself because I didn't ask to be different but knew that I was.

The consequences of not knowing for that long were dire: compromised self-esteem, bullying, and hardships around dating, relationships, and making friends, to name a few. Initially, being identified as autistic didn't help matters. Finding out caught me off guard in that I was unable to reconcile what I knew about the autistic individuals I had known with what I had just learned about myself.

When my autism was uncovered, what I needed most was a lifeline, and that's precisely what I was granted during the years that would follow as I was working with various clinicians and researching what autism is and what living with it entails.



Eventually, I was able to come to terms with, accept, and ultimately embrace it as being core to who I am, understanding that if I failed to accept this about myself, I would never feel whole and would, therefore, never find true happiness. That lifeline would not have surfaced had it not been for my learning about neurodiversity.

Neurodiversity is a paradigm which provides an alternative lens through which autism and other diagnoses are viewed, not as medical pathologies to be fixed or cured but instead as neurotypes (the way a person's brain and nervous system are wired) which carry not only unique challenges but unique attributes, abilities, and talents as well. As such, the minority neurotypes under the neurodiversity umbrella (autism, AHDH, and learning disabilities, to name a few) are looked at as differences, not deficits.

Just as biodiversity is a term that encompasses all of life on Earth, neurodiversity embodies the neurological variety that has always existed within the human population. It speaks to all of us and in so doing, radiates inclusivity. What a word! Neurodiversity provides a counter-narrative to the medical model of disability, aligning instead with the social model of disability. Put another way, societal expectations, primarily around socialization, communication, and behavior, become more disabling to us than our own intrinsic hardships. As a believer in neurodiversity, I reject the notion that I am broken and in need of repair. Rather, I feel burdened mostly by external influences, chief among these, ableism.

Neurodiversity is a global movement centered around social justice and human rights, which seeks to de-stigmatize neurodivergence and cultivate greater understanding, acceptance, and belonging. Those of us in this movement who are neurodivergent pursue these goals through the sharing of our lived experiences, by calling out damaging stereotypes about us and by fighting for greater neuro-inclusion in society, particularly at the workplace, in clinical settings, at educational institutions, and wherever else neurodivergent individuals face marginalization.

Above all else, in the neurodiversity paradigm, I found the lifeline I had been longing for, which enabled me to attain self-acceptance and ultimately learn how to love who I am. When autism is de-stigmatized, when the "disorder" label is dismissed, when we realize that we no longer bear

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# **Building Self-Advocacy Skills in Autistic Young Adults**

### By Priya Winston, PhD, LMSW Transitions

dulthood is the time when teachers and parents can no longer advocate for their children the same way they could during the school-age years. Much of it becomes the responsibility of the adult. At the beginning of my career, I had the opportunity to develop an evidence-based curriculum in partnership with an expert from Virginia Commonwealth University's Autism Center of Excellence on self-advocacy for young adults with Autism and learning differences. I spent years teaching this course as well. Here are a few pieces of the curriculum that clinicians, educators, and family members of Autistic young adults can use with Autistic people in their lives. Of course, Autistic adults can utilize these strategies themselves as well.

#### Self-Awareness

Everyone must identify their strengths and areas where they may need support in their lives. Additionally, Autistic people have to reckon with a diagnosis that may change the way they view themselves. It often helps them to look into the stories of noteworthy Autistic people such as Anthony Hopkins, Lionel Messi, Jonny Depp, Bill Gates, Dr. Temple Grandin, Susan



Boyle, and many more.

It's Okay to Ask for Help

Once people identify areas where they might need more support, they can start to ask for help. When they start to see that their diagnosis can include several strengths, they can start to see asking for help as a necessary part of their growth. When they learn about the stories of other Autistic people who have lived fulfilling lives, they will start to learn how they sought support and asked for help as well. Asking for help is necessary for everyone, but our society often teaches us that it is a weakness when, in fact, it can be the most courageous thing one can do. When educators, clinicians, and guardians of Autistic Children start encouraging this at an early age, the children become more comfortable with it when they are adults. Offering encouragement and positive reinforcement when children ask for help can be life-changing for them. Of course, it's never too late to start intentionally practicing asking for help.

#### Practice

It often helps to prepare ahead of time before self-advocating. It is helpful to develop a script. There is an evidence-based practice called social stories for this. Social Stories are tools with images and/or text that are used for effective communication between Autistic people and the rest of the world. Autistic people can create them with educators, clinicians, or loved ones. They can also find ones that work for them online. Autistic young adults can ideally practice this at an early age as children. For instance, they can order their own food at a restaurant if they are old enough. Looking at the menu ahead of time will help them prepare a script to help them order. They can use a communication device like an iPad if they prefer to do this without speaking. This is a simple way to empower them to self-advocate at an early age. After speaking at a conference, the first person who approached me was a young man who was carrying an iPad in his hand. His mother and I both waited patiently for him to communicate what he wanted to say. He shared an incredibly kind message about my presentation with his iPad. He may not have done this had his mother or I rushed him and insisted that he speak audibly. The same thing can be done with a laptop or notebook.

# Three Artists with Autism. Three Voices with Purpose: Laura Nadine, Blair Bunting, and Stuart Neilson

### By Tom Ortega

Director, Mulzet Center for Expression First Place Global Leadership Institute

rtists invite their audiences into conversation. A piece of music, a photograph, a painting—each is a personal statement created to connect emotionally or intellectually with listeners and viewers. These expressions and the methods used to create them are shaped by lived experiences, some painful and difficult to endure.

Laura Nadine, Blair Bunting, and Stuart Neilson are artists with autism who engage with and change the world around them through three distinct voices. For each, art is a language they have learned to embrace and trust.

Nadine, a violinist, composer, and music educator born in Atlanta and living in Toronto, often prefers to let her instrument do the talking. "It is something that speaks when I can't," she said. "I get very frustrated trying to explain things to people, expressing my needs, expressing my emotions. Things can get very complicated just trying to find words to communicate with others. But with music, it never fails. If I want the audience to laugh, they laugh. If I want them to cry, they cry. It just never fails."

"I remember the time I figured this out about the audience," she continued. "I'd only been playing maybe a year. I was playing the piece 'Humoresque,' a well-known piece by Dvořák. I looked out at the audience and noticed that if I did something humorous, they would laugh out loud. When I hit the peak of the song, where it was deeply emotional, I could see that people had wet eyes, and I remember taking that in and going, 'Wow, this is really cool.'"

Nadine considers that connection her goal. "There's an energy that changes in the room," she said. "You can almost tell when everyone is vibing on the same frequency.



Photographic study of public space by Stuart Neilson



Freight train outside Flagstaff, Arizona by Blair Bunting

Anytime I'm performing, that's what I'm looking to do—I'm taking in the context, I'm taking in the energy of the room, and I'm trying to meld us together so we're in this constant state of flow."

Blair Bunting, an internationally acclaimed commercial photographer who makes his home in the mountains of Flagstaff, Arizona, discovered the communicative power of his pictures in high school. A reserved teenager who wanted to relate with others his age, he struggled internally with conversation. "I just crawled in my skin," he said. "I never had an easy time connecting with people because my personality was probably a little different. It was that shy guy trying to overcompensate. It was grueling."

All of that changed with the click of a camera—a 1972 Nikon F his father gave him that Bunting still uses today. "Picking up the camera and making art with it was a way of starting conversations that I wanted to talk about or that I was comfortable expressing," he said. "I would make pictures and could go to a person and show them."

Bunting reflected on this further: "You know, a picture is worth a thousand words, and those were words that I wanted to convey. Until I started creating images, I wasn't able to."

Stuart Neilson communicates through pictures, too. He picked up his first camera as a child when his family lived in Ethiopia. Back then, it was a Kodak Instamatic; the subjects were the surrounding landscapes and wildlife. In his 50s, as a college professor with a Ph.D. in statistics in Cork City, Ireland, he began using a digital single-lens reflex camera to open up and deliver a personal message to his class. He was experimenting with ways to show students how difficult normal, everyday life was for him as an adult with autism.

Neilson struggles with busy public spaces. Navigating the flow of pedestrian traffic and physical amenities is difficult and often prevents him from completing the most mundane tasks. Walking into his local market and buying a loaf of bread can be overwhelming. "I was teaching disability studies and started photographing places that I was finding difficult to get into or to find my way around," said Neilson. He started using stop motion photography and heat maps to identify the patterns and intensity of movement, revealing potential sensory refuges for him and others.

"I'm trying to photograph things that are really unremarkable to most people," said Neilson. "How to walk into a shop, something people do hundreds of times in a week. And I'm saying, "This is hard,' and they're doing it all the time, and they can't see why it's hard."

In the process of conducting these photographic studies, Neilson is creating beautiful compositions: "They end up looking very abstract. Something that's really dull and boring becomes an abstract piece of art."

Fully knowing oneself is important to fully expressing oneself. And while they began to explore their art early in life, it was years later that Nadine, Bunting, and Neilson discovered they were living with autism. Nadine was in her late 20s, around the same time her son was diagnosed. Bunting was almost 40, well into his struggles with panic disorder. After experiencing the stigma of being labeled "educationally subnormal" as a child and living through in-patient psychiatric care, Neilson was diagnosed at 45. His son is also autistic.

For all three, awareness brought clarity—and a greater sense of purpose.

As a music educator, Nadine teaches children with disabilities how to discover and amplify their own voices through music. Determined to create an impact that carries like a long, sustaining note on her violin, she also teaches other educators how to make music more accessible to students with greater support needs.

More than anything, Nadine wants young musicians to believe in themselves—regardless of perceived ability. There is hard-earned strength in her words when she says, "I love music. I have managed to make a living doing nothing else. I think it's important. And I think it's important for people to understand that you don't have to be Taylor Swift to make a living at it. My teaching is the arts, my performing is the arts, my writing is the arts. I am selfmade from my own artistic vision. I think people should hear that so kids coming up now aren't dissuaded."

Bunting, a highly sought-after photographer who has shot all over the world for brands like Nike, Chevrolet, the Discovery Channel, the NBA, ESPN, and Sports Illustrated, suddenly realized why he would retreat to his hotel room after a day of shooting celebrities and break down crying. The reasons for years of social anxiety were finally coming into focus.

That newfound understanding allowed him to become more present on set and more attentive to the people around him.

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Laura Nadine performing at the 2023 First Place Global Symposium Photo credit: Good Eye! Media

# Real Boys Cry: Gus Walz, Neurodiversity, and the Fight for Disability Rights

#### By Robert Naseef, PhD Clinical Psychologist, Author, and Parent of an Adult Autistic Son

t was a heartwarming viral moment that many will never forget. As the father of an adult son with autism who is nonspeaking, it struck a deep chord in me. Most men have grown up with the maxim that "Big Boys Don't Cry." Breaking that traditional masculine model with exuberant cheers and tears of joy, Gus Walz gave his dad a standing ovation, shouting, "That's my dad!" A healthy model of masculinity was displayed before the world. The whole Walz family, along with millions of us, embraced Gus—an obviously neurodivergent teenager.

Tim and Gus were not restrained by what William Pollack, PhD, has called the "gender straitjacket" that locks down boys and men from expressing the tender side of their emotions. The moment transcended politics and touched the full range of the human heart. The traditional model relegates anger as the primary socially acceptable emotion for boys and men. In contrast, anger is often seen as socially unacceptable for girls and women. This is a harmful effect of the gender straitjacket on human society. The potential for change exists, but progress has been slow.



**Watch** Tariq's Story: Navigating Autism and Intellectual Disabilities with Love and Care

Gus Walz has an advantage because he is neurodivergent and capable of expressing himself authentically in the moment. His parents told People that he was different from his peers and that "Gus preferred video games and spending more time by himself." By his teen years, he was diagnosed with non-verbal learning disorder, anxiety, and ADHD. His parents also shared, "It took time, but what became so immediately clear to us was that Gus' condition is not a setback — it's his secret power." As his heart overflowed with pride and joy at what his father was speaking about, he wasn't concerned about what people would think. This reminds me of how my son, in his 40s, will still hold my hand when we go for a walk in the park or put his head on my shoulder when watching cartoons on the sofa. I'm guessing from my own lived experience that Gus has taught his father a few things about what it means to be human.

Besides pride and joy, Gus' display of emotion also evoked fear and possibly shame outside our bubble in the broader society. Some mocked Gus' tears online, which unleashed a torrent of insults that are frequently used to bully and intimidate people with disabilities. Ableism in its most vile manifestation was evident, but it is part of something bigger and more insidious—fear of those who are different.

Violence online and violence around the world creates horrific situations, especially for children and women. Wars raging in various parts of the world often result in the deaths of innocent civilians mostly children and women. As Matthew Rycroft said in a speech to the UN at the Security Council Open Debate on Children and Armed Conflict, "How a society treats its most vulnerable is always the measure of its humanity." Living in one of the world's most prosperous countries, we have to do better.

There is much we can learn from Gus Walz's pride, joy, and tears. The tears and hugs are authentic and healthy. War, racism,

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# **Tips for Autistic Adults Navigating Full-Time Employment**

#### By Andrew Arboe Autistic Self-Advocate

ull-time employment is not something that is usually discussed in autism circles. When I was initially part-time, I had no idea how it looked at. All I knew was that I needed a full-time job to make a living, and it allowed others to pay for larger quality of life investments like homes or getting a loan for a used car. During the COVID pandemic, I started full-time as an autism transition coordinator because of a collaboration between a neurodiversity focused firm and a driving school. I was full time for about two years before I was laid off, and looking back on those years, they were full of bright and bumpy moments. I learned valuable lessons on managing change, time, and relationships in the workplace, which I am going to share for autistic individuals to consider for their future full-time jobs.

### Communication Standards

It is important to establish communication standards with you and others in the workplace. Discuss with your employer their expectations about communication. If you are unsatisfied with the communication styles at your company, come up with ideas that may work for you and check in with your employer to see if they



are willing to try your ideas.

#### Customizing Your Workspace

If you work in an office setting, ask if you are allowed to customize the space. Since you are there for most of the day, it does not hurt to make the space more familiar to you. In the space I used to have, I had various items that related to my special interests. I had two video game posters that showed my fondness for the NieR series. I had a big plush from the same series on its own chair, mostly for sensory reasons. These items never distracted me, and I was able to do the work I needed to do. Make sure the items you can bring are realistic and not something that could add problems for the workplace.

#### Establishing Boundaries

It is important to set up boundaries with work. One example is how to approach work emails. I used to be okay with weekend emails, but during overtime and near the end of my time there, weekend emails became a trigger. Another important boundary is to not visit your workplace during your time off, even if you have access. I was guilty of visiting my office too much, and it eventually created a longterm issue. Creating work-life boundaries can help prevent burnout.

### Watch Yourself with Budgeting

When you have more income, it might be tempting to overspend. I had some trouble with this when I was employed, and I realized I was spending too much and needed to cut down in areas like eating out and video games. It took a lot of trial and error to make a budget, but you can see what works for you or not. You cannot plan for everything, but you can create standards for yourself.

#### Knowing When to Let Go When Workplace Gets Out of Control

When you start feeling burnt out in your job, it may be time to consider moving on. Burn out feels differently for everyone, and for me, my workplace felt mentally draining, making me nervous and sad. In the end, I knew I had to either leave the company or continue the work in some form. If this is something you are experiencing, I

# What I'd Like to See Change in the Disability World Over the Next 50 Years - Part 3: REAL Culture Change

#### By Michael John Carley Facilitator, New York University Connections ASD Program

n 2003, I was about to say "no" to the offer to start what would become GRASP. I had been a minor-league diplomat who, throughout the ten years of working for my organization (if you can believe this...), they had gone through five Executive Directors in one six-year period. Twice, I was offered the post at Veterans for Peace, Inc., and twice, I turned it down (we had a brilliant but very difficult board of directors). Being an Executive Director, in my second-hand experience, was an exercise in self-loathing.

But while mulling the offer, I read a New York Times Sunday Magazine article written by one Harriet McBryde-Johnson. McBryde-Johnson, a Georgian who had significant enough physical challenges that she required assistance to accomplish basic bodily functions, had in her life risen to become a successful lawyer and disability advocate.

A very famous philosopher, Peter Singer, had been writing about how it would be more humane to kill people like Mc-Bryde-Johnson at birth. The justification for him lay in his judgment that her life



Harriet McBryde-Johnson, who was an American author, attorney, and disability rights activist

wasn't worth living and that it was too full of suffering. Singer, a handsome, best-selling author of several books, a noted animal-rights activist, and a strict vegan, had read McBryde's writing through the organization she belonged to, Not Dead Yet. And he noticed that in some of her writing, she criticized him. In response, he invited her to a public discussion that would force her to defend her right to live. The discussion would be on his home turf of Princeton University, where he taught. Should she accept such an awful proposition?

Her article, "Unspeakable Conversations," chronicled the entire experience. The first line, "*He insists he doesn't want to kill me*." is impossible to walk away from.

That two supposedly progressive causes, animal rights and disability rights, could be such polar opposites is a reality of assumed alliances that our culture has not spent enough time examining. Needless to say, it doesn't take an enormous investigation to discover that Singer, in both of these causes, assumed that he had the right to judge the value of lives that were anything but his own.

But this is not a unique situation. The disability community has often advocated against physician-assisted suicide and instead for the rights of the victim (whether they are voluntary or not) to live and for more access to treatment for depression or more successful pain medications.

There are even such butting of heads *out-side* disability, wherein we "progressives" get caught being intellectually sloppy, such as the progressive value of organic farming. If the food they put into our grocery stores is more expensive than non-organically-farmed food, then economically challenged people don't have access to it. By design, if poor people get shut out of any development, then it cannot be progressive.

Margaret Sanger, Planned Parenthood's founder, believed in eugenics so much that

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# **Diagnosis, Resources, and Behavior Changes - A Journey of Self-Discovery**

#### By Eric Schissel, MS Editor Mental Health News Education

ime changes our framing of incidents. When they go poorly, it's not unusual to replay them in our minds in search of a more acceptable arc. This narrative is what I've learned from a situation that resolved well but which has also coughed up useful lessons.

In the two or three years after my diagnosis with what was then called Asperger's Syndrome at the age of 24 and the end of my postgraduate studies, I decided I wanted to stay in the city where I was. I moved to an apartment on the outskirts of town, found a series of temporary jobs, began a more long-term part-time job that ended up lasting from 1997 until the beginning of the pandemic, and generally started finding ways to settle into my post-school life.

Slower to settle in was my understanding of what my new diagnosis meant. I had been misdiagnosed for a long time and initially resisted the new one. It was several years before I saw how it helped me to understand and tell a more coherent story about parts of my past and think differently about my future.

I remember reaching these insights from an unplanned combination of life experiences that included therapeutic horse riding, attending conferences for people on



the spectrum and their families, reading some very interesting articles, and having good conversations with members of the community. The horse riding fit in there when one of the articles I read discussed proprioception, your sense of your body in space - and the vestibular sense, which is the sense of balance, and how horse riding seemed to help some people on the spectrum with these senses.

Sometime during my twenty-seventh year, I attended a coming-of-age ceremony for a relative. This was held fairly near where my parents lived, and I was visiting. I had, and have, much love for most of my family and was glad to be there. Celebrations and parties, however, I approach more ambivalently. Some do go well. Too often, I feel like I've fallen on my proverbial face.

After joining in the ritual, listening to the appreciated celebratory speeches on behalf of the honoree, and participating in dinner, I accordingly braced myself for the party. As I had dreaded, the music was chaotic, repetitive, and very loud, and for me, unchosen and also at that moment, headache-inducing. Although I was steeling myself to barrel through the onslaught and not make a scene, my sister saw that I was closing in on myself and offered to drive me back to the parents', an appreciated offer which I accepted, especially because of my lack of a license and correlated limited mobility. No further incidents interrupted that evening or week that I can remember.

A year later, in December 1997, I applied for a job at a peer-run mental health social club as a part-time staff person. I worked there for over two decades while taking other part-time jobs, too, and learned a fair amount from them. I also went back to school briefly to augment my computer skills. The social club, meanwhile, transitioned into a peer support center and offered useful staff trainings - mental health first aid, listening, and peer support certification-related training, for example.

These training sessions were not only helpful for my work as a staff person, but also for me as an individual on the spectrum. Learning about the Wellness Recovery Action Plan (WRAP), for example, encouraged me to write down specifically what behaviors were signs that my mental health might be doing worse. The Listening course encouraged patience and paying attention not to what we are convinced someone will say but what they do say. A Mental Health First Aid course concentrated on skills useful for providing help to

# Zoning for Neuro-Inclusive Communities: Challenges, Foundations, and Lessons Learned

#### By Chenchen Zhang 2023-24 The Daniel Jordan Fiddle Foundation Public Policy Fellow at the First Place Global Leadership Institute

cross the United States, there's a growing focus on making communities more inclusive for individuals with autism and other developmental disabilities. This shift reflects a broader commitment to ensuring that all residents, regardless of their needs, can find supportive and accessible living environments. While zoning policies offer promising avenues for achieving this goal, significant hurdles remain.

### Understanding the Barriers Created by Zoning

Zoning regulations play a critical role in shaping neighborhoods and communities, determining land use, building standards, and architectural styles. However, these regulations can also create barriers, particularly for low-income individuals and people with disabilities, including those with autism spectrum disorder (ASD).

Autism spectrum disorder encompasses a range of conditions that impact social skills, communication, and behavior. People with ASD may experience challenges



From left: Lyndsey Eaton and Lauren Heimerdinger, future residents, check out the First Place–Phoenix construction site in 2016. Photo Credit: Good Eye! Media

in understanding social cues, making eye contact, or engaging in conversations, often accompanied by sensory sensitivities (NIH, 2020). These diverse challenges highlight the necessity for personalized support and comprehensive interventions that account for cultural, ethnic, and socioeconomic factors.

One way that zoning can support neuro-inclusive communities is through inclusionary zoning policies. These policies either require or encourage developers to set aside a portion of new or renovated housing units for low-income residents. In the U.S., over 1,000 jurisdictions have implemented some form of inclusionary zoning (Gentry et al., 2021). Policies can vary from mandatory to optional, with some cities offering incentives such as reduced parking requirements or expedited issuance of permits to facilitate compliance by developers. While cities in Arizona cannot mandate inclusionary zoning, they can offer voluntary measures that help incentivize developers (Gentry et al., 2021).

Zoning regulations also impact building design and accessibility. These rules often prescribe architectural standards and building features, contributing to the overall look and functionality of a neighborhood. Accessibility features, mandated by the Americans with Disabilities Act (ADA), ensure that new and renovated buildings accommodate individuals with disabilities (ADA Standards for Accessible Design, 2023). This includes everything from entrances and ramps to elevators and accessible restrooms.

However, zoning regulations can also create barriers. One major barrier is low-density zoning, a restrictive zoning practice that limits affordable housing options and exacerbates social and economic

see Zoning on page 49

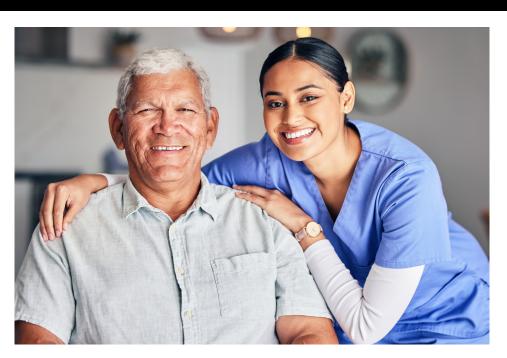
# The Complexities of Aging: Addressing the Unique Needs of Autistic Elders

#### By Mary P. Donahue, PhD Psychologist / Consultant Mindful Paths Psychological Services

Ithough there is little known about autism and aging, elders nonetheless need appropriate care now. Through learning about appropriate and intentional assessment and treatment, providers and allies can make a big difference, even in small ways.

Although autistic traits are seen far back in history, autism as a diagnosis was identified in the 1940s. In the 1990s, it became a special education category, which began the rise of research and access to services, mostly relating to early intervention. But what of the aging autistic population? What do these elders need? And how do we provide it appropriately?

There is a dearth of research on older autistic adults. Yet, there is a population of autistic elders (AEs) who continue to age and need appropriate care. The immediacy of this appropriate vs. aging problem suggests the need for more accurate, specialized training in how to work with AEs to influence their direction and quality of life. Unfortunately, research into provider knowledge and competence in this area demonstrates a serious lack of skills and confidence (Maddox et al., 2020.) Indeed, there seems to be a disconnect between training with 'typical' subjects and trans-



ferring that learning into the unique world of AEs. Inappropriately, autism is often viewed as an overlay to a typically functioning brain, although it's an entirely different form of operating system.

While the geriatric field largely lacks specificity in treatment for the EA, their lived experience presents several current considerations. First, treatment must focus on the word "appropriate." Indeed, lived experience indicates that many common treatments and environments are hurtful, unsafe, and inappropriate (Morgan, 2023.) When uninformed helpers provide services without understanding the different perspectives of AEs, what looks like common conduct is often invalidating and anxiety-provoking in a situation likely already overwhelming, confusing, and exhausting. Unrecognized masking and poor reporting bring wasted results.

As well, uninformed assessment sets in motion a host of ineffective, harmful actions. For example, seeing an elder become more aggressive or cognitively rigid than usual might be assumed to be a cognitive decline. Reviewing the AE's ecological development leads to an understanding of sudden changes causing the elder to act out or shut down communication. Imagine if a provider immediately saw organic cognitive decline without deeper assessment and prescribed medication or referral. The assessment would be wrong, and the treatment would further confuse or upset the elder, leading to greater, long-lasting harm.

#### Life Experience

An elderly autistic person recently inherited money. Their friend's death had upended their life, and they needed time to adjust. But, the paperwork and very personal information estate administrators needed caused even greater confusion. The elder, trying to regulate their changed world, stopped answering the phone, yelled at people coming to the door, and couldn't find the documents needed. Their doctor saw this as a serious, sudden decline and reported it to elder services, who sent people out for a home check. The elder was direct and seemed quite rude, refusing to open the door. The well-meaning investigators looked in the windows, saw a mess, and left their card with a request to call.

# Autism BrainNet: Promoting Understanding of Autism Through Brain Donation

#### By David G. Amaral, PhD and Marta Benedetti, PhD Directors Autism BrainNet

ike every unique person, autistic people contribute to the richness of our experience in the world. But autistic people also face challenges that vary in severity and complexity. The Simons Foundation supports multidisciplinary research into many aspects of autism with the hope that new knowledge will reduce autistic challenges and lead to a better quality of life for autistic individuals.

Autism BrainNet is a program of the Simons Foundation that provides a bridge between the autism community and the worldwide community of scientists who are dedicated to a greater understanding of autism. Autism BrainNet has a very particular function. It promotes the post-mortem donation and distribution of brain tissue to scientists who use the resource to carry out state-of-the-art research (Amaral et al., 2018). Thinking about brain donation can be uncomfortable. It doesn't feel the same as organ donation, which directly and often immediately changes a patient's prognosis and quality of life. Nor can you check a box at the Department of Motor Vehicles to indicate your willingness to



donate your brain alongside other organs. It's a separate and distinct process. However, it can leave a legacy through research that impacts many more people than the single individual receiving an organ. A single brain donation can facilitate hundreds of research studies!

Who Do Scientists Need Actual Brains for Research?

There is wide consensus that autism spectrum disorder (ASD or autism) is a

neurological condition. Beyond the diagnostic features of autism, individuals often have epilepsy, anxiety, intellectual disability, and sleep disorders – all presumably due to alterations of brain function. While there are many strategies for studying the human brain, such as magnetic resonance imaging (MRI), none are able to examine the brain at a cellular and molecular level. Research using post-mortem brain tissue provides one of the most direct paths to understanding the biological causes of autism and identifying potential therapeutic targets. Brain tissue cannot be replicated in other ways (e.g., by a computer model or virtual reality), which is why it's a critically important and valuable resource. Other neurological conditions, such as Alzheimer's Disease, have benefitted from more than a century of post-mortem brain exploration (Alzheimer, 1907). Many of the preventative measures and treatments for Alzheimer's disease now undergoing clinical trials are direct outcomes of post-mortem brain research.

While post-mortem research on the autistic brain has lagged behind other neurological conditions, the availability of tissue for research has sparked a renaissance. For example, this summer, a new study describing gene expression in a neurodevelopmental syndrome (Dup15q) that greatly increases the risk of autism was published in The American Journal of Human Genetics (Dias et al. 2024). The authors acknowledge that the key findings are only possible through the fit of post-mortem brain donations. This study found, surprisingly, that changes in gene function affected different cell types in the brain differently. An earlier neuroanatomical study demonstrated that neurons in the amygdala, a region associated with anxiety, have a different developmental trajectory in the autistic brain

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# **Bridging the Gap: Advancing Research and Services for Autistic Adults**

By Fred R. Volkmar, MD Dorothy B. Goodwin Family Chair in Special Education, Southern CT State University, and Irving B. Harris Professor Emeritus, Yale University

everal factors have led to a general improvement in the outcomes of children and adolescents as they become adults. Both earlier diagnosis and better treatments play important roles in this improved outcome, although it must also be noted that a minority of individuals remain significantly intellectually disabled and in need of care (Howlin and Magiati, 2017). More and more young adults are pursuing job training or college (White, Brewel, et al., 2023). However, available data suggest that adults with ASD are underemployed and, when employed, are often underemployed, i.e., earning less than would be expected given their educational attainment/training (Solomon, 2020).

As the title of this article implies, the challenges facing those of us who work with or who are adults with ASD come both from the research and service provision side (the latter ideally being informed by good research (Volkmar, Reichow, et al., 2024). Although adults with ASD have been with us for decades, research that focuses specifically on adults is rather limited. A recent paper on federal funding



(Heinrich, Colomer, et al., 2023) reminds us that very little federal support is available. If one looks at the other side of the equation, i.e., the research that stems from funding, the picture is equally dismal. For example, for many years, I was able to tell my students to read the article by Piven and Rabns (2011), and they would have essentially mastered the field of work on autism and aging – i.e., it was basically limited to this one article. Fortunately, this is beginning to change e.g. (Roestorf, Bowler et al., 2019), and now there are nearly 2000 titles in an online search for articles with the words "adults and autism" or "ASD" in the title!

There are a few exceptions to be noted, e.g., psychopharmacology (Thom, Thom, et al. 2024), where adult populations are easier to engage in the research enterprise. More work is being done on supporting students with ASD in college (White, Brewe1, et al., 2023). Also, there are some important new or recently adapted areas of work, for example, the work on social skills training in adults (Laugerson, Ruth, et al., 2024) and new work on adapting cognitive behavior therapy for the anxiety and depression so common in adults with ASD (S.W., Golt, et al., 2024).

From a personal perspective, having recently retired after 40 years of very active clinical practice, I've seen several generations of young children with ASD grow up and sometimes do very well. This has been gratifying, but as I hear from these young adults and their parents, the lack of effective services and knowledge about such services and ASD itself is frustrating. Having retired from active clinical work at Yale,  $\bar{\mathrm{I}}$  am now heading the autism center at Southern Connecticut State University, where we have been actively engaged in a wide range of efforts to spread knowledge not only to teachers but to parents, college students, and adults. We've engaged in first responder training as well as offering drivers with autism the ability to experience a 'practice' police traffic stop (Grindle, Sassu, et al. 2024) using the new Connecticut blue envelope program. We are addressing the needs of students at our own University and doing outreach to community colleges and high schools.

In an effort to address these needs, my colleagues and I have designed a virtual, synchronous workshop series this fall and

# Demystifying the Evaluation Process for Your Infant, Toddler, and Preschool Child with Developmental Concerns

By Ernst VanBergeijk, PhD, MSW and George "Brandon" Gordon, EdS Elwyn

uspecting something may be wrong with your child's development is a scary thought. It can be confusing as to what one does next. If your child is born with an apparent disability, the pediatrician will refer your infant or toddler to the birth-to-three system, where a team of professionals will assess your infant or toddler. Should your child qualify for services under the Individuals with Disabilities Education Act (IDEA)-Part C, then the team, which includes the parent as a vital member, will develop an Individualized Family Service Plan (IFSP), which is a detailed approach regarding how the service team will support you and your child in addressing their developmental delay or disability.

To qualify for services in the birth-tothree system, a child will go through an assessment using standardized assessment techniques, observations, and parental interviews regarding the infant or toddler's behavior. Some medical conditions automatically qualify an infant or toddler for services. Others are less obvious and need a thorough assessment. The infant or toddler must demonstrate on appropriate diag-



nostic instruments a delay of 25% of the infant or toddler's chronological age in one or more developmental areas of cognitive development; physical development, including vision and hearing; communication development; social or emotional developmental and adaptive developmental (OCDEL, 2013). If the infant or toddler scores 1.5 standard deviations or greater from the average score of an infant or toddler at that age or stage of development, the standardized measures are normed, meaning they have taken measures of thousands of infants and toddlers to calculate what is typical behavior at that age. The recognized standardized test must be valid (i.e., measures what it is supposed to measure) and reliable (i.e., produces the same results for an infant each time it is used). A standard deviation is the amount of time

a particular score varies from the average score. An infant or toddler qualifies for service by scoring 1.5 standard deviations below the mean on an assessment for one or more developmental areas, has a diagnosed physical or mental condition that has a high probability of resulting in a developmental delay, or, in the opinion of the assessment team, the infant or toddler is at risk of a developmental delay. Regarding the latter option of determining eligibility for services, the process is referred to as Informed Clinical Opinion. It is reserved for situations where it is difficult to measure aspects of child development and is used to determine the potential need for early intervention services (OCDEL, 2013). Diagnosed conditions can include:

- Chromosomal abnormalities
- Genetic or congenital disorders
- Sensory impairments
- Inborn errors of metabolism
- Disorders reflecting the disturbance of the nervous system
- Severe attachments disorders

see Evaluation Process on page 53

# **Creating Autism-Friendly Environments for Workplace Inclusivity**

By Zac Muncy, MS, MBA Author and Neurodiversity Advocate

n an increasingly diverse and inclusive world, creating autism-friendly environments in the workplace is not just a noble endeavor but a practical necessity. Autism Spectrum Disorder (ASD) affects millions of people worldwide, and many of them possess unique skills and perspectives that can be invaluable in a professional setting. However, traditional workplaces often fail to accommodate the needs of neurodivergent individuals, leading to underutilization of their talents. This essay explores the importance of creating autism-friendly environments in the workplace, the strategies to achieve this, and highlights several major companies that have established employee resource groups for neurodivergent employees.

#### Understanding the Need for Autism-Friendly Workplaces

The first step in creating an autism-friendly workplace is understanding the unique challenges faced by individuals with ASD. These challenges can include difficulties with social interactions, sensory sensitivities, and a need for routine and predictability. Traditional workplace environments, with their open office plans, unpredictable schedules, and social expec-



tations, can be overwhelming for neurodivergent employees. This often leads to stress, reduced productivity, and high turnover rates.

Creating an inclusive environment not only benefits neurodivergent employees but also enhances the overall workplace culture. Diverse teams are known to be more innovative and better at problem-solving. By accommodating the needs of employees with autism, companies can tap into a pool of talent that is often overlooked. Furthermore, an inclusive workplace fosters a culture of empathy, understanding, and mutual respect, which can improve employee satisfaction and retention across the board.

#### Strategies for Creating Autism-Friendly Workplaces

To create an autism-friendly environment, companies need to implement several key strategies: Sensory-Friendly Spaces: One of the most common challenges for individuals with autism is sensory sensitivity. Companies can create quiet zones or provide noise-canceling headphones to help employees manage sensory overload. Adjustable lighting and ergonomic furniture can also make the workplace more comfortable. Sensory-friendly spaces can be nice for neurotypical employees, too.

**Clear Communication:** Clear and direct communication is crucial. Providing written instructions and using visual aids can help neurodivergent employees understand their tasks better. Regular feedback and one-on-one meetings can also ensure that they are on the right track.

**Flexible Work Arrangements:** Flexibility in work hours and the option to work from home can be beneficial for employees with autism. This allows them to create a routine that suits their needs and reduces the stress associated with commuting and navigating a busy office environment.

**Training and Awareness:** Educating all employees about autism and neurodiversity can foster a more inclusive culture. Training sessions can help coworkers understand the challenges faced by their neurodivergent colleagues and how they can

# **Expanding Horizons: Tips for Life-Changing Inclusive International Travel**

By Cara Streit, EdD, MSW, LCSW Founder & Director Embark Inclusive Travel

"Travel makes one modest. You see what a tiny place you occupy in the world." - Gustave Flaubert

nyone who has traveled abroad knows the feelings of wonder and excitement that come with exploring new places. Experiencing other cultures, customs, landscapes, food, art, and architecture expands our perspectives and helps us to understand that we are one small part of a much larger world. This understanding builds awareness, acceptance, and empathy for others.

Travel challenges us by taking us out of our comfort zones and giving us new experiences we never could have anticipated. It teaches us flexibility and increases our tolerance for change and uncertainty in ways that feel exciting and meaningful, even when it's also a little scary. Numerous studies document the positive impacts of travel on psychological well-being, life satisfaction, and even job performance (Chen & Petrick, 2013). Even short-term educational travel yields deeply meaningful experiences for participants (Iskhakova et al., 2023).

For autistic travelers/travelers with autism, advance planning and the support



An Embark Inclusive Travel tour group in front of the Rock of Cashel in Tipperary, Ireland

of a travel group knowledgeable about disability inclusion and prepared for the common travel barriers faced by neurodivergent travelers can make international adventures more accessible, comfortable, and fun (Hamed, 2013). Inclusive travel opportunities are often group-based, and social engagement is an inherent part of the experience. Skilled group leaders for inclusive tours can facilitate connections between travelers who struggle to engage on their own. Staffed group outings, buddy systems, roommate pairings, and communal meals create natural shared experiences, which is an excellent foundation for new friendships.

Not only can group travel promote the development of friendships on tour, but it also helps travelers connect with others when they get back home. In the (translated) words of medieval traveler Ibn Battuta, "Traveling leaves you speechless, then turns you into a storyteller." Having an adventure gives us something interesting to talk about with other people. This is especially powerful for travelers who face barriers to developing strong social connections or making small talk. Stories about adaptive zip lining in Costa Rica, visiting a parmesan cheese factory in Italy, or that wild Karaoke night in Tokyo can spark interesting conversations.

Adults can find travel opportunities through for-profit and nonprofit organizations that specialize in adaptive or accessible travel. Nonprofits may subsidize spots for travelers with financial need. Many neurodivergent travelers can also thrive with non-specialized companies that design individual and group travel experiences for all adults, with or without disabilities. Group tours are typically carefully organized, may have travel insurance options, may be all-inclusive, sometimes offer monthly payment plans to help with saving and budgeting, and often have extensive emergency preparedness plans. For more information on accessible and inclusive travel, try internet search terms like

see International Travel on page 54

# The Power of Person-Centered Planning in Supporting Autistic Adults

By Nicole O'Neal Senior VP for Adult Residential Services Bancroft

Represent the support of the support

For those of us whose job it is to support adults with autism, person-centered planning is our most valuable tool. It allows us to truly understand each person as an individual, laying the groundwork for better outcomes and a better future.

#### Understanding the Individual

Person-centered planning starts with a simple but powerful belief: every person with autism is unique, with their own preferences, strengths, and challenges – just like each of us. This approach isn't just about looking at a diagnosis; it's about seeing the whole person, with their desires, aspirations, and values.

This requires going beyond standardized treatment plans for caregivers in human service agencies. It involves deeply engag-



ing with each person's story, learning about their likes and dislikes, and understanding their unique way of communicating. Information is power – the more we know about a person, the better we can tailor our services to meet their specific needs, help them grow, become more independent, and advocate for themselves.

> Their Voice is Heard: Advocating for One's Own Life

At the heart of person-centered planning

is the idea that the individual should have the biggest say in creating the environment they want to live in. We all want this – whether it's choosing where to live, how to spend our free time, or getting the right support. It's about having a voice in the decisions that affect our lives.

Empowering adults with autism to make these decisions is crucial because it helps them build confidence and develop the skills they need to advocate for themselves. Self-advocacy isn't limited to knowing your legal rights or fighting for legislative change; it's about being able to speak up about your everyday needs, like what you want to eat, how you want to spend your day, how you take care of your health, and your employment opportunities.

Self-advocacy opens the door to critical services. The National Autism Indicators Report from Drexel University (2020) highlights that many adults with autism struggle to access services that are critical for their independence. For example, fewer than half (around 40%) of young adults with autism received job training or employment services. Self-advocacy skills (and caregivers who empower the development of these skills) are essential for these individuals to secure the services they need.

When caregivers focus on truly listening to the individual, they create an environment where adults with autism feel they have ownership and control over their lives. Advocacy isn't just about being heard—it's about being respected and valued for who you are.

Creating an Environment of Belonging

Person-centered planning goes beyond decision-making to create environments where adults with autism feel they belong. We all need to feel like we're part of something, and this is especially important for

# Mask of Your Own Face - Experiences with Masking as an Autistic Adult

#### By Emily "Ly" Stewart, BA(Hons), MSc Media Psychology Graduate and Journalist

magine for a moment that you are a kid. As far as you're aware, you're like every other kid, but as you go throughout your childhood and adolescence, people start pointing out parts of you that seem a bit...off. Maybe your interests are strange or inappropriate; maybe the way you talk and move is off-putting or annoying; maybe you're just far too emotional – either way, the people around you make it clear that there's something different about you. As you get older, you try to change these behaviors to fit in better, and for the most part, it works - but people can still see that something isn't quite right.

Then you find out about autism.

As an adult, you manage to get a diagnosis, and everything starts to make sense. All those 'weird' behaviors you grew up with were just early indicators of your place on the spectrum. Gradually, you start to see more and more people talk about their experiences with autism and how receiving a proper diagnosis allowed them to get back in touch with a part of themselves they had to hide to be a part of a neurotypical society.

There's just one issue, though: when you try to do it, it feels basically impos-



sible. No matter how hard you try to be unashamed of your interests or more compassionate towards your unique needs and younger self as a whole, you just can't bring yourself to do it.

You are unable to stop masking.

If you're autistic or are active within autistic spaces, there's a likely chance you've heard the term masking before. Masking is defined as "the conscious and unconscious suppression of natural responses and adoption of alternatives," particularly in regard to socializing, movement, sensory responses, and general behavior (Pearson & Rose, 2021). While masking acts as the more general term, recent studies into autistic behavior suggest that it is split into three parts (Hull et al., 2019):

- 1. Compensation: making up for social failings
- 2. Masking: actively hiding autistic characteristics

3. Assimilation: trying to fit in with others

While technically everyone performs these behaviors, for people with autism, they are imperative to surviving in a neurotypical world and those who can't suffer for it.

When I was growing up, nobody knew I was autistic. In the 2000s and 2010s, knowledge of autism amongst the general public was limited. As a generally well-behaved child or just by merit of being a girl (Hull, Petrides, & Mandy, 2020), I slipped under any kind of time-appropriate radar for being on the spectrum. However, that doesn't mean there weren't signs - and it certainly doesn't mean people didn't notice. My high emotional sensitivity and conformity to schedules and rules got me called 'bossy' and a 'drama queen' when I was little, while my intense and unique interests and social ineptitude got me called a 'weirdo' in high school. Teachers and family would praise my high intelligence and creativity, but it would often come with some kind of caveat, usually in relation to the aforementioned social difficulty.

As a result, I quickly learned that I had to start changing my behavior if I wanted to be perceived differently. Over the years, I started trying to be less open about my interests and emotions whilst also being more personable and sociable. After all, if

see Masking on page 47

# **Prioritizing Autistic-Centered Self-Care for Mental Health and Well-Being**

By Izabelle Azevedo

Openly Autistic Visual Storyteller, Content Creator, and Mental Health and Neurodiversity Self-Advocate

could never relate to most social media posts with self-care ideas, especially the ones showing nails getting done or drinking wine in a bathtub. The thought of going to a beauty salon has always given me anxiety, and baths were never my thing. I couldn't really find selfcare tips or ideas that I enjoyed or that felt good afterward. And I didn't understand why. It all started to make sense once I was diagnosed with autism and ADHD at 34 years old: my brain works differently. And though every autistic individual's experience is unique, I believe most of us would agree that the self-care being sold out there doesn't seem to work for us.

Spas and beauty salons, with their noises, lights, and small talk, can be a sensory nightmare; meditation, though beneficial, can be an overwhelming experience; and adding extra activities in the name of "selfcare" to our (possibly already complicated) routines can lead to frustration, meltdowns, and even burnout. However, self-care is not just a buzzword with capitalist implications. According to this article from the National Institute of Health (NIH), selfcare is "taking the time to do things that help you live well and improve both your



physical health and mental health." Considering that we are 4-times more likely to experience depression in our lifetime, that at least 40% of us have elevated anxiety, and that we are at a much higher risk of suicide compared to the general population, I believe prioritizing it is crucial to maintain our mental health and well-being. But it is also crucial that we find "autistic-centered" self-care practices.

What is Autistic-Centered Self-Care?

When I took a look at the NIH article's "self-care tips section," my anxiety start-

ed to build up. While one can't deny that eating healthy and exercising, for example, are important for our overall health, these activities usually require effort and structure that don't play well with executive dysfunction. For me, they feel more like chores that drain my energy instead of recharging it. The reason why popular selfcare tips we can find on the internet and social media don't seem to work for us is because they were not created or thought out with us in mind. If our brain works differently from the neuro majority, our needs will be different from theirs, and so should be our self-care routines. So, autistic-centered self-care is self-care that caters to the autistic experience and needs, keeping in mind that each of us is unique and that our needs ebb and flow.

What Does an Autistic-Centered Self-Care Practice Look Like?

As someone who is currently working on getting out of autistic burnout, I have been thinking a lot about this, and, well, there isn't a one-size-fits-all answer. Each of us is truly unique. What works for me can lead to a meltdown or shutdown for other autistics, and vice-versa. However, there are common threads that can help find a self-care practice that works.

For example, we know that autistic individuals of all ages struggle with emotional regulation to a certain degree. Emotional regulation is not only an important aspect of autistic existence; it is also a major factor affecting our mental health. As I reflected on my own experience with self-care and autistic burnout, I came to realize that I had been neglecting my emotional regulation "coping mechanisms" for a long time. And in all honesty, I didn't even know I was doing it because I didn't know what these coping mechanisms were in the first place. Simple things like singing in the shower, having time to hyperfocus on my special interests, using my creativity, and learning

# Just Because We Can Mask Doesn't Mean We Don't Need Support as Autistic Adults

#### By Michael Gilberg, Esq. Attorney-at-Law

e spend a lot of time in the Autism community focused on children and how to support their needs. I admit this is the focus of my career, but we sometimes forget that autistic children become autistic adults. And while progress is often made as autistic people age and mature, there will often always be a level of support needed. Even for those of us who "mask" fairly well and can pass in most situations as neurotypical, we still have support needs. In many cases, I would argue those of us who can mask better are often overlooked compared to many who are more "obviously autistic" and have difficulty masking.

In my life, I have had people tell me that I don't "look autistic," whatever that means. I did not know there was a way to look autistic. I have also had people say, "But you seem so normal," without explaining what normal means. I have had people say to me (with no disrespect to her, of course), "But you are not like Temple Grandin," assuming all autistic people must be just like her. I have had people assume because I am an attorney that, I might have "conquered" my autism. As many in the community



have said, just because we have "lower support needs" than others does not mean we do not need support.

In my experience, people will see someone stimming who is either non-speaking or has limited verbal ability and looks developmentally behind, they often will assume that is someone with Autism. In many of those cases, services and support are available when the person lacks the ability to be independent in performing even basic tasks. Of course, there are assumptions made since there are many non-speaking autistics who are able to be independent. Obviously, when those life skills include toileting or feeding oneself, and someone needs support, it becomes readily apparent. However, many of us who have graduated college and/ or graduate/professional school and are able to mostly take care of ourselves independently are overlooked because people assume we don't need support, and yet most of us do. In some cases (I will admit this applies to me), we require emotional support. Some people need help with certain tasks involving executive functioning, like buying groceries, managing money, and other things, but people just assume they can do these things because they "seem normal."

One thing I have found both in children and adults with autism is that many of us, in order to not create trouble or make a situation uncomfortable if we understand that might happen, suppress feelings and thoughts inside and suffer in silence. Rather than address an uncomfortable situation we suppress these feelings and let them fester inside of us until something worse might happen or it affects our health. I have seen this with both children and adults where people will say, "But he seemed so normal," without asking what was going on inside. On the other hand, those with greater support needs will often not be socially aware, so they will just say whatever is on their mind or not realize an awkward situation. Many of us spend years learning what not to say, so we just keep it inside and let it bother us so we do

see We Can Mask on page 54

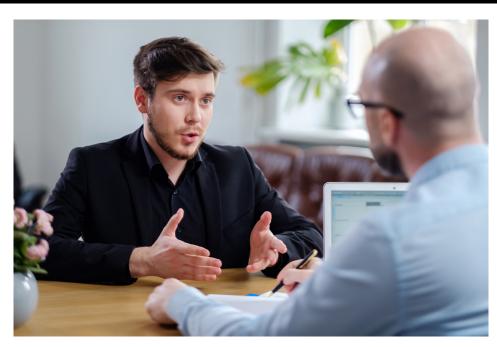
# Navigating Career Pathways: Challenges and Opportunities for Autistic Individuals

#### By Cory Morrison Freelance Writer

t is, indeed, not easy for many people to make sense of the job market, but often, additional obstacles make autistic people's lives much more challenging. With both finding a job and sustaining it, and at every level of the employment process, we face challenges which, unfortunately, may affect our professional success (Davies et al., 2024). Expert advice and my personal stories, along with practical tips for employers, will help many get a big picture as to why certain parts of the working world are more difficult for us.

### Challenges in Job Searching

One of the biggest barriers autistic people face is the job search itself. Traditional hiring, for instance, via interviews seldom takes the neurodiverse into consideration (Davies et al., 2023). Interviews tend to go toward social skills and quick thinking, which are areas where autistic individuals usually struggle the most (de Vries, 2024). With this, employers often pass over autistic people who are highly skilled candidates since an interview process would not allow them to reach their full potential.



<u>Personal Experience</u>: For me, the interview process always seemed to be a test of how well I could mask my autistic traits rather than an opportunity to show my skills. Pressure for making eye contact, catching social cues, and quick responses tended to drown out the actual qualifications.

One time, I applied for a job which I wasn't only qualified for, but I also had tons of writing samples to prove that I was

qualified. I was passionate about it. I'm sure the employers knew this deep down. However, after two interviews and nearly a month after the first interview, I got the email saying I wasn't picked. I feel as if my social interaction skills were the main reason I didn't get the job. For some positions I didn't get picked for, I admittedly was behind numerous candidates regarding qualifications, so they weren't huge letdowns. This one, however, was a tough pill for me to swallow.

Expert Insight: As Dr. Ludmila N. Praslova, an autistic professor of organizational psychology, says, "This discrimination is a systemic problem. For instance, consider a major workplace barrier: the job application process. Both the process and the content surrounding "how to nail a job interview" heavily favor neurotypicality. As a consequence, many autistic people feel pressured to follow popular advice and appear as non-autistic as possible to land and keep a job" (Praslova, 2021).

Specific Career Pathways: Opportunities and Challenges

Fortunately, some professions will fit better into the strong abilities most autistics have (Cope, 2022). Even so, as I implied in my above personal example, this does not always mean that autistic people won't have great struggles finding their desired career.

### 1) Technology and IT

<u>Opportunities</u>: Because of the structured nature and requirement for skills rather

# A Presumption of Competence: Empowering Disability Advocacy and Independent Living

By Gyasi Burks-Abbott, MS Author, Public Speaker, and Autism Self-Advocate

n June 18, 2024, the White House hosted an Olmstead 25th Anniversary Observance to commemorate the Supreme Court decision (Olmstead v. L.C.) that ruled institutionalizing people with disabilities who were capable of community living was a violation of the Americans with Disabilities Act (ADA). One of the speakers at the event was Tony Coelho, the former congressman and chief author of the ADA, who shared his basic philosophy of life: "Give me the right to fail, but in order to do that, give me the opportunity to succeed."

This philosophy is encapsulated in the phrase "Dignity of Risk," which I often hear in my work as a disability advocate. And it makes perfect sense. Personal growth often comes from experiencing failure and learning from mistakes. Why should things be any different for people with disabilities? That doesn't mean we don't need guidance and support -ma safety net while still trying to get the hang of the high wire act.

When it comes to the phrase "Presume Competence," I think it's important to note



Gyasi Burks-Abbott, MS

that being competent doesn't mean I'll never mess up; it means I'll always be teachable. Don't throw your hands up at the first sign of trouble. If I'm doing something wrong, tell me how to do it right. When I look back on the missteps I've made in my life, I can contrast the people who were willing to offer me some grace and give me another chance with those who seemed to immediately write me off as a lost cause. Independent living is another concept that needs to be unpacked. Though I live alone and do many things for myself, I still depend on other people for assistance, whether it's the maintenance workers I call upon when something breaks down in my apartment or the accountant I go to for my taxes. And this is not because of my autism. Disabled or not, no one is completely self-reliant. We are all interdependent, and the real trick to successful adulting is knowing when, how, and who to ask for help.

My mother helped me hone my adulting skills by opting for Power of Attorney as an alternative to guardianship after I turned 18. With my Power of Attorney, my mother had the right to speak for me even though I was an adult. However, she continued, as she had throughout my childhood, to encourage me to speak for myself. Whenever we had business with social security, for instance, I always made the call. My mother would prepare me and give me some notes; during the call, she'd feed me lines while I relayed back what the person on the phone said.

This system usually ran smoothly. It was easy to tell my mom what was said when there was a pause in the conversation, and I could also repeat things in a way that seemed natural like I was just verifying that I'd heard correctly. But sometimes, there would be a glitch. Maybe the person on the phone would say something my mother disagreed with, or they'd take issue with what my mother was communicating. There'd be an impasse, but my mother always hesitated to take the phone. She really wanted me to learn how to handle things myself.

see Disability Advocacy on page 42

# **Empowering Autistic Communities: The Role of Co-Creation in Research Partnerships**

By Celeste Michaud, PhD, University of Arkansas-Fayetteville and Jessica C. Kitchens, MS, MBA, LPC, Allied Collaborative and University of Central Arkansas

articipatory research is an approach that can empower autistic community members through the co-creation of knowledge, addressing power imbalances, and fostering meaningful collaboration between autistic community members and academic researchers (Stack & McDonald, 2018). By actively involving autistic community members in all stages of the research process, tending to power differentials, and reflecting on procedures to ensure accessibility and needed accommodations, participatory approaches can lead to equitable partnerships that value lived experiences and empower autistic community members.

#### What is Empowerment?

Empowerment is a multifaceted concept that extends beyond individual characteristics or skills. It encompasses broader environmental and social factors influencing a person's access to opportunities and ability to thrive and self-advocate. Zimmerman (2000) suggested that empowered people



often demonstrate skill acquisition, increased proficiency in navigating resources, and decision-making influencing outcomes.

In the context of autism, empowerment takes on specific dimensions. Autistic people involved in research and advocacy efforts described empowerment as a mindset and a set of behaviors. According to a study by Stack and McDonald (2018), autistic participants described an empowered mindset as one that leverages personal strengths while acknowledging areas for growth and recognizing when to seek support. This mindset also encompasses positive self-esteem and confidence in one's abilities, essential for personal development and well-being. Behaviorally, empowerment manifests as active participation in decision-making and self-advocacy (Stack & McDonald, 2018). This active engagement encourages autistic people to have a voice in matters that directly affect their lives and champion their needs, wants, and rights. The study by Stack and McDonald (2018) further detailed that research partnerships with autistic people that embodied inclusion, co-leadership, co-learning, accessibility, and trust were particularly effective in fostering empowerment, leading to broader systemic improvements in the lives of autistic people.

#### What is Participatory Research?

Participatory research (PR) itself does not directly empower autistic people, but using the approach creates opportunities for partnership and impact that can enhance a sense of empowerment (Chen et al., 2024). PR is a collaborative approach where community stakeholders work alongside researchers throughout all stages of a study, from defining research questions to conducting the research and sharing results. This approach emphasizes building trust and respect, ensuring that all participants, regardless of their background, are contributing research partners (Israel et al., 2010). The goal is to empower communities by integrating their perspectives and priorities, which promotes capacity building and

# The Autism Theater Project's "The Voice Inside:" Changing Lives and the Entertainment Industry

#### By Gena Sims Founder and Executive Director Autism Theater Project

y name is Gena Sims. When I was 18 years old, God gave me this vision. I was in my room, thinking about how isolated families in the autism community can feel. I thought of my sister's fears that the kids on the playground wouldn't understand her. I saw my family's struggles to celebrate unexpected victories while managing unfulfilled expectations. And I smiled thinking about the refreshing honesty of my fellow 18-year-old at Friendship Circle, who bonded with me by creating hero stories, and helped me see life with new eyes.

Then I thought of the secret stories my friends bravely revealed in psychology class at New World School of the Arts. And the fact that we all feel exceptionally different from time to time. In ways that make us proud and ways that make us want to hide. But our collective heartbeat proves that we are all the same. Why is that so easy to forget?

At that moment, as an almost-college-freshman in a dark bedroom, I realized that my purpose was to bring the stories of resilience from the autism com-



"The Voice Inside" Actors Zachary Hoaglund, Gena Sims, and Kaylah Taylor at Savor Cinema Red Carpet Premiere

munity to the mainstream entertainment industry. And bring people together in the process. And I am deeply grateful for all of the people I've met along the way who helped me make that vision a reality.

In college, ATP created our first production, "In the Life of a Child." Thanks to the heart of Carnegie Mellon School of Drama students and my professor, whose experience with her brother on the spectrum inspired her to inspire me, we brought the story of my sister to the stage. When I saw the audience understand my sister's "voice inside" (expressed by a voice-over), I woke up from my own sense of self-isolation. Feeling the audience's empathy while I danced onstage awakened me to a truth that I knew in my soul but was ignorant to in my mind: People are moved by your story that you fear no one may understand.

ATP brought "In the Life of a Child" to Actors Playhouse and Miami Children's Theater in 2018 and even performed a scene at a theater conference in Florence, Italy. There, I learned that ATP's message of empathy and resilience transcends language barriers.

Fast forward to 2020, at 23 years old, in the middle of the pandemic, I was removed from the highs of applause I was accustomed to as a performer. While facing my insecurities, feeling lost without a stage, I discovered who I was meant to be while homeschooling my little sister. Inspiring my sister to find confidence in herself, in turn, inspired my own. Still, I allowed the pandemic to blind me from the opportunities still at my fingertips. A terrifying tragedy in May woke me up from my self-absorption.

A drama student I taught back in that eye-opening summer when I was 18, who helped me realize my love for helping others express themselves, was drowned by a caregiver who had lost hope. At 2 a.m.,

see Autism Theater on page 57

# The Cost of Literacy for Autistic Adults

#### By Holly Hedger, RT(T), BS, MBA Parent Advocate

oday, more than ever, literacy agencies nationwide are being called upon to assist adults with low literacy. Here are some eye-opening literacy statistics:

#### Literacy Statistics

- "48 million adults lack basic reading, writing, and math skills beyond a thirdgrade level" (Literacy Facts, 2023).
- If every adult in the US functioned at or above a 6<sup>th</sup>-grade reading level, our country would generate an additional 2.2 trillion dollars in annual income (Literacy Facts, 2023).

#### Should Valuable Resources be Used to Improve Literacy in Autistic Adults?

Throughout my autistic son Zech's school years, we moved often. Each state's special education experience differed. During Zech's later high school years, it felt like the education system had given up. Placed in a vocational training program, where he mastered the ins and outs of cleaning toilets, Zech graduated with minimal literacy skills. Our years of maneuvering through the special education



system gave me a profound respect for the exceptional educators and ethical agencies we met along the way.

Years later, at age 35, Zech's lifelong goals of gaining employment, obtaining a driver's license, and living independently remained unmet. So, while living in Williamsburg, VA, we sought out a literacy program that would help. The Literacy for Life organization welcomed Zech with open arms. Zech completed assessment testing, and we were placed on a waitlist. From our first interaction with Literacy for Life Human Service Coordinator Mary Lynch, Zech and I were respectfully treated with an expectation of literacy success.

Months later, Mary called with the good news that a tutor had volunteered to work with Zech. Karen loves education and compassionately cares about her students. Zech was matched with a tutor who changed his life.

Karen, a retired teacher, bonded with Zech almost immediately. Initially, the tutoring took place individually for one hour twice a week via Zoom. About 12 months in, another student, who had been waiting for a tutor, was keen to join. Zech continued one weekly individual Zoom meeting with Karen, and then the three met in person once a week. After consistently working with Karen from January 2022 till May 2023, during a total of 98.75 tutored (individual and group) hours, Zech's reading grade level advanced by two years, according to results attained from CASAS Goals Reading Assessments.

Literacy for Life unconditionally accepts anyone into their program as long as the client's needs are within the scope of service (Literacy, n.d). Literacy for Life will suggest other programs to clients, but only if they perceive the disability as too severe. Literacy for Life programs, exceptional volunteers, and the literacy success of many students are related to the intuitiveness of Mary Lynch.

Shortly after another move, a new search for literacy help began. The Manatee Literacy Council web page boasts a mission to help every adult in Manatee County improve literacy and live independent lives. The council will evaluate individuals over 18 years old who desire improved literacy (Manatee, 2023).

When my son and I arrived for his appointment, Zech was given an assessment test, and after a worker reviewed his answers, we were told he would be placed on

# Tapping Into Strengths: Empowering Autistic Individuals to Self-Advocate in the Workplace

#### By Liz Gallardo Candidate Success Advisor Integrate Autism Employment Advisors

p to 85% of autistic individuals with a college degree are unemployed or underemployed (Autism Society). This often is attributed to a variety of factors, including differences in communication and challenges in reading social cues and making eye contact, all of which are an integral part of the traditional job application and hiring process. A factor that also affects this number is the lack of awareness or knowledge that many organizations possess to successfully support autistic individuals. Even with that knowledge comes bias and hesitation to discuss accommodations and resources that pose an obstacle for this talent pool. What many companies don't realize is that the strategies used to support autistic candidates do not require a significant number of resources. Additionally, these are practices that all supervisors should be using to effectively manage a team despite their neurodivergence.

Regardless of the reasoning behind the underemployment numbers, it is often more convenient to attribute this as the fault of the individual and the challenges they face because of their diagnosis. People



generally do not as easily identify strengths associated with having an autism diagnosis. However, there are business, financial, and societal benefits that employers need to be educated on to shift this mindset.

> Benefits of Using a Strengths-Based Approach

Hammond (2010) emphasizes the benefits of utilizing a strengths-based approach: "Clients learn how to set goals and expectations, confront rather than avoid challenges, and build self-esteem and competence. Most importantly, clients learn effective interpersonal skills in order to look for assistance and support when needed" (Principles of Strength-Based Practice | Resiliency Initiatives).

One of the most effective places in which this can be facilitated is in a college setting. College is a pivotal time for autistic students to develop these self-advocacy skills because, for most of their adult lives, they have had the guidance of their parents/caregivers along with supports within the education system. Entering the workforce post-graduation is often the first time they will have to independently move on to the next phase in their lives. Therefore, it is important that tools and strategies are taught to them during their college experience so that they can self-advocate effectively as they make this transition.

### Self-Advocacy Strategies

There are several components that make up self-advocacy, including understanding one's own needs, knowing what kind of support is available, and communicating needs to others (Understanding Self-Advocacy | LDA of America). There are a few key strategies that can be utilized to equip autistic students with the tools to become confident in this process.

Self-reflection is critical for students to develop a good understanding of their own needs. In a college setting, as it relates to job readiness, reflection requires the student to think about what skills they possess as well as those that they need to develop. Additionally, they should be creating concrete

see Strengths on page 59

# Are Therapy and Accommodations Sufficient for Autism Empowerment?

By Annie Kent, MA Mental Health Systemic Advocate, Educator, and Freelance Writer

Please Note: The terms Aspie, ASD/Neurodivergent, and Autistics will be used to refer to people with Autism.

quick Google search for "supporting" or "empowering" Autistic people brings up pages recounting our impairments and suggested accommodations in education and employment. In the workplace, being *Autism-Friendly* means to "speak to the employee directly about what helps them be productive... [Because the] work environment can have a significant impact on the degree to which autistic professionals feel comfortable and able to focus on their work" (Sommer, 2024).

Support is important in nearly all circumstances. Aspies are surrounded by Neurotypicals (NTs) who often know little about ASD. Integration in schools and workplaces means more opportunities for those who are higher functioning. And yet, Neurotypical co-workers still expect autistic people to *fit in* or *get out* because our natural way of being is at odds with societal norms (Jasmin, 2024). In spite of the laws requiring employers to accommodate autistic workers, requesting adjustments means at least minimal disclosure of one's disability. Fur-



thermore, not all Aspies are willing to "unmask" in order to ask for adjustments.

A Neurodivergent disability advocate on LinkedIn, Ben Van Hook, recently wrote, "If you want to know why disabled people are afraid to unmask and are unable to 'bring their whole selves to work'... [or] disclose and share their stories... When we unmask...When we show any glimmer of our authentic selves...We become subject to hatred, abuse, harassment, or worse - physical and psychological violence. People see us as immature. People see us as unemployable, incompetent, or incapable. People see us as deficient, inferior, and unworthy of being seen or treated as a human being. ... The problem is... society has not given us...a reason to feel safe being our true authentic selves without facing serious backlash or repercussions" (Van Hook, 2024).

#### Individual Needs Inform Accommodations

"Research finds that autistic people... face problems in the workplace, including changing careers regularly and struggling to navigate workplace relationships... Autistic people tend to respond well to set ways of working and routines," (Jack, 2022) as long as the rules make sense.

Some of our difficulties arise from myths, such as Aspies being rude, lacking empathy and social skills, and not being able to form loving relationships. Autism is still stereotyped as a male condition, disadvantaging women and non-binary people who may go undiagnosed and unsupported—especially if we're unable to articulate our support needs.

Some people are afraid of us due to the myth that all Aspies are violent. Or they may tell us that we can't be autistic because we don't *look autistic*. In a former workplace, one co-worker told me exactly that, while another asked (before my diagnosis) if I was autistic because she saw similarities in me that were evident in her autistic daughter.

#### Legal and Organizational Supports

Legal and organizational approaches to empowering autistic people involve school and workplace adjustments that benefit institutions and organizations as much or more than autistic individuals. Accommodations such as quiet breaks, noise-canceling headphones, organizers, and time extensions on assignments or job completion may augment our productivity and industry profits but do not necessarily change attitudes.

see Autism Empowerment on page 60

# **Embracing Neurodiversity:** A Social Revolution of Autism and New Perspectives

#### By Nicholas Primavera, MS, MBA Program Coordinator WJCS Shelanu and Supper Club

ver the past 25 years, I have noticed a movement that has been gaining momentum, aiming to reshape societal views and acceptance of autism and the broader community of individuals with intellectual and developmental disabilities (IDD). If I could name this movement, I would call it Embracing Neurodiversity. It seeks to highlight the strengths and unique perspectives of individuals on the spectrum, advocating for their inclusion and recognition in all aspects of society. By promoting awareness and understanding, we can challenge long-held stereotypes and foster a more inclusive community, allowing individuals with autism and IDD to thrive and contribute meaningfully to society.

# Challenging Stereotypes and Fostering Inclusion

For far too long, society has viewed autism through a narrow lens, often focusing on perceived deficits rather than recognizing the diverse abilities and potential of those on the spectrum. I see a shift in this paradigm that emphasizes the strengths and



unique viewpoints that individuals with autism bring to the table. This underscores the idea that autism is not a disorder to be "fixed" but rather a different way of experiencing and interacting with the world.

By challenging stereotypes and advocating for acceptance, we can aim to break down the barriers that prevent individuals with autism from participating fully in society. This includes advocating for inclusive education, employment opportunities, and social activities that recognize and celebrate the abilities of those on the spectrum.

Empowering Individuals/Families by Promoting Awareness and Understanding

Creating a sense of community is crucial for combating the isolation that many individuals with autism and their families often experience. Providing a supportive network and opportunities for social engagement is vital in helping individuals on the spectrum build confidence and develop meaningful relationships.

One exemplary initiative is Shelanu/ Supper Club, a membership community at Westchester Jewish Community Services (WJCS) in Westchester County that is specifically designed for young adults (ages 18-35+) with autism spectrum disorders and their friends. Shelanu, which means "ours" in Hebrew, provides a supportive atmosphere for sharing experiences, participating in recreational activities, skill-building, and developing friendships. With the involvement of WJCS social workers to address mental health issues as needed, the programs ensure that members who come from diverse backgrounds receive the support they need to thrive.

Shelanu and Supper Club are groups that partner with schools, businesses, and community organizations to promote advocacy and provide information to the community and a new perspective on the meaning of individuals with autism/IDD. We do this by fostering empathy and understanding and, in turn, hope to create a ripple effect that will lead to more inclusive practices across all sectors of society.

see Revolution on page 41

# **Creating Autism-Friendly Workplaces: Strategies for Inclusivity and Success**

### By Corinne Isaacs Certified ABA Technician

reating autism-friendly environments in workplaces involves implementing strategies that accommodate the unique needs of autistic individuals, fostering inclusivity, and improving overall workplace productivity. Research and expert opinions emphasize the importance of clear communication, sensory-friendly adjustments, and modified interviewing and hiring processes to make workplaces more inclusive for those on the autism spectrum. This will, naturally, entail hiring managers with "flexible leadership thinking," as validated by Expert Ludmila N. Praslova, PhD, SHRM-SCP (Psychology Today). Managers with "flexible leadership thinking" skills can understand the necessity of clear communication, sensory-friendly adjustments and environments, and the significance of modified interviewing and hiring processes. This will not only create an inclusive work environment but also a productive work environment for both employer and employee.

#### **Clear** Communication

One of the most critical aspects of an autism-friendly workplace is clear communication. Managers should provide direct,



unambiguous instructions and set specific deadlines. This approach minimizes misunderstandings and helps autistic employees perform tasks efficiently. Ambiguity or indirect communication can be confusing and stressful for autistic individuals. For example, instead of saying, "We have a project we would like you to be a part of," say, "We have a project that begins September 20<sup>th</sup> with a deadline of October 1<sup>st</sup>, and we would like you to be a part of the project." Concrete and clearly defined expectations are far more effective than vague, abstract instructions (accessate.net). Sarcasm should be avoided in the workplace with all employees, but especially when communicating with a neurodivergent employee as it may be taken literally, hurt feelings, leading to misinterpretation and unintended responses, behaviors, or reactions from employees, generally, and particularly employees with autism.

#### Sensory-Friendly Adjustments

Workplaces should consider sensory

sensitivities by providing quiet spaces, reducing unnecessary noise, and avoiding flickering lights. Sensory overload can be distracting or overwhelming for individuals on the autism spectrum.

#### Interviewing and Hiring Process Adjustments

Traditional hiring processes often do not accurately reflect the abilities of autistic candidates. Standard interview formats can introduce biases that disadvantage autistic individuals. Alternatives such as aptitude tests or practical skill assessments can better showcase strengths. Providing interview questions in advance and allowing more time for responses can lead to more accurate and concise answers. Bright lights during an interview can be uncomfortable, and employers should also be mindful that lack of eye contact is not a sign of disinterest or disrespect in an interview but rather a coping mechanism for managing sensory input. If you stop and think about it, you will see that many cultures have different beliefs about direct and indirect eye contact. Even though Western culture identifies eye contact as a form of politeness, that is not to say all cultures maintain this same social education belief system. Therefore, interviewers must be considerate, generally, and apply the concepts of equity,

#### Endowment from page 8

Linda Walder, Founder and CEO of The Daniel Jordan Fiddle Foundation, savs: "The Daniel Jordan Fiddle Foundation is proud to take the lead in elevating the roles of direct care service providers with this opportunity to attain the professional and academic status of a post-doctoral capstone. The Medical University of South Carolina College of Health Professions has unparalleled expertise to be the home of our sixth adult autism-focused endowment, as the need for qualified direct care providers is a challenging and complex issue for the autism community. It is our hope that this endowment advances the profession of direct care service as a valued career choice for dedicated individuals who wish to work with the adult autism population.'

The first DJFF Direct Care Service Provider Fellow will be named on October 1, 2024. The Fellow will be jointly chosen by The Daniel Jordan Fiddle Foundation and the MUSC -CHP Professor Dr. Michelle L. Woodbury, PhD, OTR/L, through a formal application process.

**Dr. Zoher Kapasi, Dean of MUSC College of Health Professions, says:** "We are grateful to Linda Walder and The Daniel Jordan Fiddle Foundation for creating this unique opportunity to partner in support of adults diagnosed with Autism Spectrum Disorder (ASD). Their generosity empowers our PPOTD students to change what's possible with this diverse population by informing evidence-based practice for direct care service providers across disciplines."

It is estimated that there are currently more than 5.6 million adults living with autism in the U.S.

For more information about The Daniel Jordan Fiddle Foundation, visit their website. For more information about MUSC-CHP, visit their website.

Linda J. Walder is the Founder and CEO of The Daniel Jordan Fiddle Foundation for Adult Autism (DJFF). Walder pioneered the focus on adult autism nearly 25 years ago establishing ground-breaking resources and programs nationwide addressing all aspects of adult life. In 2014, Walder created the first adult autism endowment funds in the world at America's great universities known as The Daniel Jordan Fiddle Foundation Adult Autism Endowment Funds that will in-perpetuity address housing, jobs, creative expression, research, community life, support/resources for the families of adults, and importantly the vital roles of direct care service providers for adults. Ms. Walder and the Autism Society of America jointly honor a leader in adult autism annually with The Daniel Jordan Fiddle Foundation Leader in Adult Autism Award. For more information, visit www. djfiddlefoundation.org.



Dr. Zoher Kapasi, Dean of MUSC College of Health Professions and Linda J Walder, CEO of The Daniel Jordan Fiddle Foundation

#### Empowerment from page 1

Autistic Society in the U.K. and parent of a child with autism, describes this in a 2015 post on the blog *The Social Issue* as "...meaningful conversations that acknowledge the [enduring presence of human rights], even in the absence of legal rights.... No decision should be made which has not already been discussed. [That is the minimum human right to which someone is entitled]" (2015).

Regular screening, assessment, documentation, and discussion across interdisciplinary team members and caregivers will allow status changes to be identified and addressed. Funding models typically prescribe formal team reviews at a minimum of annually. Interdisciplinary teams should use these as opportunities to approach and document these decisions earlier in life by identifying the physical, social, psychological, and spiritual wishes of the individual (Ferguson, 2016). Caregivers who know an individual well or did in the past play an integral role in identifying someone's preferences that have difficulty expressing them. In recent years, there has been a positive shift in implementing an individualized approach toward assisting our school-aged individuals to plan proactively for their futures when district-funded services end. The same future planning models must be modified and executed as our adults become even *older* adults. Normalizing these models may lead to outcomes such as decreased avoidance of making end-oflife decisions and ensuring personalized, compassionate, and effective supports are implemented across the lifespan.

While some individuals experience an acute illness or health event, often, a more

gradual change is observed. In one experience, an individual began to decline in communication, hygiene, self-care, and a loss of interest in things the person previously enjoyed. The legal guardian was reluctant to engage in any conversations regarding end-of-life care planning. Unexpectedly, the guardian became ill and passed away. The individual being served continued to decline and, at a point, required emergency medical care. The facility advocated for a hospice consult and to allow the individual to be cared for in their own residence that they had resided in for decades, surrounded by familiar caregivers and peers. Because there was no planning or documentation in place, the hospital was resistant to collaborating with the intermediate care facility to determine the next steps. While some individuals in our care may not have an outwardly evident response, a person is impacted by their changing bodies and the likelihood of stress and worry surrounding them. While the facility was able to eventually advocate for the individual to be released back to their home under the care of hospice, the result included a lengthy hospital stay and a delay in providing the comfortable and compassionate care the individual was entitled to in their final days.

In more recent months, our interdisciplinary team was faced with a similar situation. An individual who had resided in the same residential facility for 49 of their 50 years of life began experiencing a number of medical challenges. The team and family began to discuss end-oflife care. Hospice was consulted, and the plan of care shifted from curative medical treatment to comfort and support. When the individual's ability to eat diminished, she continued to ask for preferred food and drink items. Caregivers provided bites of applesauce and yogurt paired with sips of juice while allowing her favorite show, the Golden Girls, to play on a loop in the background. The individual passed peacefully in the night with plans in place for who to call and what would happen next.

While the team felt the emotions of the loss for both individuals, having the action steps pre-determined and discussed ahead of time, as with the second individual described, allowed all resources to be directed solely to caring for the individual. Compassionate care was able to be provided in their final days, taking into account their preferences and the family's wishes. Accessing the voice of the individual always remains the priority, and planning for end-of-life care early on can lead to a better quality of life during the individual's final days.

Amanda L. Duffy, MEd, BCBA, LBS, is Director of Clinical Services – Adult Programs, Kristina Gasiewski, MOTRL/L, MEd, BCBA, is a Behavior Analyst, and Lara Redcay, MEd, BCBA, is Assistant Director of ICF/IDD at Melmark Pennsylvania.

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#### Vote the Spectrum from page 6

this is our moment to reignite another decade of inclusivity and accessibility. As noted by political analyst Richard Stengel (see video in the list above), Martin Luther King, Jr. reminds us that "the U.S. Constitution was a promissory note," and it's up to us to continually expand the circle of liberty. We do that by voting.

But, for many individuals with A/I/ DD, voting rights and procedures remain unclear. These individuals and their loved ones deserve to be aware of their rights and the changes underway in several states, including Arizona, where a May 2024 Court of Appeals decision, Wood v. Coconino, ruled that individuals under guardianship should not automatically lose their right to vote. Prior to the decision, individuals under guardianship could only restore their voting rights if they proved they had the capacity to do so. However, the Court of Appeals agreed with the plaintiff's argument, noting that placing the burden of proof on the ward violates the due process clause of the 14th Amendment of the U.S. Constitution. The court found that the burden of proof must be met by the petitioner seeking guardianship - whether a parent, sibling, or public fiduciary - to show that the individual lacks the capacity to vote.

To further clarify individual rights and

My greatest independent living skill: voting.

maintain momentum in this pivotal voting year, Vote the Spectrum has received unwavering support from Arizona Secretary of State Adrian Fontes (D) and Maricopa County Recorder Stephen Richer (R). These stalwart leaders recognize what it takes to build stronger, healthier communities that work for all Arizonans.

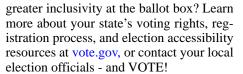
Consider the era of cars without seatbelts and airbags, prescription medications without child-resistant caps, and unrestricted use of tobacco and consumption of alcohol without health warnings. Imagine life without federal support for the oppor-



tunity to receive an education, the ADA, or the reauthorization of the Autism CARES Act of 2024. Then, imagine life with more connected communities and a healthier population. Such protections are all attainable - and sustainable - through the power of democracy.

Now is the time to make all collective voices heard in a concerted effort to strengthen social infrastructure and community diversity through an ongoing, open dialogue that a healthy democracy empowers.

What can you do in your own community this election year and beyond to promote



**AUTISM SPECTRUM NEWS ~ FALL 2024** 

To learn more about Vote the Spectrum, join us for "Dimensions<sup>™</sup>," the 13th First Place Global Symposium, in person or virtually October 16-18, 2024, in Phoenix, Arizona. We'll explore the many dimensions that define our community and share challenges, approaches for mutual understanding - and ideas for navigating and creating the places and spaces where we want to live, work, play, and thrive.

You'll be among many other trailblazers and courageous leaders for three grounding, informative, and fortifying days as we work together to fuel a new marketplace of housing, healthcare, and community options for adults with A/I/DD.

Denise D. Resnik is founder and president/CEO of First Place® AZ, a char*itable* 501(c)(3) *advancing innovative* residential, healthcare, and community options for adults with autism and other neurodevelopmental disabilities. She is also mom to Matt, an adult with autism, and her North Star.

For more information, visit firstplaceglobal.org, email denise@firstplaceaz.org, or call (602) 228-3928.

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#### Self-Advocacy Skills from page 23

Developing a Support System

Developing a support system can be crit-

#### Self-Care from page 31

are not just regular activities. They are all essential to my emotional regulation.

Sensory processing is another important aspect for us, and that is linked to our emotional regulation. Understanding our sensory profile is an important step to finding self-care practices that work for our needs. For example, I seek vestibular input because I am under-sensitive, but I am over-sensitive when it comes to touch and smells. For me, having vestibular input, like moving around my house and rocking on my chair while working, is essential for my sensory regulation, and that helps with my emotional regulation as well.

Perhaps you or your autistic loved one needs a lot of downtime and quiet, while other autistics need a high volume of sensory stimulation. For me, though I enjoy and need to "chill," if I do that for too long during the day, I have difficulty sleeping at night because I don't give my brain enough stimulation. Often, taking care of myself is putting the same Frozen 2 song on repeat and moving around the house while singing to it as if I am rehearsing for Broadway. The more I read about the common threads of having an autistic brain, the more I un-

ical for developing self-advocacy skills. Once young adults can identify people in their lives that they can reach out to for support with their goals, they can feel comfortable knowing that there are peo-

**Izabelle Azevedo** 

derstand my own needs and what self-care

Now, once we find what works, it is

important to make these activities part of

our routines. The good news is that they

are probably already part of our lives, and

we haven't realized it yet. If that is the

case, great! I understand, however, that

looks like for me.



ple out there who are willing to help them. This can include family members, educators, friends, healthcare providers, clinicians, and others in their lives. Having a

few trusted people in one's life can make a life gets in the way, and we might stop

doing the things that are beneficial to us for one reason or another, also without realizing it. I know that became true for me. That is when prioritizing these self-care activities (or whatever you want to call it)

may be necessary. If I know that I need to stim while working and have breaks to move around, I need to make sure my environment and accommodations allow me to do that. If I need quiet time but have trouble sensing what my body needs, then let's schedule those breaks. Adding labeled alarm reminders on my phone has been a big help, even for the basics, like food. If what I need is to hyperfocus like there is no tomorrow, I try to bring snacks, fidget toys, and noise-canceling headphones to accompany my session. And if what I need is a bit of my day or my week where I have no structure at all, then I might need to make an effort to make that happen. I know this last example can be a hard one for me to keep up with, but for me personally, it is the most important one for my needs, at least at the moment. Perhaps I need to make it a non-negotiable selfcare practice. Perhaps we all need to have non-negotiables in order to really prioritize our autistic-centered self-care practice.

huge difference.

Priya Winston, PhD, LMSW, is Director of Curriculum and Clinical Supports at Transitions.

Izabelle Azevedo is an openly autistic visual storyteller, content creator, and mental health and neurodiversity self-advocate who writes from her own experience. Izabelle's work can be found at Cloudful Drive and RedSkirtMedia.com. You can follow/contact her on LinkedIn or Instagram @DizabledWithAZ and @ CloudfulDrive.

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- Autism & Emotional Regulation:
- Autism & Sensory Abnormalities
- Sensory Processing & Emotional Regulation
- Sensory Profile

#### Low Vision from page 12

paying via electronic means. The IEP will need to reflect those means, including using debit cards, money transfer apps, and online banking. This is difficult to teach because the concept of money is abstract. The abstraction is further compounded by the notion of using credit to pay for things. As the child enters high school, parents and educators should work together to provide opportunities for the student to use real money, debit cards, and applications to pay for items and activities outside of the school and at home. A crucial component of this is teaching students how to protect personal information and prevention strategies to avoid being a victim of financial fraud. As the team continues to identify goals for the future, they may realize the student will need additional support in this domain even after years of effort and interventions. Here, parents can aid special educators in identifying these resources by inviting state social service agencies to IEP meetings during the transition age years. State agencies like the Commission for the Blind offer Vocational Rehabilitation Services that provide additional community resources and training.

The ability to travel independently in the community is another critical skill to living and working as independently as possible. Orientation and mobility specialists are trained professionals who teach individuals who are blind or visually impaired how to navigate environments safely and confidently. The transition plan should include mobility goals, with a focus on gaining comfort, exploring the community, and making connections. This can be done in a myriad of ways that are fun and exciting but will depend upon the interests, aptitudes, and strengths of the student. Goals can be developed that include traveling to work and recreational outings, as well as using public transportation. Recreational activities can consist of things like adaptive horseback riding, ice skating, swimming, biking, and canoeing. There are numerous adventure education and adapted physical education groups across the country that are available to provide resources and support. Exploring the community can also include going to the grocery store and accessing the public library. Parents can support the work of the schools in this area where the student takes the lead in planning outings for the family using public transportation during nights, weekends, and school breaks.

For young adults whose goals are around post-secondary education and living away from home, getting the student used to separating from the family will be important. Sleep-away summer camps are an excellent way to help with the process. In fact, one study showed that campers with autism showed significant improvements in prosocial behaviors, maladaptive social behaviors, and autism-consistent behaviors (Brodoff, 2017). The American Camping Association has over 11,000 programs in its database. These include day and overnight camps and even family or adult camps, many of which serve students with a range of disabilities, including autism, blindness, and low vision. Summer programs and so-



A young woman uses a white cane to navigate campus independently

cial experiences outside of the home and school build confidence, encourage friendships, and promote the development of critical independent living skills. For students with extended-year services, a summer transition program can be written into their IEP if it supports their transition plan goals.

#### A New Transition Program for Students with CVI, Low Vision, and Co-occurring Conditions

Perkins School for the Blind has been helping students with disabilities find their place in the world for almost 200 years. Working with local educational agencies, special educators, parents, and students, the Perkins faculty and staff design individualized programming that meets the needs of the range of student profiles that they serve. Next year, Perkins will open an innovative new transition program that addresses the critical gap in our educational landscape for intensive transition programming for young adults with complex disabilities. Life Launch is a multi-year residential program that prepares young adults who are visually impaired with multiple disabilities for independent living through hands-on work experience, concrete skill development, and real-world community engagement. The Life Launch Program will welcome the first class of students to campus in July 2025. For more information or to apply, visit: www.perkins.org/ transition-center/life-launch/

Perkins also offers individualized transition counseling for families and a range of impactful programming and resources. The Transition Center offers a digital library that includes downloadable tools, virtual events, and practical information on a variety of transition-related topics, including college alternatives, housing, person-centered planning, and guardianship. For more information on these programs and resources, visit: www.perkins.org/transition-center.

Ernst VanBergeijk, PhD, MSW, is the Founder and President of Ernst Equitable *Education Solutions, a consulting firm that helps parents find appropriate educational* settings and solutions for their children, and helps organizations evaluate and design programming for special needs children, youth, and young adults. He has over 35 years of experience in the special education field including working as the executive director/dean of two college-based transition programs for students with a wide variety of disabilities. Dr. VanBergeijk was recently appointed as the Senior Director, Local Education Agency, Early Learning Services, Elwyn. Elwyn is the



A student explores a new job opportunity washing dishes in an industrial kitchen

oldest and largest agency of its kind serving the I/DD population.

Alexandra LaVoie, MSOT, is the Director of the Transition Center at the Perkins School for the Blind and is a licensed occupational therapist and special education administrator. Alex has worked in the field of blindness education for over 10 years and has a deep understanding of the unique supports and accommodations that are needed for BVI students to achieve their post-secondary goals. She is passionate about Perkins' mission to empower students with disabilities to unlock their potential and live as independently as possible.

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#### Food Insecurity from page 17

to community fridges. "This collaboration transcends more than the food provision; it showcases that people with disabilities can make meaningful contributions and are integral members of their communities," says Darinka.

In May, AHRC NYC's day program participants and staff attended training sessions with S:US' leadership team to learn about the protocols utilized to clean the refrigerators and pantry, including recommended supplies, various canned and non-perishable food for re-stock, frequency of food delivery, how to organize pantry food, and how to interact with an eager public waiting to access food. Jajaida Gonzalez welcomed the collaboration, which would help expand the program. She shares, "Our community fridges aim to foster a sense of community, impart skills, and address food security challenges in our neighborhoods. Partnering with participants and staff from AHRC NYC underscores the significance of our collective efforts to address complex issues like food security in our city. This is a collaborative endeavor emphasizing the mutual benefits of skill development for all people with I/DD and ASD and not limited to the people that S:US supports.<sup>3</sup>

Volunteers and staff from AHRC NYC began volunteering on a weekly basis by maintaining the cleanliness of the refrigerator and pantry, stocking food items, and ensuring freshness. Initially, staff from AHRC NYC provided guidance for the stewards to support them in their endeavors. But the volunteers have become seasoned in their roles and staff now wait in the background in case assistance is needed. Yolanda Benjamin, Community Support Supervisor at AHRC NYC's Day



Day hab participants from S:US and AHRC NYC unbox and prepare fresh produce for the community fridge.

Program, appreciates the partnership and remarked, "[This collaboration] opens new avenues for people we support and staff. John Hardnett Jr., a program director from a home managed by S:US near the fridge, came to help our group, which was so kind. Our stewards and staff are eager to help in the community."

Brittney, a steward, likes to volunteer. She shares, "My favorite part is to clean the fridge with paper towels and cleaning wipes so that when people come to get food, there is a clean space. The staff helped guide and train me to build my skills to volunteer which I really appreciate." Deniece Dwyer, Community Support Professional at AHRC NYC's Day Program, also really enjoys working with the fridge program. "The participants are very eager to volunteer, they love it and they're very hands-on. They look forward to it all

week long, and we know that we are doing good work. It can be a bit overwhelming when so many people are eager to retrieve the food when we are still stocking the pantry, but we help put smiles on people's faces. Everyone is eager to help and pitch in," Deniece explains. The neighborhood's eagerness to access food staples from S:US community fridges emphasizes the abundant need for these resources to support food security in our communities. Sophia, another steward from AHRC NYC who volunteers weekly, shares, "I like to clean the fridge and help out in the community with the other volunteers. It feels good to help other people." Both Brittney and Sophia, along with their peers and staff, appreciate having a positive impact in their community and being able to witness the benefit of their efforts firsthand.

The S:US community fridges not only

offer nourishment to people living in the Bronx and Brooklyn, but they also provide a sense of connection and purpose for people with I/DD and ASD. As the New York Times columnist David French wrote recently in his article *The Loneliness Epidemic Has a Cure*, "With fellowship comes joy. With connection comes oppor-

ings than to forge a bond with a person and provide a place where they belong."<sup>4</sup> The people we serve with I/DD and ASD are developing a deeper sense of meaning, purpose, and connection by maintaining the community fridges. We look forward to cultivating our partnership with AHRC NYC so more New Yorkers can access free food.

tunity. There are few higher and better call-

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#### Later Stages from page 20

all these shameful mistakes I made as a young person growing into the world without adequate guidance and support.

With a lot of work, it has dwindled to a mostly-managed background hum instead of constant daggers in the place where my neck meets my shoulders. It was with me, though, all the times I didn't ask for a raise, all the times I let others take credit for my thoughts, all the times I should have spoken up in meetings and my words failed me. It was with me when I settled in relationships, agreed to less because there would be less friction, put up with things I shouldn't have.

As a dreamy teen raised by undiagnosed autistics who had more or less fallen into teaching, the idea of really having a think about what I might like to do for a living was never really presented to me. If it had been presented, it would have been a moot point: I didn't understand why people did anything that they did, and all of the things I was interested in doing weren't allowed, so the idea of thinking about what I might "like" to do was a non-starter. I expected to just fall into something as my parents had. I expected the great, inscrutable system that everyone else understood would simply issue me an appropriate job at some point.

I did well in school, and though I didn't understand it at the time due to low self-esteem, I could have gone to almost any school. I wanted to stay home and become a carpenter but capitulated to applying to *at least one school*. Once I was accepted,



Johanna R. Murphy, MFA

my parents stopped pretending that college was my choice: I was going. It wound up being a great choice, firstly, it got me away from home. I came into my own in a variety of ways. However, I still didn't really understand the "why" of it, and I came from a family that valued education as personal enrichment, not job preparation. Like I said, undiagnosed autistic.

I had also spent most of my life being simply unable to breathe. Except for my intelligence, there was almost nothing my parents seemed to like about me, and they didn't even know the full truth of it. I wasn't deferential to my father the way girls were supposed to be, I wasn't ladylike by any stretch of the imagination, I

wanted friends, but the other girls did boring things, and it was frowned upon for me to play with the boys. I questioned everything and came to my own conclusions. I wasn't intentionally defiant, but so much of what I was supposed to do was patently stupid or went against my grain (holler back to having no idea why people did what they did.) I realized in my teen years that this was all meant to train me away from being gay because I was clearly a very tiny lesbian from day one, and every effort was made by the world around me to stifle that. So yeah, getting away from home was really good for me, but the distraction of just surviving in my own skin, combined with autistic naivety, meant that I just took any old job after college. I figured they were all pretty much the same since people seemed to have no real reasons (to me) for anything that they did. I'd do something white-collar because that's what my parents told me to do. It wasn't what I wanted to do, so how could one be different from the other? Anything I experienced as satisfying work wasn't available to me, and most of the other things I was good at didn't make money.

Mix executive dysfunction into the fly-by-the-seat-of-your-pants and I-don't know-how-anything-in-the-world-works cocktail, and you have the perfect recipe for poverty and precarity. Oh, and let's not forget time blindness- even when I earned sufficiently, I would foul things up by confusing which day or month it was, pay heavy fines for lateness, and generally mess everything up. These problems weren't solved until after my diagnosis. Now, I have a "Daily Money Manager" who prevents me from forgetting November entirely, a small savings account, and multiple reliable income streams. What I've learned is that money is like timeyou've got to build redundancy into your system because there are no guarantees.

Now in my 50s, I have no children, am still wildly uncomfortable around most of my family, and all of my autistic women friends are in the same boat. The particular mix of precarity, health problems, and persistent drive for autonomy to preserve dignity that are sidecars to my own personal autism means that at some time in the not-too-distant future, I will have significant difficulty getting around, but I won't suffer the humiliation of asking for help after a lifetime of feeling rejected. I've worked since I was 14, but I don't have much put away for retirement. I foolishly invested what I did have in a house flip that was ruined by a divorce. I am extremely uncomfortable in group settings, yet I will inevitably wind up in some sort of subsidized elder care that will be both a sensory nightmare for me and deprive me of the solitude I need in order to feel alright.

The idea of being dependent on carers, around strangers, and in any sort of communal living is absolutely intolerable to me, but that's where I will end up.

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#### AUTISM SPECTRUM NEWS ~ FALL 2024

#### Extreme Weather from page 18

service workers with information about what autism is and how it can impact behaviors amid disastrous circumstances.

"A lot of times, individuals with autism are very concrete and literal thinking," Jerry said. "They need predictability, so planning out what is going to happen is almost as important to them as air. So, natural disasters throw a major wrinkle into the plan. Loss of control and predictability can, for these individuals, bring them to a place where they're inconsolable."

Using the example of a family with a 12-year-old autistic child, Jerry listed many tools that could support the child, their parents, and present responders: access to digital technology like tablets or iPads, fidget toys, designated quiet spaces, weighted blankets, or noise-canceling headphones.

Autistic self-advocate Alex Mann has visited over 470 police stations across five states, including his home state Pennsylvania, to educate officers and first responders about autism. His training series "Autism and the First Responder" coaches emergency workers through potential interactions with autistic individuals. He advises



**Emily Blumberg** 

responders to be patient with individuals and give them time to process their circumstances.

"Be prepared to almost treat them as a friend and give them as much love as you possibly can. Going through a weather emergency can be very scary and unpredictable," Alex said. New Jersey-based autistic self-advocate Kerry Magro said Jerry's claims ring true to his own experiences during Hurricane Sandy, where a power outage in his home disrupted his typical routine — another common, challenging obstacle for autistic individuals like himself.

While trainings like Jerry's and Alex's are available through her local Autism Society chapter, Cassie said educational resources about autism and natural disasters need to be expanded.

"More definitive plans need to be in place across the board," Cassie said. "Even my emergency preparedness binder doesn't give you every scenario or say exactly what is needed. Not everyone has designated, familiar evacuation spots like we do."

While there are no current federal policies designated to aid individuals with autism and their families during these circumstances, Sherman says his office aims to encourage inclusive interpretations of existing policies. He gave the example of the Biden Administration's 2021 Equity Executive Order, which requires the federal government to pursue fair and impartial treatment for all historically underserved communities. Sherman and his team have visited shelters and disaster recovery centers nationwide to identify gaps in physical and emotional accessibility.

"There's so much more to learn and so many autistic people that we owe it to ourselves to better understand it so that when we encounter a person with autism, we can do a better job of accounting for their needs," Sherman said.

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#### Transition Program from page 19

skills in ADLs and building safe social connections. Services to help families and patients with housing, financial support, and guardianship should also be provided in an effective transition program. For patients who are more independent, the transition program should also focus on community and social connections, including dating and internet safety.

When considering education and vocational needs, the medical transition team must be aware of the academic and vocational services available to their patients post-high school. Many patients and families rely on school staff to develop and coordinate these plans, but they do not recognize how these supports will end after high school. Effective transition plans will help patients identify vocational and educational support post-high school as well.

Of utmost importance, transition programs also have to adjust goals for each patient individually. Some patients may be able to become totally independent with their healthcare needs, while others may need significant assistance navigating the healthcare system. Effective programs



**Carrin E. Schottler-Thal, MD** 

should develop plans so that all patients can develop achievable goals. Creating "Transition IEPs" is a creative way to make sure all patients are included in developing this important skill.

Transition Programs should also make sure that all services, including the medical team that the patient is transitioning to, are provided in an autism-friendly environment. Appointments for autistic patients can be conducted at a time that is less busy so that the waiting room is not loud. Additionally, giving the provider more time for appointments also allows for alternative communication techniques to be used more effectively, as well as more time to review the many medical, social, and community issues that need to be addressed. Sensory Friendly environments, so that patients are comfortable and/or given tools to help them feel more comfortable, are also important.

Autistic individuals deserve excellent health care. They should feel safe when interacting with the health care system. This should start early when given care as a child, and the healthcare community needs to make sure that the transition to adult care is carefully organized so that autistic individuals continue receiving good healthcare throughout their adult years.

Carrin E. Schottler-Thal, MD, is Associate Professor of Pediatrics at Autism Medical Home and Medical Director at Albany Medical Center. For more information, email her at schottc@amc.edu.

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#### Revolution from page 36

# Creating Opportunities for Meaningful Contribution

It is important to recognize individuals with autism have the right to meaningful employment and opportunities to contribute to society. Our society has been moving towards more inclusive hiring practices and supports initiatives that help individuals on the spectrum find and maintain employment. By focusing on the strengths and abilities of individuals with autism, employers can tap into a pool of talent that is often overlooked.

Teaching self-advocacy helps individuals with autism be more assertive and take an active role in shaping their own futures. These skills can be taught through workshops and mentorship programs and help individuals acquire the tools and confidence.

#### Final Thoughts

Society's perception and interaction with individuals on the autism spectrum have undergone a profound transformation. As awareness and visibility have grown, long-standing stereotypes are being challenged, leading to greater inclusion. This shift allows individuals with autism and their families to thrive and make meaningful contributions to society. This social revolution goes beyond changing attitudes; it aims to build a society where diversity is celebrated and everyone has the chance to reach their full potential. Together, we can ensure that individuals with autism and intellectual and developmental disabilities (IDD) are not only included but are also recognized as essential members of our community's enriching society for everyone. Feedback from members of WJCS Shelanu and Supper Club has been incredibly valuable. Members have said, "I've made lifelong friends at Shelanu. It's a place where I feel understood and appreciated," and "Joining the Supper Club has been one of the best decisions I have ever made in my entire life. The activities are enjoyable, and I always look forward to the next event."

For more information about WJCS Shelanu/Supper Club and other programs for individuals with intellectual and developmental disabilities, please go to www.wjcs.com.

#### Red Tape from page 18

where I only handled emails, tickets, and live chats with customers across the world, an ideal occupation for an autistic such as me. It would end a few months later due to my refusal to be trained in the phones, and I found myself back in the same call center as before.

I was promoted to my final full-time paid position a few months into training for another customer service representative position, which would last until May 2023. My parents continued to submit my pay stubs to the SSA until I was terminated, after which they reported my firing. They seemed fine with it at the time, only to about-face the following February when they ended my Medicare and other federal disability benefits on account I was no longer "disabled," accounting for a continuing process where my father had to submit appeal forms, the first of which the government lost. The second forms submitted went through, only for my father to need to fill out more forms and mail them back.

This summer, due to accumulating post-traumatic stress stemming from my domestic life and worldly affairs, I made the decision to move out of my home into my own apartment in town, the process of which wasn't terribly difficult to accomplish online, where I paid my deposit and other fees and ultimately moved in. However, untimely communication on the part of the apartment managers, who are situated in one town over, needlessly delayed the process. After I moved in, I researched and sought what state programs I was eligible for, eventually applying online for Texas programs such as SNAP, although I am still awaiting a response as of writing.

I had researched other possible benefits such as rent assistance and called 211

several times, only to get the constant runaround, which has been my biggest issue in dealing with programs like those I have received, along with the mentioned untimely communication, and long periods in between status updates, alongside needless complexity, which is a huge deterrent to anyone, disabled or not, attempting to seek governmental assistance, and I have yet to find any concrete help for my monthly rent. I believe, in the end, that far better and quicker communication, in addition to a more widespread application of the KISS (keep it simple, stupid) principle, would go a long way in helping autistic and other disabled individuals get the help they need.

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**Remy St. Gallen** 

#### Disability Advocacy from page 33

As awkward and frustrating as these exchanges sometimes were, they prepared me for when my mother would no longer be there to feed me lines or take the phone from me in a pinch. As the old saying goes, my mother didn't just give me fish so I'd eat for a day; she taught me how to fish so I could sustain myself for a lifetime. In the seven years since my mother's death, I've often marveled at the previously unfathomable things I've managed to take care of on my own. But sometimes, in moments of extreme stress, I might forget just how much I've grown.

I compare myself to the elephant that is tied to a pole when it's young and tries to pull away to no avail. By the time the elephant is big, the tether has been internalized. The elephant could just easily walk away from the pole, but it won't because of the memories of when it couldn't. Like the elephant, I sometimes get stuck in the past. I forget how much I've developed over the years, how I'm far more capable than I was when I was younger.

July is Disability Pride Month, and this past July, I was reminded of my value to the disability community. I attended the Annual Conference of the National Association of Councils on Developmental Disabilities (NACDD) in DC, where I was inducted into the Self-Advocate Leadership Circle. I was nominated for this honor by colleagues at the Massachusetts Developmental Disabilities Council, where I served as Chair of the Policy Committee.

There's some debate over whether the phrase "Self-Advocate" is a misnomer since most people with disabilities are not advocating simply for themselves. At the Conference, one of the NACDD administrators suggested calling people with disabilities "Subject Matter Experts." This idea aligns with my point in an Autism Spectrum News article that Self-Advocacy is my field of expertise. I don't mind being called a Self-Advocate—if it's understood that most of what I advocate for will never benefit me personally. What does benefit me personally is the sense of belonging and purpose that comes from being part of something greater than myself.

A highlight of my trip to DC occurred before the NACDD Conference. A group of us joined the National Council on Independent Living for a rally in support of their 5 for 5 Campaign (referring to \$5 million for the 5 core services provided by Independent Living Centers across the country). A heavy rainstorm followed us down Pennsylvania Ave., at one point pummeling us with powerful raindrops that seemed to penetrate my umbrella. But we soldiered on chanting, "We're here. We're loud. Disabled and proud!" and "5 for 5." We also improvised. "We're here. We're wet. Our needs must be met."

Miraculously, the weather cleared, and the sun came out as we neared the Capitol

just in time for the rally. But for me, the most powerful image was a group of disabled people, some with mobility impairments, making their way through a torrential downpour while managing to maintain their resolve and good humor. It perfectly encapsulated the strength and resilience of the disability community.

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#### Supporting Women from page 13

through different life stages, such as education, employment, and relationships. They focus on peer-to-peer support, empowerment, and navigating gender identity and autism. They run mentoring programs, publish articles, and provide a platform for women with autism and their shared experiences.

Empowering and supporting women on the spectrum is crucial, not only to support their mental health and overall wellbeing but also to break down barriers, stereotypes, and misconceptions about women. The differences between women and men on the spectrum highlight the importance that autism can manifest differently based on gender and individual characteristics. Tailored support and recognition of these differences are essential for providing appropriate care and improving the quality of life for both women and men. Supporting women with autism can help develop greater independence and self-advocacy skills, which, in turn, will not only improve the quality of their lives but will improve upon societal understanding of autism. Addressing these areas and empowering women to make informed decisions about their lives, advocate for their needs, and pursue their goals with confidence will lead them to better navigate their world authentically.

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#### Wealth Building from page 20

gone up by an average of around 7% or so. A great book on this simple path of generating wealth is a book by JL Collins called A Simple Path To Wealth (Collins, 2015).

#### What Money Can Buy

Ultimately, what attracted me to learn about investing and money was a deep desire to have options and freedom. As a late-diagnosed autistic person, I have felt like I have lived my whole life pushing myself. I began working at age ten, and I have never stopped. I never felt like I had a choice to work or not. It was only when I discovered investing that I learned about how many folks have learned how to retire early or experience varying levels of freedom from required work due to investing diligently and living below their means. The movement toward financial freedom is sometimes called the FIRE movement (Financial Independence Retire Early). The first time I learned about the FIRE movement was when I read the article The Shockingly Simple Math Behind Early Retirement by Mr. Money



#### **Danielle Aubin, LCSW**

#### Mustache (Mustache, 2012).

#### Conclusion

The knowledge I have to pass along from 10+ years of finances being my special interest is simple: if you make an income, be mindful of your expenses so that you can

invest what you do not spend. I started my journey with financial independence when I was making \$17/hour living on my own in the Bay Area. I am not saying everyone can do this, and I am not a "pull yourself up by your bootstraps" type of person. However, I do believe that what I have learned is valuable, and I hope to pass along what I have learned to my children. Mostly, it is possible to go from \$0 net worth to millions, even if you are not a high-income earner, even if you are disabled. The money story I was taught was that investing was something only rich people did. I hope what I have shared today shows that is incorrect.

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#### Navigating Sex from page 22

can lead to discovering boundaries around touch during sex. This is true for the other senses as well. Actions or stimuli that are overstimulating outside of sex may not be overstimulating during sex and vice versa. When it comes to experimenting with sensory needs during sex with a partner, it is important to have a partner with whom you feel safe disclosing these needs and trust that they will honor those needs (Weir et al., 2021). Sensory differences are one reason many autistic people are also a part of the kink community. Some autistic people report their draw to kink is that there are explicit conversations about consent and boundaries that are honored in a safe container (Weir et al., 2021). Kinky or not, autistic individuals deserve to have their needs met and boundaries honored in a sexual container.

Other relevant accommodations could be related to difficulty with transitions and a need for structure. The transitions that naturally arise during sex can feel confusing, overwhelming, or activating (Weir et al., 2021). One example of accommodating this may be having more verbal communication during sexual acts and your partner(s) stating what they are transitioning to or asking if you are ready to transition. This may sound clinical when reading it, but there are ways this can be integrated in



#### **Britt Boylan**

a fun, sexy way that can meet an autistic person's need around transitions.

The need for structure around sex can often feel too rigid for partners of autistic individuals, so again, it is important to have an open dialogue with one's partner(s) about how everyone's needs can be met. Structure in sex could be scheduling sex, but it does not have to be. For example, there can be a structure around acts that are done and in what order, a discussion prior to sex about what everyone would like to do, or really any other way that the autistic person can meet this need and meet the needs of their partner(s).

When accommodating an autistic person during sex, it is important to have open, explicit conversations about what is happening for them somatically and for them to reflect on what their needs may be. All sexually active adults, whether autistic or not, deserve to have their needs considered and met and accommodations to be made for them so sex can be as fulfilling and enjoyable as they would like. Again, due to the infantilization that can occur towards autistic adults, there may be shame in stating something is overstimulating or that they do not enjoy an act that is stereotypically "enjoyable."

There is an increased sexual victimization that can occur for autistic people across their lifespan, and one way to combat this is to push against the stigma that autistic adults are not sexually active or do not enjoy sex (Weir et al., 2021). To empower autistic adults to name their sexual needs and to seek out consensual, fulfilling sexual relations with themselves or others will help push for change to be made on a larger scale. Sex is not a onesize-fits-all topic, and it is important to highlight the specific struggles that autistic people may experience during sex that fall outside of the neuronormative and cisheteronormative society we live under.

Discussing how autistic adults may navigate sex challenges these oppressive systems and empowers autistic adults to live their lives authentically and openly and to feel they deserve to be accommodated and have their needs met.

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#### Social Groups from page 14

providing participants with a sense of self-efficacy (Lorna, Rajendran & Stewart, 2023).

Finally, another benefit of facilitating social groups with ASD clients is that the relationships that form can potentially become social connections that the clients have beyond the parameters of the group. Unlike psychodynamically-oriented process groups, clients can be encouraged and supported to communicate outside of the group. As the facilitator of these groups, I purposefully sat two clients next to each other when I perceived that there were common interests or I felt that they would like each other as people. I have also casually prompted clients to take the next step to actualizing social plans with each other. For example, a client was excited to find that a peer in a less structured group had the same interest in movies that he has, and there was a vague exclamation of "we should go together" followed by silence. Being present and sensing that the connection was genuine,

I was able to casually ask, "How will you guys get in touch with each other in order to set that up?" which then prompted appropriate follow-up.

For me, as the director of a department whose mission is to promote the mental health of ASD clients, it is essential that group-based interventions be a part of our therapeutic offerings.

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#### Driver Education from page 19

predictable manner. Providing a low-stress driving environment and gradually progressing from simple to more complex driving skills are crucial. Caregivers and driver's ed instructors play a vital role in empowering autistic individuals to achieve their goal of driving. Below are a few strategies to use to support autistic individuals while they learn to drive.

- Sensory Sensitivities. Many autistic individuals have sensory sensitivities that require sensory integration strategies to minimize sensory overload. Providing an environment with reduced noises, lights, strong odors, and large groups of students helps with sensory integration. Strategies could include smaller or individual classes, sensory breaks, or slow sensory exposure to loud noises such as traffic noise or emergency vehicle sirens.
- 2. Wording. Concise wording is essential when explaining driving concepts and instruction. For example, to teach backing out of a parking space, say, "Drive backwards until your side mirror is parallel with the other car's bumper, push on the brake, and turn the steering wheel to the left until the wheel stops."
- **3.** Class Structure. Break down driving skills into small steps with ample practice opportunities; repetition and consistency help autistic drivers effectively master skills and build confidence. Since many autistics are visual learners, use visual supports, such as schedules, checklists, and pictorial diagrams, to teach driving procedures and rules, especially how to interpret complex social cues from other drivers or pedestrians.
- **4. Drive Time.** During drive lessons aim for 20-minute lessons—focus on one driving skill and take frequent breaks. Shorter lessons help reduce sensory overload, and breaks can be used for reflection and feedback.
- **5. Tailored Instruction.** Traditional driver's education programs often follow



### Heidi Hillman PhD, BCBA-D, LMHC

a one-size-fits-all approach; however, tailored instruction is key to helping autistic individuals adapt to new stressors and become safe drivers. Examples include using one driving session to just sit in the car, allowing the autistic driver to become accustomed to the surroundings. Use a second session to explain all the devices (such as windshield wipers, turn signal, brake, and gas pedals) and how the autistic driver would use them on a typical drive. Work on intersections with stop signs before moving to intersections with stop lights. Tailoring lessons to the unique learning style and sensory needs of each autistic learner significantly enhances their ability to grasp and retain driving concepts.

6. Practical Driving Experience. Driving in real traffic situations is irreplaceable for building safe driving skills. The use of driving simulators or virtual reality settings is not recommended, given the low transferability of observations from a driving simulator environment to real on-road driving (e.g., Lee, Cameron, & Lee, 2003). Rather, provide driving practice in low-stress environments, gradually increasing the complexity of driving conditions as the learner gains confidence. Lastly, given that autistic individuals are susceptible to anxiety, their driving experience is very likely to deteriorate in a test environment. Hence, have the autistic driver complete at least three "road tests" using a driving route comparable to the test route before attempting an official road test.

- 7. Positive Reinforcement. Celebrating progress, no matter how small, facilitates a positive learning experience and further empowers the autistic driver. Providing frequent positive feedback and encouragement helps maintain the learner's motivation and commitment to mastering driving skills by reducing their anxiety and building their confidence.
- 8. Feedback and Route Planning. Verbal feedback is usually provided while student drivers are driving. However, this can cause sensory overload for an autistic driver since they are already processing a lot of visual and audio information. Rather, stop the car before providing feedback. Secondly, explaining the driving route to the autistic driver helps reduce sensory overload. To further decrease anxiety, use a visual map of the route (Google map), allowing autistic drivers to acquaint themselves with roads and intersections. Knowing a route helps the autistic driver feel less anxious since they can focus on driving techniques rather than worrying about new roads and locations.

#### Conclusion

Learning to drive is a milestone that offers benefits such as indewpendence and self-confidence. Autistic individuals, like everyone else, seek the opportunities that driving provides for connectivity and participation in life. Achieving this may require specialized support and tailored instruction; inclusive driver's education programs can help autistic learners navigate the roads safely and confidently. For autistic individuals, the goal of driving is independence, while the goal for caregivers is empowering that independence. Recognizing the diverse needs of autistic drivers is essential for fostering an inclusive society where anyone can achieve driving independence and enjoy its benefits.

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#### Resilience from page 22

can bring joy, excitement, and even awe to an autistic person's life. Being involved in a focused passion can make an autistic person feel empowered, happy, and accomplished. If it can be their life's work, they might be the most knowledgeable, content, and focused person in their workplace.

There are other strengths as well, such as honesty, fairness, attention to detail, creativity, and problem-solving. These strengths can be used by autistic people to come up with unique ways to take care of themselves and be ok in a world that's not made for them, filled with people who do not understand them, and support that is not recognized as support.

Overcoming adversity builds resilience and makes a person stronger for the next adversity that comes their way. Using self-care as described above helps to build resilience and take care of oneself at the same time. A sense of awe and wonderment, rich inner worlds that are safe and a place to just "be" for a while, and using autistic strengths are as beneficial to autis-



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tic people as the world we live in is harsh. The result is resilience.

To that end, I guess I could also say "Resilience" is my middle name... but alas, it's still Rae. Lisa Morgan, MSW, MEd, is a Consultant at Lisa Morgan Consulting LLC. She can be reached by email at lisamorganconsulting@gmail.com or via text at (603) 370-7207.

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#### Cultural Studies from page 21

of itself. It is a healing venture at both ends without the need for dissection, a direct service through its own existence.

Even developing such an ethnography, such a cultural program, required serious paradigm shifts. After several iterations, trial and error, and finally opening up to the engagement of every participant, the format finally evolved into the core of the program: invited speakers and facilitators from every background, language, parent culture, socioeconomic bracket, life experience, language, age, and identity, offering workshops, hangouts and think tanks - all recorded for truly collaborative research and for posterity.

Our speakers and facilitators have talked about every facet of autistic culture from birth to aging and brought these facets to life through unique lived experiences: autism in Indian culture, autism as a sensory experience, autism and gender, autism from a First Nations point of view and through voices of Black and brown people, autistic people and their relationship to animals, the creative expressions of autistic people in all of their forms – each have unfurled new maps and new areas of exploration.

#### What Does Autistic Culture Look Like?

The first thing we learned about autistic culture is that it can't be put in a box. Throughout the process, everyone was welcome, whether they were self-identified, officially identified by neuronormative people, peer identified, or simply fit with the group, and that soon led to the evident reality that autistic culture is not based on hierarchy. Though I started the ethnography, it immediately became much bigger than me or the sum of the parts as people caught fire with the awareness that they belonged to something real - that we all understood each other and had similar core ways of experiencing the world.

The initial ethnography, now the expanded cultural autism studies program, has revealed patterns of cultural cohesion among autistic people beyond expectation and offers nothing less than a revolutionary shift regarding how we define what autism *is* and who autistic people are.

There is, of course, actionable utility in the patterns that our cultural autism studies have uncovered and documented, and these patterns are of vital importance toward providing better support and services for autistic people as we live the model: nothing about us without us. We have developed wonderful collaborations with other institutions and autism advocacy groups, working as equal partners with our allies. While its utility is thrilling, it is also thrilling to look at the ways that this momentum was generated from the seeds of its beginnings.

What was evident early on was that the group comprised of autistic people interested in their own culture was taking a *different kind* of social shape. Occasionally, there was what a non-autistic observer might perceive as "chaos" as people found themselves excitedly talking to other autistic people in a truly supportive environment that saw autism as a cohesive way of being - a deep understanding of each other – our motivations and essence, a shared, functional understanding of the autistic process. There was a real social engagement with a shared, complex network of ideas and experiences. Given a safe space



**Dawn Prince-Hughes, PhD** 

to express their own culture freely, many conventions of neuronormative expression were abandoned. Without the stress of masking and the activation of onion layers of dysfunctional coping mechanisms fomented by a lifetime of cultural oppression, participants felt free to simply be themselves.

One of the first patterns that was evident was that keeping topics and ideas neatly compartmentalized gave way to natural webs of interrelation. "Staying on the topic" looks very different through the lenses of autistic and neuronormative cultures and belies core differences in perception structuring and relevance. So, for example, if the topic is what kinds of sensory spaces work best for autistic people, autistic and non-autistic cultures organize responses to that topic in very different ways. For non-autistic people, "staying on topic" would likely take the form of an hour-long discussion from a "nuts and bolts" perspective (what the dimensions of a room might be, a list of items to furnish it with, etc.). Staying on topic for autistic participants is a more reflective discussion, including connected topics and personal anecdotes about, for instance, bullying, relationships, a time someone was physically hurt on a playground, the tools needed to build an herb garden, and what kinds of pollinators are attracted to various indigenous plants, how someone relates to their service dog, ancient uses of color symbolism, and their favorite stims through the years. To Ethnography participants, these contributions are on topic because, for autistic people, a positive sensory environment is an inextricably linked nexus of emotional safety, physical safety, movement, creativity, the joys of positive sensory immersion, and opportunities to heal from past trauma.

Within this autistic, "neuro-holographic" style of communication, other cultural patterns became evident: a style of straightforward dialogue and a unique rhythm of turn-taking that was strikingly different from those of a neuronormative society. It is clear that natural styles of communication for autistic people require adequate dialectical space and feelings of shared communicative resonance in order to unfold properly. The clash of cultural styles - cultural dissonances-profoundly interferes with intercultural communication and cooperation between autistic people and neuronormative society. This reality in a hierarchical and reductionist system has caused untold trauma to autistic people.

Despite obvious layers of trauma, the warmth and openness of the group have been emotionally moving. The group's resonance with one another's creativity, an active enthusiasm for new ideas, unique rhythms of turn-taking, and the natural understanding of one another's complex emotional workings - these social mechanics, made possible by a forcefully claimed cultural matrix, flowed smoothly from unspoken rules (or, perhaps "value-driven protocols" is a better term). The shared values that underpinned and facilitated the expression and building of autistic culture were quite different from those of a neuronormative society. Most notably, autistic culture is grounded in unusual honesty, genuine and expansive empathy, and palpable respect. When participants had to turn off their cameras, mute sound, walk incessantly during different kinds of sharing sessions, or ask another participant if it was possible to address something in the background that was challenging to them on a sensory level, acceptance and cooperation was a foregone conclusion. When people responded to another person sharing a difficult situation they were going through or a painful memory, offering a personal story of a similar situation or memory was understood to function as an expression of empathetic emotional layers rather than being an example of self-centeredness.

To me, this is the most exciting part of the cultural autism studies program: participants completely reframing and affirming autistic cultural experiences in positive ways. This reframing hasn't required overt attention, discussion, or procedural consensus – it has flowed from a shared, mindful structure. "Oversharing" transforms into a means of expressing emotional honesty in an efficient and relevant way. "Monologuing" and "restricted areas of interest" become expressions of admirable expertise. "Going down rabbit holes" are lauded explorations of possible new connections or discoveries of meaningful patterns that non-autistic people wouldn't register. "Outbursts" and "meltdowns" are opportunities for silent support and healing. "Stimming" is a kind of sacred, ritual pantomime for feelings and sensations that defy reductive human speech. "Naivete" and "lack of boundaries" are expressions of the awareness that everyone and everything is connected - an inextricable part of the self.

Autistic people, in general, simply don't have (and don't admire) the kinds of invented boundaries and needless disconnections that non-autistic culture manifests from its contrapuntal root. Whether it is on a sensory level, a social level, or a species level - the cultural studies program has illuminated an unusually active sense of responsibility among participants that has hummed into a cohesive force that will have global implications. The program shows that the transformative force of cultural connectivity exponentially enhances our self-esteem, confidence, and the applied energy of these passions.

The energy of these passions is increasing. We open the next academic year with a truly global program, welcoming autistic people and allies (as well as neuro-adjacent people) from Brazil, Italy, England, New Zealand, Ghana, Australia, Senegal, India, Mexico, Canada, Taiwan, Portugal...and the list is constantly expanding. Topics and explorations continue to expand as well. Already this year, we have scheduled autistic psychologists talking about mental health, speakers exploring autistic/animal alliances, specialists in environmental and sensory issues, people sharing life stories of all kinds, facilitators proving space for alternative means of communication, ethics hangouts, physics hangouts, explorations of autistic music, literature, art, and other special interests.

#### All Are Welcome

This global/holistic orientation of autistic culture should, in my opinion, be embraced not only by anyone who identifies with autistic culture but by a neuronormative society that has obviously run out of ideas for ensuring social equality for all, restoring the living planet, avoiding violence, and restoring compassion, patience, egalitarianism, and creativity. Autistic people are unique pattern processors and problem solvers who often have an inherent talent for finding unique ways of engaging and interacting with the world. An empowered autistic culture, based on these ways of being, has deep significance for the future of all. My hope is that autistic culture, now reified and fortified, can help to heal the wounds that its absence allowed. Cultural Autism Studies at Yale is a place that cultivates alliances between autistic and non-autistic cultures, as well as any program or disciplinary field dedicated to enriching autistic life.

Autistic voices always come first, but people of like purpose are welcomed.

#### How People Can Get Involved

The best way to get involved is to visit Cultural Autism Studies at Yale's online Cultural Community Center and the CASY Facebook Page to find our calendar and announcements for exciting upcoming sessions and hangouts. All of the sessions are free and provided on Zoom. Also, check out CASY on YouTube. We invite individuals, sister support organizations from other universities and institutions, and collaborators of all kinds to attend sessions and reach out with their own suggestions.

We are especially interested this year in involving more People of Color, non-speaking autistic people, and other underrepresented groups. We also extend an especially warm welcome to different language speakers to schedule their own offerings through the program.

It is such an exciting time. To be part of this cultural revolution, this steep paradigm shift is unlike anything any of us have experienced. The energy is electric. We hope that you will join us and grow the autistic culture with every voice.

Dr. Dawn Prince-Hughes is Co-Chair of Cultural Autism Studies at Yale. She started her anthropological career learning from gorillas, which led to a long-time association with the Jane Goodall Institute and a PhD in interdisciplinary anthropology in the areas of cultural evolution, universal archetypes, and relational culture. For her work in these areas, she was nominated for a MacArthur Award in 2012. She has written many peer-reviewed papers and several popular and academic books on the subjects of culture, liminality, and radical expansivity. Her best-selling book, Songs of the Gorilla Nation: My Journey through Autism, is now under development as a feature-length film. In addition to her work at Yale, she is working on a new series of books exploring monsters as cultural messengers.

#### Travel Guide from page 21

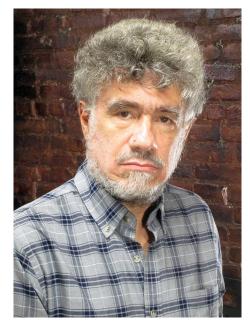
As to luggage, I strongly recommend, if viable, a carry-on bag or suitcase (especially for air travel, since both TSA and the airlines specify a maximum size). This prevents the ordeal of waiting for baggage claim and eliminates the possibility of lost suitcases, the latter of which can ruin a trip for anybody, but for an autistic already at a high level of anxiety, is nothing less than catastrophic. A sturdy suitcase with wheels and an extendable handle is a good idea, as is bringing as few items as possible (i.e., only what is necessary). Also, try to leave some extra room for souvenirs or other items you might want to bring back (especially where a special interest is concerned).

#### Planning a Trip

As with anything, it is always best to be as informed as possible before embarking on a journey. Much as it may be an enjoyable adventure for some to go wherever the journey takes them and experience each day at a time, this is generally not a good idea for autistics, who are often challenged by unfamiliar or unexpected situations. It is best to acquaint oneself as much as possible with what can be expected at the destination, especially if this is your first time traveling independently or your first trip overseas.

The choice of destination is often made well in advance of the planning stage and, for autistics, can be based on either a special interest in the specific place or in attractions located there, on an event taking place in that location, or on people that one knows (relatives, friends, or other members of an autistic or special-interest community) who reside or are meeting there. For those who simply wish to travel but don't have a specific destination in mind, travel books, magazines, and videos may be a good source of inspiration as well as information. I find the Rick Steves videos on European travel, which appear on PBS and are available online, especially enjoyable, even when I am not interested in visiting a specific place.

Good travel guides are extremely helpful, if not essential. Some libraries have an entire section of such, as do many bookstores (the latter more likely up to date). I found that some series of travel books are especially good – I particularly like those that contain a maximum of practical dayto-day information about the destination, whether domestic or foreign, along with lists of good (and affordable) places to stay and to eat. Better still, some contain self-guided (e.g., walking) tours that you can do yourself and sometimes unusual trivia that you would otherwise not know about. Personally, I like the Lonely Planet books, as well as the Let's Go guides. The latter are intended mainly for college students but are good for young adults regardless of student status. These and other youth-oriented guides can also be good for older autistics, who often have interests, preferences, and tastes closer to those of younger adults (this is certainly true for me, and I am a senior citizen!). At the same time, some travel guides focus extensively on such things as rating higher-end hotels and restaurants that are beyond the budgets of many autistics. Others deal exclusively with budget travel to the exclusion of other considerations. I found these to be of little or no value and, as such, best avoided by



#### Karl Wittig, PE

most autistics.

Years ago (and perhaps still), many countries had tourist offices in the U.S., and these provided a wealth of information. As such, they are worth checking out if they haven't been supplanted by websites. Many popular U.S. destinations offer such information as well. Years ago, when planning a trip to Germany, I visited the German Tourist Office in New York, which had brochures and pamphlets for virtually any destination there. They even had one devoted to technical museums in Germany, which, of course, I immediately took!

For travel abroad, it is especially important to be aware of things that are different from the U.S. and to familiarize yourself with such. A good travel guide will provide such information. For example, it helps to know about local transportation (streetcars, metros, intercity trains, and buses), including how to pay for it. This is one area where autistics who are interested in trains and transport really have an advantage, as they will have an easier time learning this. Also, you need to be familiar with the coins and currency of the country and have some idea of the exchange rates. Since coin collecting was a special interest of mine for many years, this was hardly a problem for me - once again, an autistic trait turned out to be of considerable help.

#### Getting There

Travel to a destination where significant distances are concerned requires some planning. Nowadays, this means booking air, rail, or bus transportation. Foreign travel, as well as long-distance U.S. travel, usually involves making reservations with an airline. In the past, this was arranged by a travel agent, who also took care of hotel accommodations as well as organized tours. Nowadays, it is done through websites such as Expedia, which places a burden on the traveler. For autistics who are comfortable with such, especially those skilled in computer and internet use, this will not be a problem (they may be capable of helping non-autistics), but it can present a challenge for those who are not. In such cases, they need to seek assistance from a more knowledgeable person.

Bus transportation is widely available in the U.S. and may be preferable for short-distance travel, as are trains (i.e., Amtrak) in corridors that have frequent service (e.g., Boston – New York – Washington). For those who prefer ground transportation, either to see the country or to avoid air travel, either of these is an option. Nowadays, bus service is more frequent and widespread, not to mention less expensive, whereas rail service is far less frequent, offers fewer destinations, and has become very expensive. Still, autistics with an interest in trains will often prefer it. Once again, reservations need to be made, and this is usually done online nowadays.

In some cases, taking a bus or train may be preferable to flying for longer distances if the former is more convenient and less stressful even when the travel time is longer. On one trip from New York to Pittsburgh, I decided to go by bus because, even though it took longer, this avoided the need for airport transportation (not to mention the airport itself) in both cities (saving time, money, and inconvenience); the bus terminal in New York was close to where I lived, and the one in Pittsburgh was practically next to my hotel and the conference center. It is always a good idea to consider the benefits of different options when planning a trip.

In the post-9/11 world of tight security, airports and air travel have become more stressful than ever, in addition to the crowdedness resulting from airlines filling their aircraft with as many passengers as possible. While this affects virtually all air travelers, it can be especially daunting for autistics, who often have a low threshold for such. Getting to and from an airport, especially in large cities with heavy traffic, can be difficult and time-consuming, and the long lines and procedures for going through security (e.g., removal of personal possessions and clothing items when going through scanners) are a well-known nightmare for everyone. Even the boarding of the plane, with its crowded cabins, while carrying suitcases and bags, is horrendous. For autistics, this can be very stressful and even unbearable. Some autistics, with proper documentation, have successfully gained disabled access for these procedures. An adult autistic should, at the very least, be physically and mentally prepared to endure these ordeals and, where appropriate, investigate the availability of special accommodations provided by the airport and airline.

#### Where to Stay

Reservations for hotels or other lodgings need to be made in advance. This can be done online for larger hotels and chains as well as on travel websites, but it is best (and may need to be) done by telephone for smaller establishments. When traveling abroad, it becomes necessary to speak with someone who knows English (unless, of course, one speaks the local language); this is usually not a problem. Finding a suitable hotel is probably best done with the help of an up-to-date travel guide for the destination, as these provide information about prospective accommodations that would not be available on travel websites. Nowadays, apps such as Airbnb have become very popular and sometimes offer good lodging possibilities, but you must be especially careful, as many kinds of problems have been reported with these. In any case, reservations for any hotel or lodging need to be completely confirmed before departure. Nobody wants to arrive at a distant location to find that they have no place to stay, and I can't even imagine what such an experience might be like for many autistics.

#### Getting Around

Upon arrival at a destination, finding local transportation is usually essential. If you have not already done this and are not driving or renting a car (many autistics do not drive, and even those who do may not want to in an unfamiliar location) or part of an organized tour, information about local public transit (maps, schedules, prices, etc.) should be obtained immediately upon arrival. This is readily available anywhere in Europe and in most larger U.S. cities. For destinations outside the U.S., currency exchange also needs to be done as soon as possible, although nowadays, most major credit cards can be used to pay for many expenses directly. Travel guides often provide advice on where to get the most favorable exchange rates.

Many countries offer rail passes that are good for unlimited train travel anywhere, and the Eurail pass is good almost everywhere in Europe. If you plan to do extensive travel in one country or throughout Europe, these are definitely worth investigating. They can save you the time and inconvenience of purchasing a ticket for every train trip, not to mention a lot of money if you are making many trips. What's more, discounts are offered for young adults and for senior citizens. Needless to say, for autistics who have a special interest in or preference for trains, they are an absolute must.

#### When You Get There

As with so many other things, autistics often have very strong preferences while on a trip that are quite different from those of a typical traveler. These frequently revolve around specialized interests. It is not unusual for an autistic person to be less concerned about attractions that are popular with most tourists but to be extremely interested in things that others might not be aware of, let alone care about. This can cause problems for autistics traveling with a group. Even when the group consists of family, friends, a school trip, or a local organization, this may create difficulties and possibly conflicts. If an autistic is interested in a particular attraction and aware of such prior to arrival, every effort should be made to accommodate this, perhaps by allowing them to spend extended time there while the rest of the group separately does something not of interest to the autistic. In cases where the attraction is discovered only after arrival, contingency plans should be made to arrange this on shorter notice. I can remember a trip to Budapest that I took with my late wife, during which, while we were together, I wanted to visit a small museum that featured a collection of electric utility meters (there really was such a place!). Needless to say, she was not very happy about this.

The above problem can be even more serious for an autistic person in an organized tour group. For this reason alone, I do not recommend organized tours of large areas or regions for autistics, despite the terrific opportunity they offer to see many different things (not to mention the convenience of having everything arranged for the traveler). At the very least, the itinerary of such a tour should be thoroughly scrutinized before embarking. Few things are more frustrating for an autistic than being close to an attraction of special interest but

#### Masking from page 31

everyone else could do it, why couldn't I? However, this didn't always work out the way I wanted it to. It turns out that pushing down fundamental parts of yourself makes you a bit stressed and causes you to come across as wildly anxious instead of normal and cool.

By the time I was 21, I had been masking – albeit mostly unintentionally – for years, and as I entered young adulthood, it had served me well. I was able to talk to

people and make friends, I was maintaining a romantic relationship, and I had gotten through my entire undergraduate degree and started a master's degree without issue – but then I got diagnosed with autism.

While I wasn't exactly surprised that I was autistic, actually seeing it on paper and taking the time to think about it was a very emotional experience. I had to go back and reassess every single thing I had ever done with the new perspective that I was autistic the entire time. It explained a lot, but I found myself angry and upset that no one had noticed anything. It hurt thinking that I could have had this knowledge sooner. Instead of growing up knowing that I was autistic and that I just naturally would function differently from others, I went through life thinking that there was something inherently, fundamentally wrong with me and that it was my job to change it.

After a few months of assessing these feelings on a personal level, talking a lot with my partner and friends, and going to therapy, I was able to be a little kinder to myself regarding my diagnosis, but then another unique issue raised its head. Most, if not all, of my friends are neurodivergent in some way – including my partner, all diagnosed at varying stages of life with



Emily "Ly" Stewart, BA(Hons), MSc

entirely different experiences and support needs. While we all get along exceedingly well, I started noticing how I reacted to certain things they did. If a friend was too excited about their interests or more vocal about the ways they needed to accommodate themselves, I would get an almost anxious, aggravated feeling in my gut. If I was out with a friend and they suddenly couldn't control their volume, I would immediately tell them and try to keep them quiet. I didn't like the fact that I did this, but I was also unable to stop it, and I didn't know why.

Then it hit me: I was still masking.

Despite getting my diagnosis, despite thinking I understood myself more, I was entirely unable to take the mask off. I couldn't help but hold myself and my autistic peers to neurotypical standards. Even if I did give myself a rare moment to unmask, usually by rambling about my interests or partaking in self-regulating behavior, I would feel immense embarrassment afterward. I even experience it when I'm completely alone like someone's going to jump out of my wardrobe and tell me I wasn't being 'normal' enough. Even though I'm more confident and content than I've ever been, the years of having my autistic traits criticized and not receiving the correct accommodations still affect me to this day. I can't really say I know the *real* me, the me I was, or the me I could have been if I didn't feel the need to mask from childhood.

As I said, most of my friends are autistic, but the restrictions I've placed upon myself due to growing up undiagnosed make it hard to fully connect with them. At the same time, I can never truly relate to neurotypicals because - even when I mask – I can't hide the fact that I'm on the spectrum. It puts me in an unfortunate situation, often feeling like I don't really fit anywhere, and, judging by recent research, I'm ironically not alone. Many autistic individuals have discussed how prolonged masking has permanently damaged their sense of self, exhausted them, and made it nearly impossible to know who they truly are or what they need, which makes attempting to unmask an emotional, arduous task (Miller, Rees, & Pearson, 2023).

My inability to rip the mask off has become an unfortunate truth I've had to face as a late-diagnosed autistic adult. I can't partake in the same autistic joy some of my friends indulge in, and I struggle to give myself the grace my partner gives herself – but I'm still trying. I'm definitely not the first person on the spectrum to struggle with unmasking, and I certainly won't be the last. Even if the best I can do is live alongside the mask I've created, I can still appreciate the support system I have and take some joy in the journey to rediscover and craft my own identity.

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#### Travel Guide from page 46

not being allowed sufficient time there or, worse still, not being able to visit. I once went on an otherwise wonderful organized tour of Britain in which this happened a few times - I wanted to see or visit several places (related to my interests) located near a location in the tour, but the schedule did not allow me to do so; very frustrating indeed. I also remember, on at least one tour that I went on, spending significantly more time at a venue of interest than the rest of the tour group. Upon my finally rejoining them, I was met by loud cheers and applause from tourists who were not nearly as interested and were eager to move on. Believe me, this was not a pleasant experience.

City tours, as well as local tours of small regions, are a different matter. These allow you to get to know the city or area more thoroughly and, if an attraction of special interest is discovered, permit you to return later, on your own, to spend adequate time there. As such, I strongly recommend these for autistic travelers and tourists. Such tours are available in almost all major cities, in most smaller cities and significant towns in Europe, and in just about any popular U.S. destination. Although not nearly as good, many places also offer a so-called "multimedia experience" that serves a similar purpose - these may be worth your while as well.

For most autistics, however, I suspect that individual exploration is probably the best way to visit any destination for which doing so is feasible. Since we tend to have very strong preferences not just in what we do but how we go about doing it, we are usually better off being independent and enjoying things on our own terms.

#### Other Considerations

There are numerous other issues that autistics need to consider when traveling that are of little or no concern for the typical tourist. These can involve personal routines or, especially, sensory sensitivities. The autistic traveler needs to take these into account, preferably before embarking on any trip; this is especially true for travel outside the U.S. The very idea of an autistic person being forced to endure a major unanticipated sensory violation is nothing short of frightening and, as such, should be avoided at all costs.

As it happens, my most significant sensory issue has always involved severe selective eating – to this day, I largely eat the kinds of foods that are found on a "children's menu." This is now recognized as ARFID (avoidant/restrictive food intake disorder – more common in autistics than previously thought), and I also have lived with food neophobia and perhaps even mild food aversion my entire life. This can certainly become an issue when traveling to any place where unfamiliar or (worse still) unpreferred foods are the norm. Apart from the fact that we all need to eat, culinary exploration is a major reason for many people to travel, and culinary tours of just about any world destination have become more popular than ever. Clearly, this is not the case for me or for any autistic person who lives with this issue.

I learned to deal with this problem by studying menus very carefully before going to any eating establishment. In particular, at least in the U.S. and Europe, children's menus have become more common - I can always find something suitable to eat. Furthermore, by looking at the children's offerings, I occasionally found something unfamiliar or new that I was willing to try. This is as close to culinary travel as I will ever get! I also came up with the idea of having a local beer, wine, or other indigenous adult beverage with my meal. This gets me into the spirit (no pun intended) of the locale and mitigates potential misunderstandings that my peculiar diet in any way reflects feelings about the local culture.

Another common sensory issue that I have always had is clothing sensitivity. Fortunately, it is completely acceptable for a tourist, presumably on vacation, to wear very casual attire. It is probably a good idea for many autistics to do so as well.

Finally, I have discussed only U.S. and European travel, which takes place within the developed and industrialized world where all the amenities that we are accustomed to are the norm. Travel to other locations, particularly in the developing world or locations where amenities are different, involves even further considerations for an autistic person, especially if traveling independently (I have not done any of this myself). Such travel needs to be considered and planned even more carefully than what I have described. Also, unless one is very familiar with the destination (e.g., has family or friends who live there and can serve as hosts), it is probably best to undertake such travel as part of an organized group.

In conclusion, autistic individuals have numerous considerations that the typical traveler does not. This, however, should not deprive the autistic community of the experience of travel. In many ways, it is as valuable an experience for us as it is for anyone else; in other ways, the personal experience can be very different. Perhaps the availability of organized tours and travel services that cater specifically to autistics might be of value to our community if such could ever be provided.

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sole responsibility for our own disabilities, and when we begin to view our neurotype as naturally occurring within the umbrella of neurodiversity, it becomes easier for autistic individuals to establish a strong sense of self no matter what challenges we face. In my experience, nothing matters more.

Change doesn't just happen when somebody needs or asks for it to happen. It must be fought for and requires a prolonged, "all hands on deck" team effort in order to take hold and last. This is how the neurodiversity movement works to affect change at the societal level, working to flip the prevailing narrative around neurodivergence. And, this is how I fought for change deep inside myself as I figured out how to conquer my own internalized ableism and finally achieve self-love. Hard-fought and involving small steps forward over a long period of time. Neurodiversity helped me get there.

# Neurodiversity, My Parents, and Psychological Safe Spaces

Long before Judy Singer coined the term, my parents were raising me in a neurodiversity-affirming fashion. They accepted me for who I was and never treated me as if I were disordered or broken and in need of repair. They were well aware of my sensitivities and vulnerabilities and took these into consideration while parenting



#### Sam Farmer

me. They celebrated my accomplishments, supported me without judgment when I would fall short, set realistic expectations for me, and provided constructive criticism when they felt I could use it. In short, our home was a psychologically safe space within which I could be true to myself without adverse consequences. In retrospect, my then fragile sense of self benefitted greatly from their parenting style.

Whenever I come across stories in books and in social media posts about toxic environments that pathologize neurodivergence and, in so doing, become psychological danger zones, I am reminded of how blessed I have been with respect to the kinds of environments and people with whom I have had the privilege of associating over the course of my life. Perhaps an infusion of the neurodiversity paradigm could help transform such danger zones into the kinds of safe spaces in which I am most grateful to have found myself. This is why I advocate for neurodiversity, wanting to help others in my community who haven't been as fortunate as I have been.

#### We Are Not All "A Little Autistic"

One of the more hurtful stereotypes against which the neurodiversity movement has been fighting for some time is the "but we are all a little autistic" stereotype. Not only does it undermine the fact that autism is a unique neurotype among the many that comprise humanity, but it also invalidates those of us who view our autism as an identity, a "way of being" which sets us apart.

We are not all "a little autistic." Some people are autistic, and some are not. Full stop!

Instead, society should be affirming our shared humanity, in all of its diversity, and bound together by our commonalities. Autistic individuals, including me, contribute to this diversity by sensing, processing, and responding to the world around us, communicating, thinking, and learning in ways that distinguish us from the non-autistic majority. And yet, we are equally as human as all other human beings:

- All of us have red blood flowing through our bodies.
- All of us would prefer not to be stigmatized or marginalized.
- All of us would rather not feel alone in the world.
- All of us contend with challenge, hardship, and adversity.
- All of us feel pain.
- All of us want to be treated with kindness, decency, and respect.
- All of us want to be accepted for who we are.
- All of us want to love and be loved.
- And all of us join together under the unifying umbrella of neurodiversity!

Sam Farmer is a neurodiversity community self-advocate, writer, author, and public speaker. Identified later in life as autistic, he shares stories of lived experiences as well as ideas and insights as to how one can achieve greater happiness and success in the face of challenge and adversity. A Long Walk Down a Winding Road - Small Steps, Challenges, & Triumphs Through an Autistic Lens is his first book. Visit samfarmerauthor.com to learn more.

#### Real Boys from page 25

homophobia, antisemitism, Islamophobia, transphobia, or other fears that stoke violence toward others are all rooted in insecurity and fear. Boys and men who cannot cry or show compassion to others different than themselves are not the brave ones. They are insecure and fearful. The strong ones who have caring feelings toward others can work and fight in a different way—not through mockery, hurtful words, or physical violence. Instead, we can stand strong to demand and work tirelessly for social justice and peace.

The disability rights movement has been built on the principles of the Civil Rights Movement, which include nonviolence and working within institutions to promote liberty and equality for all. Many of us, as adults, are concerned about potential rollbacks to the rights and protections that have been hard-won for our children. For the sake of our children, we must continue to move forward.

As Martin Luther King, Jr. said, "The time is always right to do what is right." VOTE and tell everyone you know how

important it is for our children.

This article was originally published on August 30, 2024, here and has been modified for publication in Autism Spectrum News.

Robert Naseef, PhD, is a clinical psychologist, author, and parent of an adult son with autism. He is the co-facilitator of a fathers' support group at the A J Drexel Autism Clinic. He serves on numerous boards and blogs regularly at drrobertnaseef.com.

#### Artists with Autism from page 24

"It was kind of a call to action to talk to people about it because I knew that it was a private struggle for me to get through," said Bunting. "So I talked to more people about it, finding out more about what was happening. I talk to others who live with it, too, so they don't feel alone."

Coming to terms with who he is also gave Bunting the mindset to tackle the unimaginable. Two years ago, he was given the opportunity by the U.S. Department of Defense to photograph Earth and an accompanying Lockheed U2 spy planefrom the edge of space. In April 2023, he spent five hours capturing images no other professional photographer had ever seen through a viewfinder. As a tribute to his father, he used the Nikkor 50mm lens from his original Nikon F. Many of those images were first displayed at the 2023 First Place Global Symposium in Phoenix, Arizona. Some are destined for display at the Smithsonian National Air and Space Museum in Washington, D.C.

Neilson's life also took on a new trajectory. In 2017, he left his teaching position and now focuses on his imaging and studies of public spaces. His statistical background and lifelong passion for pho-



#### **Tom Ortega**

tography have converged to form a single language he hopes will help shape a more inclusive future.

"I use statistics to identify what I assume has the biggest visual impact," said Neilson as he explained his refined technique. "The way I am combining the frames is using the statistical technique of finding the minima and the maxima. Finding the one most different from the average—that's the bit that ends up in the composite."

Neilson's camera has also had another impact. "The camera is like looking through a shield with a hole in it," he said. "I feel safe behind a camera. I'm not feeling the stress while I'm doing it. I take pictures of people walking and using pedestrian crossings in the busy city center. It's not a place I'd sit down on my own, but when I have the camera there, I feel a sense of comfort."

This is something he shares with Bunting, who also escapes behind the camera. "The camera is a state of mind," said Bunting. "On set, it's my comfort zone. As my daughter would call it, my safety blanket. It lets me be a little bit more expressive and comfortable—not only with the situation around me but with who I am."

Bunting also finds refuge along the train tracks near his Flagstaff home. In the award-winning 2023 documentary "Sound Tracks" that features him and Nadine, he explained, "I'm out here [the train tracks] because it's peaceful; it allows me to breathe a little bit better." When he's not photographing priceless car collections or world-class athletes, he's watching and shooting freight trains two to three days a week for up to three hours at a time. "I take seven or eight cameras, different ones, to the tracks, depending on how I feel that day," he said. Many of these images were also part of his 2023 Symposium exhibit.

From the tracks and the sets, from the classrooms and the performance halls, from the bustling city center and markets of Cork City, the conversations continue. Laura Nadine, Blair Bunting, and Stuart Neilson are expressing their true selves—through music, photography, and purpose-ful living.

Nadine provides the perfect coda: "If you want me to put together a resume that expresses who I am, it's going to be very shortsighted. If you let me put together a musical piece that expresses who I am, you'll get to know me much better."

Laura Nadine, Blair Bunting, and Stuart Neilson will be participating in the 2024 First Place Global Symposium, October 16–18, in Phoenix, Arizona.

Tom Ortega is Director of the Mulzet Center for Expression at the First Place Global Leadership Institute. He is an artist and a community activist living in Phoenix. He can be reached by email at tom@firstplaceaz.org or via phone at 602-502-9354.

#### Zoning from page 27

disparities (Massey & Rothwell, 2009). Such practices can unintentionally exclude individuals with disabilities and those with lower incomes from accessing adequate housing and community resources.

The costs associated with these modifications can also deter developers, limiting housing availability for people with disabilities. In cities like San Francisco, studies have shown that increased inclusionary zoning requirements can negatively impact property sales and construction activity, potentially worsening housing shortages (Bertolet & Durning, 2017).

Lengthy rezoning processes taking several months present another challenge, creating uncertainty for developers and discouraging investment in projects that could benefit neurodiverse communities. Zoning codes can also inadvertently restrict necessary modifications or housing arrangements for people with disabilities, necessitating a balance between regulatory compliance and inclusivity goals.

Legal challenges, such as Austin v. Town of Farmington, further illustrate the complexities of ensuring equitable treatment under existing zoning laws. This case highlights the tension between individual needs for reasonable accommodations and broader community concerns about zoning regulations, emphasizing the need for continuous legal and policy scrutiny.

Other obstacles include lengthy rezoning processes that create uncertainty for developers and discourage investment. Zoning codes can also inadvertently restrict necessary modifications or housing arrangements for people with disabilities. Addressing these issues requires a careful balance between regulatory compliance and the goal of fostering inclusive communities.

#### Promising Practices to Support Inclusive Communities

Despite these barriers, several promising practices demonstrate how thoughtful zoning can create more inclusive environments. Transit-oriented development (TOD) is one approach that focuses on building neighborhoods around high-quality public transit options, making it easier for residents to access essential services and amenities (Transit-Oriented Development, 2024). For example, First Place–Phoenix Apartments are designed to provide residents with proximity to transit, retail, and recreational facilities. By integrating residential spaces with public transit, TOD enhances accessibility and supports the needs of neurodiverse individuals.

In Austin, Texas, incentive-based zoning strategies have successfully integrated therapeutic facilities into new developments (City of Austin, 2023). Developers who include therapy centers offering applied behavior analysis (ABA) therapy for individuals with autism can benefit from expedited permitting, density bonuses, and financial incentives. These measures promote mixeduse developments that address both housing and healthcare needs, making essential services more accessible to residents.

Mesa, Arizona, stands out as a leading example of an autism-friendly city. As the first autism-certified city in the U.S. as designated by the International Board of Credentialing and Continuing Education Standards (IBCCES), Mesa has implemented initiatives to make public spaces more accessible, including sensory guides



The Daniel Jordan Fiddle Foundation Adult Autism Public Policy White Paper by Chenchen Zhang

for attractions and the Hidden Disabilities Sunflower Program, which assists individuals with invisible disabilities (Haas, 2023). Mesa's approach demonstrates a strong commitment to inclusivity and ongoing community engagement.

Streamlining Zoning Approval Processes

To further support neuro-inclusive communities, cities should consider streamlining zoning approval processes. Simplifying applications, creating online portals, and reducing bureaucracy can improve efficiency and encourage developers to invest in inclusive projects. Collaborating with planning professionals and community stakeholders is crucial to ensure that updated ordinances reflect current needs and goals.

#### A Call to Action

Creating inclusive communities requires a concerted effort by cities, local governments, and stakeholders to implement promising practices in zoning and urban planning. Municipalities should regularly review and update zoning ordinances to avoid unintentionally creating or sustaining barriers that hinder the development of housing for adults with neurodevelopmental disabilities. On a statewide and federal level, governments can incentivize inclusive zoning through grants, policy guidance, and funding for accessibility initiatives. By embracing these changes, we can build a more equitable and supportive future for all residents, particularly those with developmental disabilities.

Chenchen Zhang delves into how zoning policies shape housing for individuals with ASD, aiming to identify ways to create more inclusive communities. Her work highlights the role of zoning regulations in supporting or hindering autism-friendly spaces and proposes policy changes for greater inclusivity. Through her research, Zhang seeks to improve living environments for individuals with autism, embodying a commitment to public service and advocacy for marginalized communities.

For more information about The Daniel Jordan Fiddle Foundation, visit djfiddlefoundation.org. For more information about the First Place Global Leadership Institute, visit firstplaceglobal.org. To contact Chenchen, email chenchen@firstplaceaz.org.

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Graphic from Chenchen Zhang's White Paper

#### Culture Change from page 26

she would have criticized Singer for being too soft...

And then there are topics that are very uncomfortable to Americans, like sex. Some people with disabilities don't have the use of their hands. Well, how do they accomplish the task of pleasuring themselves without help? Such an examination really challenges our prior perceptions of both sex work and privacy itself. Going further into actual sex, I'm proud to have written the autism world's "biggest, fattest, sex book," and I often think of an example I came across wherein two physically challenged people living in an assisted residential space wanted to have sex with one another in full consent...Well, what if they needed a third person to push their naked bodies together?

These are loaded questions that we, as Americans, and not just the disability community, have to become more comfortable talking about. By avoiding them and giving in to our cultural discomfort, we don't just cause suffering; we run from the stories and narratives that could be the pinnacle of diversity and of humanity at its most beautiful.

#### Conclusion

Fifty years is a long time. What I've asked for thus far really isn't much. As a matter of fact, with the exception of money spent to make all our structures accessible to all, I've been asking for us to trash what we don't need...infinitely more than I've been asking for anything new.

And while a large number of Americans are anything but behavioral pluralists, few of us are true behavioral bigots. I'd argue there'd be little to no objection if most neurodiverse conditions were simply thought of as natural extensions of the human experience in these 50 years.

I am asking us to extend more energy and thought into how badly we still play these cards we've been dealt. As we all know, even the nicest and best-intentioned of us can be biased. For example, how many large Diversity & Inclusion departments in universities and corporations actually address disabilities? Usually, these are race and gender equity departments that should be praised for their work but condemned for the gall to call themselves Diversity & Inclusion departments.

Our ideas about inclusion are, at best, in their infancy.

# I am Autism' commercial. Autism Speaks, 2009 \*\*\* And there is a parlor trick wherein the characteristic can be spun as subliminal.

Once upon a time, there were campaigns that depicted disabled individuals like this Nazi propaganda poster, depicting the kinds of "defectives" who ended up as victims of the T4 involuntary euthanasia program.

YouTube

Some disabled people have faces that rest or relax on different expressions.

And there is a parlor trick wherein this characteristic can be spun as subliminally equating to demonic possession. It's a tool used to raise money or to scare (that fear of the unknown again). The still-standing Autism Speaks, as evidenced by the following photo, employed this tactic in their ghastly video, "I Am Autism," as recently as 2009.

Mel Baggs (1980-2020) (who used the



Photo: Mel Baggs. Used with permission.

pronouns "Sie" and "hir") was one of our earliest heroes in the autism world. Sie was a non-verbal spectrum person who communicated and regularly blogged (as "ballastexistenz") through a keyboard.

In response to a similar (and shortlived) campaign by the Autism Society of America, sie posted the following picture of hirself.

Mel then wrote the following:

'This is what I look like when I'm trying to relax, or zone out a little, or shut off vision so that I can hear what is going on around me. I have no doubt that someone could use this image to show the tragedy and despair inherent in autism...Blackand-white images such as these, and the captions that go along with them, are designed to create a reaction. Most often, disability organizations, run by non-disabled people, use them to elicit pity - and money, at the expense of the truth. Look at the autistic person in her own world, they say. Isn't it tragic? What I am doing in this photograph is no different than someone curling up with a good book to unwind after a long day...Some autistic people would even say that it's bad to publish pictures that look like this. Better to publish the ones that make us look like real people. Those are the better pictures...I say that plays straight into the hand of people who think there's something wrong with the way we look.'

What does this say about the unhealthy needs of the "abled"?

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Delray Beach, Florida Addiction and Recovery Therapist Individuals, Couples and Families

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# Autism Spectrum News Update

AutismSpectrumNews.org

Subscribe to receive the bi-weekly ASN Update newsletters featuring even more autism education, information, advocacy, and resources!

#### Autistic Elders from page 27

There was no contact, so helpers sent the police for a wellness check. Many different people showed up wanting things that didn't make sense to the elder, with no one comprehensively explaining why. The more stress put on the situation, the less capable the elder appeared. They had nowhere to regulate or feel safe as the home felt "invaded." Administrators were ready to send them to the hospital for evaluation or nursing home care.

Luckily, someone noticed that the elder was autistic, knew what that meant, and sought consultation. A different approach helped the elder to regulate and regain a sense of control. Once everyone slowed down and understood, the tension eventually eased. But it was months of (unintentional) harm by well-meaning professionals. It took a long time to recover, and the memories will linger as yet another negative influence in the elder's world.

As the above story relates, typical, well-meaning service can complicate an AE's experience, create a highly anxious situation, and lead to lasting harm. The story demonstrates that common methods of interaction, assessment, and treatment didn't accurately capture the needs of the AE. Providers must ally with their AEs, always presume competence, and work together to understand their lived experiences. Becoming culturally competent will lead to more accurate reporting and appropriate treatment.

Another reliable way to avoid unintentional harm and be aware of effective, appropriate treatment is to understand "intention." Non-autistic people tend to function on schemas common to their experience and behave in automatic ways. Schemas develop gradually and largely out of awareness. They don't require much thinking. Such "coding," however, often bypasses intentionality. In striving to become more intentional, consider these po-



Mary P. Donahue, PhD

tential barriers to appropriate treatment, as informed by AEs:

**Low or No Support** - Many AEs have little to no outside support. Their parents have passed, friendships were scant, to begin with or suddenly lost, and communities often disregard the old. Private pay care is expensive, and many autistic people are of a lower socioeconomic status.

**Health Care Self-Efficacy** - The AE is often unaware of internal body sensations like pain, hunger, and emotion. Because the AE may not be aware of decreases in muscle mass, energy levels, or hearing, they expect to do all the same things they've always done; they often rigidly cling to schedules, foods, and duties. When the body fails, the AE may not understand why they can't or shouldn't do as they've always done.

Aging at a More Rapid Rate - Autistic people can age at a faster pace and have poorer health outcomes (Mason et al.

2021.) Aging may also begin to accelerate more for autistic people by age 65, with aging symptoms presenting even more heterogeneously than at earlier ages (Torres et al. 2020.)

**Patient/Provider Communication** - AEs may not have access to or training on digital devices, so they can't navigate patient portals. As well, telephonic communication may be highly uncomfortable and complicated by hearing problems. Processing speed needs consideration, too, as providers are often in a hurry (process fast), while the AE takes more time to put things together. Also, as autistic individuals, in general, tend to have organization challenges, AEs may need specific ways of being reminded of appointments or greater latitude for missing them.

**Masking** - Autistic people learn to mask at very early ages to fit in and feel safe. Consider the many environmental aspects of caregiving, such as using a consistent room, low lighting, no smells, talking more literally, and less hand movement. The more predictability the elder has, the safer they feel. (50 words)

**Diagnosing Instruments** are not normed on AEs. Often, questionnaires, information sheets, and interviews are understood much differently than intended. For example, the pain-level scale of 1-10 can send the autistic brain into great discomfort as, for them, there are too many ways to interpret the question. Engaging with their ecology and perception can make all the difference.

**Safety and Trust** are of constant concern for the autistic person, and as they age, with body and neurological changes, that safety can easily decline. It might be important for them to attend the first few appointments with a trusted person but have a provider who still presumes the elder's competence. This is where heterogeneity affects competence, and the more the provider knows about how to empathize with the AE, the more successful the outcome. This will take time.

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#### Self-Discovery from page 26

stabilize a situation before a professional arrived. I remember how often I felt dubious about these courses beforehand and how often they seemed useful later.

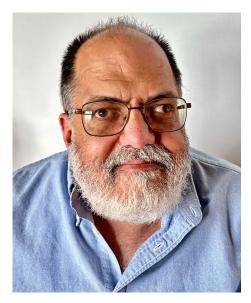
Even after I was let go from the peer support center, along with much of the staff, due to the start of the pandemic, friends suggested resources in the community like Personalized Rehabilitation Orientation Services (PROS), which offered courses to qualifying people on the spectrum and other mental health consumers, including various Dialectical Behavior Therapy (DBT) courses, yoga, employment discussion and counseling, and more. Other supports that I have taken advantage of and have been invaluable include New York Self-Direction services and supports, job coaches, and people willing to provide organizational and food-related support.

It was a combination of advice from a friend - about my having left a theatre in a huff and better solutions to similar problems - and some of these courses that have had me rethinking some of my common patterns of behavior. I have come to notice my passive or passive-aggressive tendencies and have begun to find ways to identify and hopefully improve my behaviors.

I still have a strong temptation to give my ill-at-ease younger self some advice. His impulse was to push through, to not make a scene, to do the best one could without asking to go home, if that even came to mind as a solution. In fact, holding it in, or else leaving in a huff was a pretty good description of what was wrong with my approach in those days, and it took me over a decade to have a good look at that. In that particular situation, if no one can drive me home during intermission and it's too dark to find my way home, at worst, I can sit and rest in the lobby, which is no bad option.

It's good to receive help, but it's even better to learn to identify what exactly you want or need, what help you feel comfortable asking for, and how best to go about getting it. This requires understanding I don't believe I had at the time, but with the help and support of friends, family, and professionals, I have a better insight into my own needs, and how to go about meeting them.

Eric Schissel has a Master's Degree from Cornell University. He currently works part-time editing articles for Mental Health News Education, publisher of Autism Spectrum News and Behavioral Health News.



Eric Schissel, MS

#### Full-Time Employment from page 25

urge you to move on! Quit and find the true career path you are looking for.

All in all, full-time employment can have complications, and at times, it can

make or break a person. What is important to know is that any experience, good and bad, has meaning. Even if you have a bad experience, you have the means to search for something better. It will take time, but it is out there. Take in the lessons, know what works for you and that is where you will shine the most.

Andrew Arboe is a self-advocate currently employed at FOCUS Center for Autism. He also runs a freelance website called Andrew Arboe: Autistic Self-Advocate and Speaker where he provides public speaking services to organizations. For more information about Andrew, please visit andrewarboe.weebly.com. To contact him, email arboea@gmail.com.

#### Autism BrainNet from page 28

(Avino et al., 2018). These types of studies, and ones that can't even be imaged now, will increase in number as post-mortem brain tissue becomes available to researchers and will undoubtedly lead to a far better understanding of the biology of autism.

How Does Brain Donation Work?

The time to learn about and make plans for brain donation isn't at the time of crisis – it's an idea that needs to be considered before the end-of-life is imminent. At Autism BrainNet, we strive to minimize the stress of decision-making by clearly outlining the steps required to ensure that each donor's decision is respected. Even if you contact Autism BrainNet to learn about the process, there is no commitment. Brain donation is entirely voluntary and is cost-free.

Here are the steps you need to take when considering brain donation with Autism BrainNet.

- 1. Learn More: Our website provides comprehensive information about Autism BrainNet and our work to facilitate autism research through brain donation. We also share the stories of families whose loved ones became donors and why they made the decision to donate.
- **2. Call Us:** We maintain a 24/7 telephone helpline to answer families' questions and/or arrange for a brain donation. In the case that the decision has been made to make a donation, we encourage people to call 877-333-0999 when death is



Marta Benedetti, PhD

near or has occurred for immediate assistance. Autism BrainNet clinical staff will work with the legal next of kin to provide and facilitate the process stepby-step. Though state laws vary, the legal next of kin is usually a health care agent (if named), spouse, adult child, parents, siblings, and then increasingly distant relatives based on local laws. In the case of minors, parents are typically recognized as the legal next of kin.

**3.** Let Us Handle Coordination: After Autism BrainNet gets permission for a donation, we work directly with the hospital or medicolegal individuals to coordinate the donation and ensure the donation is safely transported, preserved, and stored for future use.

4. Lean On Us For Support: After do-



David G. Amaral, PhD

nation, a clinical with Autism BrainNet will follow-up with the donor family to answer questions and provide support. They will also gather additional medical, behavioral, or family history to inform future research.

To preserve the scientific value of the brain tissue, a donation should be received as soon as possible after death (24-48 hours is optimal). That's why it is important to understand the process ahead of time. There is no cost to families working with Autism BrainNet, and brain donation does not interfere with a family's autopsy or funeral plans.

Why Should You Think About Brain Donation?

Amidst the grief of losing a loved one,

# AUTISM SPECTRUM NEWS ~ FALL 2024

we often hear from families that working with Autism BrainNet helps keep the memory of their loved one alive and builds on the legacy they leave. They tell us that they believe that donation is a positive and a comfort at the time of a loss. Autism BrainNet accepts post-mortem brain donations from people with a diagnosis of autism, even when other diagnoses are present, from people with a genetic diagnosis associated with autism, whether or not they have a diagnosis of autism, and from neurotypical people. If you want to learn more about Autism BrainNet, please visit our website at AutismBrainnet.org.

David G. Amaral, PhD, and Marta Benedetti, PhD, are Directors at Autism BrainNet.

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#### Advancing Research from page 28

winter on topics related to the needs of adults with ASD - these include talks on medical and mental health issues, social skills support, dating, romantic relationships, and recreational skills supports as well as behavioral and legal issues as well as the with use of technology support and vocational issues and lastly dealing with environmental sensitivities. This series of talks is designed for practitioners, parents, and adults with ASD. Many of these speakers have contributed to a recent book edited by me and several colleagues on the topic of adults with ASD (Volkmar, Reichow et al., 2024).

On the one hand, it has been a source of tremendous gratification to see the improving outcomes for many individuals with ASD, who are now much more fully included in our communities and daily lives. On the other hand, it's also frustrating that so little of what we know has been accurately transmitted. Hopefully, this series of talks and the growing attention paid to the needs of adults will begin to address this important topic. Here is a link to register for our new workshop series: southernct. edu/owll/adults-with-autism. We hope you will join us!

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#### Evaluation Process from page 29

- Congenital infections
- Disorders secondary to exposure to toxic substances, including fetal alcohol syndrome, etc. (EITA, 2024a)

According to EITA, there may be a child who is referred to the Infant/Toddler Early Intervention program who may be considered "at risk" for developmental delay. If the child meets at least one of six at-risk categories, they are eligible for "tracking:"

- Low birth weight (under 1500 grams)
- Cared for in a hospital neonatal intensive care unit (NICU)
- Prenatal substance exposure, including alcohol
- Referred by a county children and youth agency
- Exposed to lead
- Experiencing homelessness (EITA, 2024a)

There is a shift in the assessment process when the child reaches preschool age. Preschool age is defined as from 3 to the beginning of school. States vary in the age upon which school attendance is compulsory. This is usually at the age of 5 or 6 years old. In PA, the Informed Clinical Opinion of the assessment team can no longer be used to determine eligibility. The second significant difference from the Infant/Toddler system is that the assessment team can no longer consider a diagnosed physical or mental condition which has a high probability of resulting in a developmental delay as an automatic path to eligibility for services. Instead, eligibility is a two-pronged approach in the Commonwealth of Pennsylvania. To qualify for special education services under IDEA, both prongs must be satisfied. A preschool child is eligible if they score 1.5 standard deviations below the mean on the standardized measures described above or by being identified as a child with a disability as defined under IDEA. Under IDEA, a child is eligible for special education services if they are determined to have one of 13 disability categories, with autism being one such category. In Pennsylvania, the Preschool child must also satisfy the second prong of eligibility. The child must need special education and related services to be eligible for early intervention services (OCDEL, 2013). Further, the child's presenting needs must impact their 'ability to participate in developmentally appropriate daily routines and activities' (Commonwealth of Pennsylvania, P.42-43). Unlike the determination in the Infant/Toddler system, the assessment team may NOT use Informed Clinical Opinion to determine eligibility for early intervention services.

Under the Individuals with Disabilities Education Act (IDEA, 2004), the 13 disability categories are:



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- 1. Intellectual Disability
- 2. Hearing Impairment
- 3. Speech and Language Impairment
- 4. Visual Impairment (including blind-ness)
- 5. Emotional Disturbance
- 6. Orthopedic Impairment
- 7. Autism
- 8. Traumatic Brain Injury
- 9. Other health impairment
- 10. Specific Learning Disability
- 11. Deafness
- 12. Deaf blindness

#### 13. Multiple disabilities (34 CFR § 300.8)

For parents in the Philadelphia and the City of Chester – Upland catchment areas, the process of determining eligibility for Early Intervention services begins with a call to Elwyn's Intake Center. Here, the coordinators will ask a series of screening questions of the parent or guardian about the types of concerns they may have about a preschool-aged child. The coordinator will refer the family to the Behavioral Health Division or the Early Learning Services (ELS) Division. The family is sent a Permission To Evaluate (PTE), and an evaluation is scheduled with one of our Multi-Disciplinary Evaluation (MDE) Teams. At intake, the coordinators determine if English is the primary language spoken in the home or if the family needs a translator at the meetings: the evaluation is to be conducted in their primary language, and subsequent documentation & paperwork are to be translated into their primary language. The families are sent information regarding procedural safeguards and rights to privacy under the Family Education Rights Privacy Act (FERPA, 1975)

The Multi-Disciplinary Evaluation (MDE) teams consist of a variety of pro-



George "Brandon" Gordon, EdS

fessionals, including Speech and Language therapists (SLPs), Occupational Therapists (OT), Special Education Instructors (SI), etc., who will assess your child in several domains. Depending upon the nature of the concern, not all the professional team will participate in the evaluation. The teams will assess your child in 5 domains, including cognitive, communication, social-emotional, physical development, and adaptive behavior, using standardized tests such as the Battelle Developmental Inventory 3 (BDI-3) or the Developmental Assessment of Young Children, 2<sup>nd</sup> Edition, commonly referred to as the DAYC 2 as well as other measures and qualitative observations. DAYC 2 is a norm-referenced assessment. In other words, your child's score is compared to a group of representative children (EITA, 2024b). As part of a standardized assessment, the team may present tasks and/or directions to your child. These assessment items are done in the same way for each child tested. Further, families and caretakers are often required to respond to standardized interview items that help capture children's developmental skills that may otherwise be difficult to capture through assessment items and/or be difficult to have an opportunity to observe. (Newborg, J., 2020, P. 43). Norm-referenced tests are useful in determining eligibility. However, they are not the complete picture of your child. Teams must use a variety of approaches such as parent and/or teacher interviews, direct observation of the child in play and/ or their natural environment, and review of any relevant records, including but limited to medical diagnosis. The team will also use criterion-referenced assessments, which measure whether the child has accomplished a certain set of skills. These tools are useful in planning educational interventions.

The MDE teams will use other normed and criterion-referenced assessments, depending on the area of concern. When autism is suspected, the team may opt to use the Autism Diagnostic Observation Schedule 2<sup>nd</sup> edition (ADOS-2), the Child Autism Rating Scale 2 (CARS-2), or the Autism Diagnostic Interview-Revised (ADI-R). After the evaluation meeting occurs and all the assessments have been scored, the MDE team presents its findings to the family in a separate meeting later. The MDE Team explains to the family why their child qualifies for Early Intervention Services. As a team, with the parents as equal team members, the group develops an Individualized Education Plan (IEP) outlining what kind of services the child will receive, in which setting, how frequently, and provided by whom (which professional discipline). Conversely, it is also the team's responsibility to explain to families why their child is not eligible for special education services as a part of Early Intervention. In addition, they will offer recommendations and referrals regarding where to receive support for their child who is not a part of the special education system. Parents have the right to disagree with the results of the evaluation or the team's recommendations. They also have the right to request an Independent Educational Evaluation (IEE).

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The Family Rights Educational Rights and Privacy Act (FERPA). (20 U.S.C. § 1232g; CFR Part 99)

#### International Travel from page 30

"travel agencies for people with disabilities," "accessible group tours," "international travel and autism," and related terms that fit your interests and background.

When planning to travel, it's important to consider the ways in which life abroad, even for short stretches, will be different than life at home. Planning ahead for these differences will minimize their impact and maximize enjoyment. Here are some things to plan ahead for:

**Physical accessibility:** Countries have varied laws about physical accessibility to public transportation, landmarks, hotels, restaurants, etc. It's important to research the places you want to go. When traveling with a group, make sure the group leader or travel coordinator understands any accessibility features you need. Think about airplanes, buses, boats, trains, and other methods of transit that could be involved, as well as the pace and distances you may be expected to manage each day.

**Food sensitivities and allergies:** It's not always easy to get allergy-sensitive meals in other countries, especially if you don't speak the language. If you have a serious allergy or sensitivity, in addition to the usual precautions you would take at home, carry a note card with you that explains your allergy in English and in the local language of the place you are going so you can show it to food service workers, or have a free language translation app ready to help you communicate. Make sure fellow travelers, especially group leaders, are aware of your allergy.

Other health considerations: Talk to your doctors about upcoming travel plans to find out if there are any vaccines or other precautions needed, and share important health information with group leaders as appropriate in case of emergency. Bring a wallet card that explains any serious medical conditions and lists your medications and dosages in English and the local language. Bring overthe-counter medications and hygiene products you use often; products abroad may be very different or hard to find. If you take prescription medications, consult with your provider on how to adjust the time you take them for any time change you'll experience. Bring extras of your medications with you and carry your meds in your carry-on luggage, if possible, to avoid them getting lost in transit. Finally, make sure to look up rules for bringing prescription medication into the country you're traveling to.



An Embark Inclusive Travel tour group at Nijyo Castle, Kyoto, Japan

Changes in routine: The value of traveling is as much about the experiences you can't predict as about the ones you've carefully planned out. If that thought gives you some anxiety, fear not. Routines are important, and there's no question that traveling disrupts those routines. Prepare yourself by previewing some of the possible changes, e.g., "The schedule for the day will be different than it is at home." "The food is going to be different than what I usually have." Knowing some of the changes in advance, even without being able to predict exactly what the experience will be like, can help the changes feel more manageable. It can be comforting to also think about what will stay the same: "I'll still have my headphones and music with me." "My cell phone plan will work there, so I can contact people back home."

**Communication:** Many language translation apps are free, let you type and speak into them, and give you both text and audio in the local language that you can show or play it for locals when needed. It's also becoming easier to use US cell phones and data plans in other countries, letting you stay in touch with loved ones and also contact local emergency services, a group leader, or your hotel front desk if you need help. Travelers worried about their ability to communicate their needs can also look into whether their destination participates in the Hidden Disabilities Sunflower network.

**Money:** Budgeting for daily expenses is hard, especially when using a different currency than you're used to. Downloading a

currency exchange app on your phone can help you understand what you're spending. Buy a small amount of local currency from your bank in advance and put a travel flag on your accounts for any debit or credit cards you are bringing that require one to avoid issues abroad.

**Packing:** Pack light and only bring what you can easily manage on your own, but do bring things that make you comfortable. Understanding your daily itinerary and the weather will help you to pack appropriately. Make sure to look up airline regulations for carry-on vs checked luggage, and follow TSA rules for liquids/gels/creams to minimize disruption at security. If traveling with a group, consult with the group leader about what to pack and how to pack it. Make sure to leave room in your suitcase to bring back souvenirs!

**Preparing to fly:** Fear of flying can feel like a major barrier to international adventures, but treatment can help. Accessing psychotherapy or therapeutic flying desensitization programs in advance can help you learn coping strategies to reduce and manage anxiety. Travelers can also minimize sensory overload in airports and planes by wearing sunglasses, brimmed hats, noise reduction headphones, and layers for assorted temperatures, and by including comfort items and familiar snacks in their carry-on.

**Get excited:** International travel is a big commitment of time and resources, so make sure you're headed for a destination you're really excited about. Take time to

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do some online research about the place you're going so you can understand and appreciate what you see. Celebrate yourself for making it happen!

Not convinced yet? These seasoned travelers are happy to share what they love about exploring the world:

"I feel like I'm living an adventurous life when I travel!" - Leslie, age 45

"I travel because I love to learn about the cultures of other countries. I feel independent and enjoy meeting new people. Traveling in a group makes me feel safe and secure." - Brandon, age 33

"What I like about traveling is it's a true adventure; you never know what you're going to see, you never know what you're going to run into, or what things will happen along the way that may be interesting." - Victor, age 39

"The reason I love traveling is because it is a wonderful experience for new adventures and seeking new experiences." - Olivia, age 32

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#### We Can Mask from page 32

not upset the other person.

What we need is the understanding that just because we are on the Autism Spectrum and everything appears well does not mean that we do not have support needs. I think one thing that others can do is to ask autistic adults if they know "How are you doing?" and if there is anything upsetting them or that they need help with. One thing that goes a long way is telling autistic friends and family, "I love you," "I care about you," or something similar to that, to let them know they are valued and wanted and not seen as disposable. I can personally say it took me a long time to realize people actually wanted to be my friends and were not doing it out of a feeling of pity or obligation.

So, if you have an autistic adult in your life, whether a friend, family member or something else, let them know they are appreciated and have value in your and others' lives. Ask them if there is anything bothering them that they might want to speak about or that they need help with. Just always remember just because someone can mask or "appear normal" does not mean they do not need help.

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#### Career Pathways from page 32

than social interaction, jobs within the technology or IT sectors, such as software development, data analysis, and cybersecurity, could be well-suited to autistic individuals (Palumbo, 2022). Many autistic people do super well at performing tasks that require attention to detail, pattern recognition, and problem-solving, all of which are key components of these jobs (Crespi, 2021).

<u>Challenges</u>: The challenges autistics might face in the sector, depending on what they struggle with the most, include tight deadlines, a high-pressure environment, and sometimes having to work with teams that lack structure (Demetriou E A et al., 2018, and Hendricks, 2010). Also, some might find the rapid speed of the technology world overwhelming (Geurts HM et al., 2009).

Suggestions for Employers:

- Create clear, concrete written directions and set expectations in advance (Vo, 2023).
- Try to provide options such as working from home or adjusted hours (Vo, 2023).
- Or to really go above and beyond, offer mentorship or peer support programs that can help autistics cope with the workplace's social dynamics (Vo, 2023).

#### 2) Creative Arts and Design

<u>Opportunities</u>: The creative field of graphic design, animation, writing, or music would suit a person on the spectrum who is creative and detail-oriented (Angelsense, 2021). Many of these careers sometimes allow for expression through other means than verbal communication and often are extremely fulfilling to those with particular talents in the arts.

<u>Challenges</u>: What may be particularly challenging for autistic individuals is how unpredictable creative fields may be (Demetriou E A et al., 2018). Fluctuating workloads or self-promotion demands can, indeed, be prime examples. There are also sensory sensitivities to consider in studios or workshops, such as bright lights or loud noises (Vo, 2023).

<u>Personal Experience</u>: In my freelance writing journey, one thing I have found tough for my autism is the unpredictability of being a freelance writer. When I apply for gigs, I may get responses when I pitch one week, only to get none another. This lack of routine can make it hard to stay motivated at times.

Fortunately, to make up for the little predictability there is with things beyond my control, I have created a routine for what days of the week I'll most frequently work on certain types of material. This especially helps because, as a young autistic child, over 20 years ago, one of my unusual fascinations was calendars. It adds a touch of nostalgia to that interest, as well.

Suggestions for Employers:

- Make sure you have a well-structured schedule with clear deadlines (McPherson, 2024).
- Be as accommodating as possible with changes in the workspace, such as adjusting the lighting or noise level (Vo, 2023).
- Accept that everyone works and creates differently.

3) Research and Academia

<u>Opportunities</u>: Research roles in academia, science, or market research usually draw on strengths that typically play to the strengths of autistic individuals (Jones, 2023). Such roles can also generally be solitary in nature, which can be quite comfortable.

<u>Challenges</u>: Academia challenges may involve fitting into social hierarchies (Ylijoki, 2022), needing to present orally when one may not always have confidence (Soomro et al., 2019), and the competitive field itself (Joubert, 2024). The pressure to publish and meet high standards can also be tough (Demetriou E A et al., 2018).

Suggestions for Employers:

- You can offer alternative ways an autistic employee can present findings other than public speaking, such as submitting written reports instead.
- Think about encouraging networking opportunities in more remote environments, such as LinkedIn (Worsley, 2020).
- Provide the clearest feedback and guidance toward career development that you can (Vo, 2023).

#### Workplace Accommodations

Once employers hire autistic individuals, unless the workplace environment itself adapts to their needs, problems may persist (Davies et al., 2023). Many autistic people have difficulties related to sensory sensitivity, social interaction (Kojovic, 2019), or routine (McPherson, 2024). The reality is that numerous workplaces offer neither the flexibility nor the understanding necessary for the support such needs call for (Davies et al., 2023).

#### Practical Suggestions for Employers:

- Communicate Clearly: It's best to write instructions and expectations. This way, autistic employees are able to complete their tasks without verbal instructions, which causes confusion (CCDI Consulting, n.d.).
- Design Sensory-Friendly Workspaces: Handy adjustments that you can make with the environment can include increasing natural light, reducing loud sounds, or using headphones to assist the autistic employee (de Vries, 2021).
- <u>Offer Flexible Work Arrangements</u>: This could come in terms of hours or remote working, which allows some autistic people who find the office setting too overwhelming a chance to work (Tomczak et al., 2022).

#### Supportive Working Environment

Supportive work for the autistic, besides work accommodation, also means a workplace culture that values neurodiversity (Praslova, 2021). Autistic employees are often stigmatized or misunderstood, and other colleagues may exclude them from important projects or, sometimes, even bully them (Turnock et al., 2022).

Expert Insight: Melinda Gates says, "If we want to include everyone, we have to help everyone develop their talents and use their gifts for the good of the community. That's what inclusion means – everyone contributes" (Garnett Akinsanya, 2021).

Recommendations for Autistic Individuals: For autistic people in career paths, self-advocacy and seeking out environments that meet one's needs are important. Some tips I recommend based on some of my past experiences are:

- Fully Understanding Your Rights: Take note of your rights at the workplace and related accommodations under laws such as the Americans with Disabilities Act (ADA).
- Finding Support Groups That Are a Great Fit: You can learn about autism advocacy groups and/or vocational services that can help mentor and guide you throughout your job search and career development.
- Communicating Your Needs Straightforwardly: Ask for the accommodations that would suit you best, such as written instructions, a quiet workspace, and/or flexible hours.

Creating Inclusive Career Opportunities for Autistic Individuals

The issues people on the spectrum may face in their career path can be quite unique, but with the proper help and accommodations, all involved can easily manage them. When employers accommodate individual needs through inclusive hiring practices and supportive work environments, they draw from the many talents autistic individuals provide to ensure a diverse workplace.

When an autistic person is thoroughly aware of their strengths, can actively self-advocate for necessary accommodations, or find supportive workplaces, they can have a full and rewarding career. It's all about not having an average support system but a great one.

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See the full list of references here.

#### Workplace Inclusivity from page 29

offer support. Share autism facts and celebrate autism awareness month.

**Mentorship and Support Networks:** Providing mentorship programs and establishing employee resource groups (ERGs) for neurodivergent employees can offer a support network and a sense of community. These groups can also serve as a platform for employees to share their experiences and advocate for necessary changes. Often, employers may be more than willing to support. All you have to do is ask. I asked a director and technology manager at my job, and they fully support an autism group.

Companies Leading the Way

Several major companies have recog-

nized the importance of supporting neurodivergent employees and have established ERGs to foster an inclusive environment:

**Microsoft:** Microsoft has an Autism Hiring Program and an employee resource group called "Neurodiversity@Microsoft" that provides support and advocacy for neurodivergent employees.

**SAP:** SAP's Autism at Work program aims to employ individuals with autism and provide them with the necessary support to thrive. The company has seen significant success with this initiative, noting increased productivity and innovation.

**JP Morgan Chase:** The company's Autism at Work program focuses on recruiting and supporting employees with autism. JP Morgan Chase has also established an ERG to provide a community for its neuro-

divergent employees.

**Ernst & Young (EY):** EY has a Neurodiversity Centers of Excellence program that focuses on hiring and supporting neurodivergent individuals. The company has found that neurodivergent employees bring unique problem-solving skills and attention to detail.

**Google:** Google has an employee resource group called "Neurodiversity@Google" that provides support and resources for neurodivergent employees, fostering an inclusive work environment.

#### Conclusion

Creating autism-friendly environments in the workplace is essential for fostering inclusivity and tapping into the unique talents of neurodivergent individuals. By implementing strategies such as sensory-friendly spaces, clear communication, flexible work arrangements, training, and support networks, companies can create a more inclusive and productive workplace. Major companies like Microsoft, SAP, JP Morgan Chase, Ernst & Young, and Google are leading the way by establishing employee resource groups and programs specifically designed to support neurodivergent employees. These initiatives not only benefit the employees but also enhance the overall workplace culture, driving innovation and success. As more companies follow suit, the future of work will become increasingly inclusive and diverse, benefiting everyone involved.

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#### Co-Creation from page 33

a greater sense of ownership over the research outcomes. This model values each participant's contributions, fosters mutual learning, and aims to balance research with actionable community benefits (Israel et al., 2010). Essentially, participatory research involves incorporating the views of autistic people and their allies regarding "what research is conducted, how it is done, and how it is implemented" (Fletcher-Watson et al., p.1, 2019).

#### How Does PR Foster Empowerment?

Effective participatory research, which includes a collaborative partnership between academic researchers and community stakeholders, such as autistic collaborators and researchers, offers significant benefits to both scholarly knowledge and community welfare. When implemented effectively, this model highlights a co-participatory process in which academic and community researchers contribute complementary strengths and expertise (Nicolaidis et al., 2019). This partnership not only enhances the scientific accuracy of the research but also ensures its social and holistic relevance by aligning academic objectives with the lived experiences and needs of the community. While PR approaches can vary and must be tailored to specific contexts, a well-structured partnership typically involves clear roles and responsibilities for both academic and community researchers (Michaud, 2024; Nicolaidis et al., 2019). The following outlines the potential roles involved across the conceptualization, design, implementation, and dissemination phases.

Conceptualization Phase - The initial conceptualization phase is a synthesis of efforts between community and academic researchers. Often, the community identifies the issue and proposes it as a research topic; alternatively, the academic researcher may introduce a study area they find significant. Community researchers play a pivotal role by prioritizing local or systemic concerns, defining the overarching problem, and ensuring the study's sustained relevance, often advocating for culturally appropriate practices and language when necessary. Simultaneously, the academic researcher is responsible for securing the funding required to support the study and obtaining Institutional Review Board (IRB) approval, ensuring ethical compliance and academic rigor throughout the research process. Collectively, both parties conduct a thorough review of relevant literature and collaboratively formulate research questions, ensuring the inquiry is rooted in scientific integrity and community relevance.

#### **Study Design and Implementation Phase**

- The planning and design phase involves the conceptualization and formulation of the overall study framework, including culturally sensitive methodology and sampling procedures. Academic researchers contribute by ensuring the study's design is methodologically rigorous, ethically sound, and supported by appropriate data instruments. At the same time, community researchers focus on the study's accessi-



Celeste Michaud, PhD

bility and practicality, advocating for inclusive and culturally safe practices that respect the community context. During the implementation phase, both parties collaborate in data collection and analysis. While the academic researcher ensures a diligent and scientifically valid analysis, the community researchers safeguard participants' identities and uphold cultural norms and values. Together, they synthesize the findings and summarize the results in a manner that is academically robust and holistically meaningful.

Dissemination Phase - The final dissemination phase involves both parties working collaboratively to interpret the findings, draw conclusions, and determine actionable next steps for sharing the results. Academic researchers focus on identifying suitable academic publishers and conferences for formal dissemination, while community researchers ensure the findings are shared through culturally relevant channels, such as accessible workshops, community meetings, talking circles, or social media platforms. This joint dissemination strategy enables both academic audiences and the broader community to benefit from the research outcomes, encouraging knowledge exchange and fostering practical applications in both contexts.

#### Addressing Power Differentials

The fundamental distinction between traditional research and participatory approaches lies in how power is distributed and monitored within a research team (Cornwall & Jewkes, 1995). Research teams address power imbalances in PR studies by focusing on decision-making influence, access to resources and materials, training in research processes and tools, authorship rights, fair compensation, and overall team dynamics. These elements impact team members' involvement, sense of ownership, and empowerment within the project. Each study should tailor its approach to manage power dynamics effectively, ensuring all team members, especially those from the community being studied, have meaningful roles in shaping the research process.

#### Accessibility and Accommodations

To ensure balanced partnerships and



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contributions are honored, the research team should meet and reflect regularly and attend to any access and support needs are met. It has become imperative to incorporate accommodations to ensure accessibility throughout the collaborative research process when engaging autistic or other neurodivergent populations. These accommodations should extend beyond simple adjustments and demonstrate a deep commitment to valuing the presence and contributions of all participants. For instance, modifying language to reflect neuro-affirming preferences (Bottema-Beutel et al., 2021) and adapting physical spaces to accommodate sensory sensitivities are practical measures that can enhance participation (Fletcher-Watson et al., 2019). Moreover, adjusting academic structures and minimizing bureaucratic barriers can facilitate the leadership and involvement of autistic researchers, fostering a more equitable and participatory approach to knowledge generation (Fletcher-Watson et al., 2019). Encouraging autistic leadership in research further supports inclusivity, positioning autistic individuals as meaningful contributors to knowledge creation rather than merely token participants (Stack & McDonald, 2018).

#### Conclusion

In summation, participatory research fosters empowerment within the autistic community by challenging traditional research paradigms and promoting collaboration. By addressing power imbalances and involving autistic voices, PR creates an environment where individuals can thrive, self-advocate, and participate fully. Continued adoption of participatory approaches will be crucial in creating a research paradigm that truly serves and empowers the autistic community, ultimately contributing to broader societal acceptance and inclusion of neurodiversity. These collaborations enable autistic individuals to be leaders and co-creators of knowledge, advocating their rights and influencing meaningful change in both research and society.

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#### Autism Theater from page 34

unable to sleep, I realized the boy from the news story was my student, seeing Alejandro's picture on my phone. Shaken, I read a quote in an article from the murderer saying that her son was "in a better place now." As much as I believe in heaven, I picked up on the hidden meaning of her statement. Severe mental health issues aside, is there really so little expressed hope in our society for certain children that their success in life as adults seems unattainable?

I was somewhat disturbed by how quickly the news story faded, making room for divisive political campaigns. But I shook off my angst and realized I had to do something. Something that showed families of children under all kinds of circumstances there is hope. But I wasn't sure what. Nothing I could do could bring back a life, but I figured I'd need to do something worthwhile through ATP.

Months went by, and the fire to commit to doing something intensified. My drive was compounded by my experience teaching my sister, as she taught me patience, faith, and love. I had the transformative experience of watching her achieve things she feared she couldn't, like reading a book out loud on her own on New Year's Eve. She awakened me to the reality that no matter her circumstances, she'll achieve anyway. And that led to ATP's latest project: "The Voice Inside."

"The Voice Inside" is an interactive TV show about resilient teens & young adults who come to realize this: "If you change your voice inside, you can change your



ATP Event Producer Yasser Heyaime, Gena Sims, and new ATP Member Eli Jimenes at Indie Short Fest LA, where "The Voice Inside" won the Best TV Pilot Award

life. And if you change your life, you could change the world." When the characters awaken to this truth, their world shifts: opportunities arise, and the viewers explore the different paths they could take.

I told my dad about my desire to create the series, and he suggested that I find real stories. That catapulted a journey towards meeting adults on the spectrum who have absolutely changed my life. They include Matteo Esposito, Michael Lincoln-Mc-Creight, Michelle Zeman, Patrick Davis, Kaylah Taylor, Zachary Hoaglund, Danny Keenan, Alex Astrella, and many more. I heard their stories about eye-opening transformations: going from non-verbal child to professional starring actor, struggling special education student to successful playwright, and foster care abuse victim to law-passing politician, to name a few. They expanded my view of what's possible. I believe in myself more. I complain less. And my faith in my sister's future has gone up dramatically.

Then, I magically attracted some incredibly hardworking people whose ongoing dedication to ATP led to our first major event on August 25th, 2024. Seeing our carefully designed ATP logo on the big screen at Savor Cinema, I realized this was all coming to fruition. I saw the people who I normally meet via Zoom in person wholeheartedly giving everything to make the event happen. I saw a sea of people in the audience being as inspired by those I work with as I've been every day. And I don't really know the right words to describe it.

If you take anything away from this article, take away this: you can achieve anything you set your mind to. No matter how many people doubt you, yourself included, you achieve anyway. You have, and you will. And everyone has a voice. Everyone has an inner genius and something to teach you. Take the time to listen, and you just might change your life.

ATP is currently finishing up more episodes of "The Voice Inside" for the consideration of major global streaming services, with the help of Hollywood production company TW3 Entertainment. We also plan to screen these episodes at our next event at the University of Miami in December. Please check our website for more information. Tickets should be available soon, if they aren't by the time this article is published!

We are so excited to bring our events, including screenings, motivational speakers, and musical performances, to audiences nationwide over the next year. And we can't wait for "The Voice Inside" TV series to be broadcast around the world.

In the words of "The Voice Inside" theme song, which I'm writing right now, let's be the "generation that generates hope" and inspire the next generation to do the same. Thank you for reading this. Please share

this article with someone you believe in.

\* Big thank you to ATP's top supporters for making all we do possible: Miami-Dade Cultural Affairs, National Society of Arts and Letters, Alexander Montessori School, Carrollton School for Girls, and YoungArts. Our August 25th event was also made possible by the Florida Department of State, AngelSense, UM-NSU Center for Autism & Related Disabilities, and NBI Weston.

Our supporters help us create professional jobs for actors, writers, speakers, and musicians of all abilities. If you would like to support our mission, please contact us here. We would love to hear from you.

Gena Sims is the Founder and Executive Director of the Autism Theater Project. For more information, visit www.autismtheaterproject.org.

#### Cost of Literacy from page 34

a waiting list. However, this time, different challenges persevered. The problem is the Manatee Literacy Council director explained that our volunteers prefer to work with English as A Second Language students. However, a kind worker provided a list of alternative literacy agencies.

How Much Does It Cost to Improve Literacy for an Autistic Adult?

Similar to special education resources, the accessibility of literacy programs varies from state to state. In 2020-2021, Virginia allocated \$8 and Florida \$105 per eligible adult per year for literacy education (Walderman et al., 2022). When local literacy programs are scarce or the wait list is long, online materials from seasoned educators provide resources.

> Free Resources for Autistic Adults Struggling with Literacy

- Beverly Vicker MS, CCC-SLP, offers Advice from Autistic Adults About Literacy Instruction gained from interviews conducted with 12 autistic adults (Vicker, 2007).
- Thomas Gilbert, MA, and Monica Gordan-Pershey, EdD, CCC-SLP, believe Literacy is the Key to Inclusion (Gilbert & Gordan-Pershey, 2022). Gilbert

recommends the sight word recognition teaching method (Light & McNaughton, n.d.) The www.literacyforanyone. com website provides information, teaching curriculum, videos, and more, all at no charge.

It only takes one compassionate agency or individual to change the life of an adult with autism. Today, Zech enjoys gainful employment at a local grocery store. He continues to work on his literacy skills, anticipating that he will accomplish all his goals in the years ahead.

Holly Hedger's career as an advocate, cheerleader, and mom to Zech spans 37 years. Holly enjoys traveling and received her MBA from Regent University. A 24year profession in Radiation Therapy has led to new adventures in Bradenton, Florida. To contact Holly, email hedgerholly@ yahoo.com.

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#### Person-Centered from page 30

individuals with autism who might experience social isolation or exclusion.

A study published in Autism in Adulthood in 2023 found that adults with autism are at a higher risk of experiencing loneliness compared to their neurotypical counterparts. The study noted that the prevalence of loneliness was particularly high among those who were unemployed or lacked social support networks.

By understanding a person's preferences, caregivers can help them build and foster meaningful connections and relationships. Friendships, relationships, and opportunities to meet new people are essential parts of a fulfilling life. For adults with autism, these connections can be carefully nurtured through thoughtful planning that respects their social preferences and communication styles. When caregivers consider these factors, they can help individuals form lasting relationships that contribute to their overall happiness and well-being.

# The Role of Communication in Person-Centered Planning

Communication is the cornerstone of person-centered planning. Understanding



Nicole O'Neal

how an adult with autism communicates whether through spoken words, sign language, gestures, or technology—is essential to truly knowing who they are. Each person's way of communicating is unique, and it's through this lens that caregivers can really grasp the individual's needs, desires, and goals.

When caregivers invest time in learn-

ing and adapting to these communication styles, they unlock a world of possibilities for the person they support. This understanding leads to more accurate and meaningful planning, which, in turn, results in better outcomes. Without this effort, there's a real risk of miscommunication, which can cause frustration, disengagement, and ultimately a lack of progress.

#### **Risks of Missed Opportunities**

Not offering person-centered planning isn't just a missed opportunity—it's a significant risk. Without this approach, caregivers might create an environment that doesn't engage the individual, leading to unhappiness, stagnation, and a lack of growth. When adults with autism aren't involved in planning their own lives, they may feel disempowered, which can reduce their motivation and participation in activities.

This lack of engagement can create roadblocks to growth and independence. Like everyone else, adults with autism need opportunities to develop and expand their skills. Person-centered planning provides a framework for identifying and pursuing these opportunities, ensuring the individual is always moving toward greater autonomy and self-sufficiency. Conversely, embracing person-centered planning opens doors to new possibilities with an expansive vision. It allows individuals to set and achieve personal goals, develop new skills, and build relationships that enhance their quality of life. This approach meets the individual's current needs and lays the foundation for future growth and development.

Person-centered planning is more than just a tool for working with adults with autism—it's a necessity. By placing the individual at the center of their care, caregivers ensure that their voice is heard and respected. It fosters self-advocacy, creates environments of belonging, and unlocks the potential for growth and independence.

In a world where everyone wants to be understood and supported in ways that matter to them, person-centered planning offers a path forward that honors the unique needs and desires of adults with autism. It's a commitment to seeing the person, not just the diagnosis, and to supporting them in living a life that is truly their own.

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diversion, and inclusion in the interviewing process. Providing a sensory-friendly interview environment can help autistic employees focus better and feel more comfortable in the interview (Employer Assistance and Resource Network On Disability Inclusion (EARN)).

#### Investigating and Implementing Universal Design for Learning (UDL) in the Workplace

Universal Design for Learning (UDL) was developed by Doctors David Rose and Anne Meyer, Harvard School of Graduate Education, and is becoming an insightful tool for not only Educators; UDL also provides insights and benefits to managers interested in continuing education about how to improve and create an inclusive work environment for employees with Autism. Both employers and educators could consider taking a course in Universal Design for Learning. UDL framework teaches multiple means of representation, multiple means of action and expression, and multiple means of engagement that can significantly enhance the understanding and accommodation of not only students but also employees with autism. UDL promotes flexible learning and work environments that cater to diverse needs, making it an effective tool for creating inclusive workplaces. UDL also examines the Wheel of Power/Privilege and can be exceptionally enlightening and humbling to those within the circle. What would be the key advantages for managers in the workplace who are interested in taking a Universal Design for Learning course?

#### Key Benefits of an Employer-UDL Course for Autistic Employees:

Multiple Means of Representation: UDL encourages presenting information in various formats, such as visual, auditory, or



**Corinne Isaacs** 

hands-on. This approach accommodates different cognitive processing styles common among individuals with autism.

Multiple Means of Action and Expression: UDL promotes allowing employees to express their knowledge and skills in numerous ways, whether through writing, speaking, or demonstrating. This flexibility is particularly beneficial for autistic individuals who may excel in non-traditional communication methods. By way of example, a pre-recorded work presentation would be far more effective than an in-person presentation for a student or employee with autism struggling with extreme social anxiety.

Multiple Means of Engagement: UDL emphasizes creating environments that foster engagement through individual interests, motivation, and self-regulation techniques. For autistic employees, aligning tasks with their interests and allowing for autonomy can significantly improve job satisfaction and performance.

# Creating an Inclusive Workplace

By integrating UDL principles, employers can create a more inclusive workplace that accommodates the diverse needs of all employees, including those on the autism spectrum. This not only supports individual success but also enhances overall workplace productivity and innovation and promotes inclusivity. Employers are encouraged to seek out UDL-focused training programs, which are often available through educational platforms, universities, and professional development centers specializing in inclusivity or directly from The Center for Applied Specialized Technology CAST, Inc. UDL's primary sponsor.

#### **Employee Insights**

These strategies and adjustments have been validated not just by experts but also in this article, which includes a ghost editorial interview of an employee with autism. This particular interviewee affirmed the importance of having interview questions in advance and sufficient time to respond. It helps provide concise and accurate answers without the pressure of over-speaking, which can occur for candidates with autism as they attempt to focus on answering interview questions while simultaneously facing self-consciousness about other behaviors innate to autism during an interview. Likewise, she emphasized the significance of a sensory-friendly interview environment, confirming bright lights in an interview can often be distracting. She spoke candidly about how unnecessary social interactions delaying the beginning of meetings can often seem awkward and uncomfortable for an employee with autism, feel distracting and anxiety-inducing. She opined she felt more comfortable where conversations remained work-focused

and goal-directed, as excessive personal conversations can often be confusing as they take away from the focus of the purpose of a meeting. That is not to say small chatter is impolite before or during a meeting. Rather that too much socializing pre-meeting or during the meeting can often be extremely anxiety-producing for employees with autism as they are eager to get back to work and complete the task at hand.

She emphasized individuals with autism tend to have sensitivity issues when it comes to certain types of materials and gave insight to the notion Employers can often decrease the anxiety affiliated with wearing uniforms, by providing well-fitted uniforms that are not too tight fitting and that are offered in different types of materials (such as cotton versus polyester). In offering these choices this can also enhance comfort, reduce sensitivity and sensory issues that individuals with autism often struggle with in clothing.

Creating an autism-friendly workplace requires thoughtful consideration of communication styles, sensory sensitive work environments, sensory-free clothing, adaptive interviewing and hiring practices. In adopting these strategies, employers can support the success of autistic employees and foster a more inclusive and productive work environment for both employee and employer.

"We will all profit from a more diverse, inclusive society, understanding, accommodating, even celebrating our differences, while pulling together for the common good." – Ruth Bader Ginsburg

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#### AI in Education from page 15

used to order food, arrange for transportation, and order other necessary supplies, even at times with automatic replenishment features. AI can create cover letters and resumes. Indeed, most job applicants are already using these tools. So, AI is leveling the playing field, at least to get applicants through the door. AI can do such things as create recipes with step-by-step instructions for cooking a meal. Studies are also now being done to understand how the personalization of assistive technology can help in analyzing the behaviors and responses of autistic individuals to create different tools to appropriately respond to specific needs, including physical and mental health needs (See Iannone & Giansanti, 2023).

In sum, a thoughtful and appropriate examination of the use of AI as a tool for neurodivergent students can create more benefit than risk and, ultimately, lead to academic and personal success for those students.



Tara C. Fappiano

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rodivergent students in higher education, offering transition services, assisting with accommodations requests and disability services, and supporting them when conflicts arise - including academic dishonesty and related conflicts, to assist them in staying and getting back on the path to academic success. For more information, visit www.tarafappiano.com or email tcf@ tarafappiano.com.

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process, and communicating their needs.

companies they are seeking to work for.

dents once they enter the workforce will be beneficial in navigating the disclosure process, should they choose to do so. During their time in school, these resources were oftentimes provided or facilitated for them by a parent/caregiver. In the workplace setting, they will need to be the ones to initiate the communication and find the appropriate people to reach out to. Equipping them with knowledge about how and when they should disclose and having them practice requesting accommodations in the various examples discussed above will make them more likely to be confident and advocate for themselves in these situations.

As it relates to the workplace or professional setting, communication needs can be executed in a variety of different contexts supervisor check-in, meetings with Human Resources, team meetings and projects, etc. Possessing a strong self-awareness will encourage students to be more confident in taking on projects that closely align with their skill set or even stepping up in a leadership role if working on a group project where they feel they can excel. On the other hand, in areas that they have previously identified as weaker, students might be more apt to seek out coursework or training to help them develop that skill. Similarly, they will be better prepared to advocate for themselves by asking their employer about professional development opportunities or

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goals and steps they can take to work on these skills during their remaining time in school through coursework, internship experiences, networking events, or other extracurricular activities. For example, if the student feels they are lacking in leadership skills, they could choose to join a club or organization or run for Student Government. If they feel they need to develop their professional communication skills further, they can create goals around attending the college's career fair or other networking events.

Strengths-based assessments, like CliftonStrengths Finder, can also be a useful reflection tool in guiding students to discover their unique talents, ways to manage challenges, and how to thrive in their future careers (How the CliftonStrengths Assessment Works | EN - Gallup). Focusing the reflection on career readiness skills gives the student a clearer understanding of their own strengths and areas of improvement. These are tools that they can carry with them into the future and continually reassess their progress.

Secondly, identifying resources is an essential part of the self-advocacy process. This can be done by teaching strategies on how to research companies, including how to identify diversity and inclusion initiatives on company websites, reading online company reviews, and connecting with employees through informational interviews. Questions they can use to guide their research process are: Is this company a place whose mission aligns with my values? Does the company walk the walk and not just talk the talk? As someone who is autistic, would I feel supported working here? What additional resource groups are available at this company? Additionally, during their college experience, various resources should be provided around disclosure guidance, requesting accommodations, and knowing legal rights under the ADA. The Job Accommodation Network (JAN) is an excellent resource as the leading source of free, expert, confidential guidance on these topics. The organization helps individuals navigate the process of whether to disclose, how to go about doing so, when is the best



#### Liz Gallardo

time to do so, and to whom.

The last aspect of self-advocacy is ensuring that the student can communicate their needs effectively. At this stage, they have completed some initial reflection and identified resources. Students can practice communication in the classroom or in a workshop setting through role play, observation, writing assignments, extracurricular activities, internships, or on-campus work experiences. The more practice that they have in a structured environment, the more confident they will be as they begin to take initiative and hold these conversations independently in the workplace.

#### How This Translates Into the Workplace

Providing autistic college students with space to reflect, tools to identify resources, and ways to practice effective communication are all critical in helping them self-advocate and ultimately thrive in a workplace setting. Supporting students in self-advocacy teaches them to focus on what unique strengths they possess and how to be confident with their respective future employers. Specifically, students will be better prepared to successfully advocate for themselves by focusing on strengths and skill sets as they relate to preparing job application materials, navigating the disclosure Through self-reflection and commu-

nication practice, students can be wellequipped to complete effective job application materials demonstrating the skills that they have previously identified. This can be in written materials such as a cover letter or resume and can also be demonstrated through the interview process. For example, they could highlight that as an autistic individual, they have excellent attention to detail and the ability to work with numbers, which they then could connect to the specific requirements of the job description. The self-reflection experiences and communication exercises they have had thus far will also help their confidence during the interview process and make stronger connections to the roles and to the

Being aware of resources available to stu-

projects they can work on that will help them develop skills in those areas.

These are just a few examples of how a student's self-advocacy skills can be applied to a professional work setting and how this can be mutually beneficial to both the student and the employer.

#### Looking Forward

Frequently, the focus of conversations around helping autistic students is on how to navigate challenges and overcome barriers. Using a strengths-based approach still acknowledges that challenges exist. However, it shifts the focus to the unique skill set that autistic students bring to the workplace and the ways that we can help students articulate this.

This approach is simultaneously beneficial to both the student and employers. A team of experts led by Don Clifton conducted decades of data research from polls and interviews asking what makes a great leader. They found that one of the things that the most influential leaders do is invest in strengths. Focusing on and developing an individual's strengths boosts engagement from 9% to an incredible 73% and leads to substantial gains for both employees and the organization (Rath & Conchie, 2009).

As providers, clinicians, support organizations, colleges, and employers, we all have a responsibility to make employment more equal. We can begin to do this by helping autistic students leverage their strengths and providing them with the self-advocacy tools to thrive in the workplace.

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#### Autism Empowerment from page 35

"When members of the public envision the disability of autism, they most likely envision a child, rather than an adult," reads a 2011 article called "Infantilizing Autism." And certainly, many autistic adults have faced this firsthand. Some of us might feel like it's hard to be heard or taken seriously at work, and condescending reactions to things like stimming in public can only make matters worse ... Autistic adults should be trusted to complete their assigned tasks, but support should also be readily available to them. Asking for support, even long past the probation period or indefinitely, should not be framed as them putting a burden on management or as a personal failing (Laube, 2022).

#### **Empowerment Barriers**

The greatest hurdles to acceptance and genuine inclusion of Autistics are the stigma and discrimination to which we're subjected. Praslova (2021) expresses it as follows:

"Feeling excluded and invisible is typical for neurodivergent people. Pop culture narratives make this worse. We are often infantilized or portrayed as unemotional (almost robotic) people who love tech or who struggle to triumphantly overcome everyday woes. Reducing us to stereotypes and "othering" us shapes how we are perceived by others and by ourselves. The result is an overwhelming number of autistic people who feel isolated, misunderstood, and discriminated against in life and at work.

If you are neurotypical, or part of any majority group, you likely see reflections of yourself wherever you look: on billboards, in magazines, while watching your favorite TV shows, in novels and in movies... [I]f all of that was taken away... You would feel alone. You might even lack the tools you [need]...to explain those feelings to other people, because you would have to do more work to seek out and discover them. I even invented a word for this feeling - unincludable...[W]e are not the problem. Rather, it is miseducation surrounding what it means to be autistic and neurodivergent - especially in the workplace" (Praslova, 2021).

#### #ActuallyAutistic Perspective

As an autistic person and a mental health systemic advocate, I know it is hard to change ingrained attitudes. "As a society, we may find significant limits in our ability to acknowledge and reduce racist thinking and behavior [because ableist and] racist attitudes are often unconscious" (Ashraf and Dennis, 2021).

"[E]xclusion may not always be intended to cause psychological harm, [but] exclusion can have detrimental outcomes in terms of emotional and behavioral health, academic difficulties, a decrease in prosocial behavior, and low self-esteem" (Mulvey, Boswell, and Zheng, 2017).

Even some "[D]octors assume that having a disability inevitably leads to a low quality of life. This is based on the idea that someone can only have a high quality of life if they are nondisabled...This bias... can cause medical professionals to ignore the lived experiences of their patients, incorrectly blame new symptoms on a person's disability, or withdraw medical support in the belief that nothing they do will help" (Villines, 2021).

Such attitudes are anything but supportive. So, from an autistic point of view, what might empower us to realize our best possible life?

#### Is Emotional Care the Missing Piece?

Education helps, but it's important to ensure that those around us are educated as to what is and isn't true about autism. I believe, given the widespread misunderstanding and misinformation that leads to the pervasive stigma, the vital human need for emotional care is lacking.

#### Caring Support

Caring is essential for anyone's overall well-being and happiness. Caring establishes connections, fosters empathy, and promotes a sense of belonging. When people feel cared for, they experience a greater sense of security and emotional support (Types of Caring: From Empathy to Support, 2023)

Caring takes various forms, each addressing distinct aspects of a person's well-being. For this article, my focus is on Emotional Care.

#### **Emotional Care**

Emotional care is a humanity-affirming practice that recognizes and supports individual capabilities without trying to 'correct' them. It emphasizes the importance of supporting the holistic well-being of individuals, including [Autistic] mental, emotional, physical, and social health. There are transformative powers within neurodiversity-affirming practices (Sara, 2024). These methods and approaches are not just clinical tools or educational strategies; they are pathways to understanding, acceptance, and genuine support for people.

"Relationships and social connectivity play an important role in physical and psychological well-being. Relationships are... important for autistic well-being; autistic loneliness is related to poor mental health, including increased depression and anxiety), self-harm, and suicidality. Close relationships with others give autistic people a space to experience emotional reciprocity, to express their emotions, exchange ideas, collaborate and cooperate, and practice interpersonal skills" (Crompton et al., 2020).

feel heard and understood.

"Emotional care is not limited to specific relationships or professions... Anyone can practice it by offering a listening ear to a friend, supporting a co-worker, or providing care within a healthcare setting. By understanding and practicing emotional care, we can create a more compassionate and supportive world" (Types of Caring: From Empathy to Support, 2023).

It seems ironic that emotional support and empathy-traits many Neurotypical people accuse Aspies of lacking-could be a significant key to greater neuro-inclusivity. But again, a quick review of online literature reveals a pervasive sense that NTs do not like Autistic people (Alkhaldi, et al, 2021). Our tendency to isolate ourselves from NT society is often blamed, as are our most fundamental traits, which many NTs simply do not understand. To connect with others, many Aspies would rather spend time with other Neurodivergent people.

#### Wrapping up

Governments around the world are working on strategies to empower and include autistic people in all aspects of life. However, some autistics may view these as perfunctory or symbolic efforts that fail to remove social barriers, leading autistic people to continue masking their true selves. Rejection, marginalization, and the message that everything intrinsic to us is wrong or unacceptable is a continuous source of trauma (Natri, 2021).

Nothing about autistic people deserves exclusion. Inclusion and acceptance are human needs. We happen to be human beings who are Autistic and feeling that someone cares could be as important to our well-being as any learning or workplace adjustments.

Annie Kent, MA, received her psychology degree at Lakehead University in Thunder Bay, Ontario, Canada. She spent 20-some years working in public sector disability, mental health, and infectious diseases advocacy and education. Diagnosed with three closely related types of neurodiversity, employer lack of awareness and understanding led to burnout and early retirement. However, she remains an active advocate, always learning and engaging remotely with Autism and ADHD organizations and forums. For more information, visit her website, www.aspiefemmepress.ca, or email Annie at ajollymo@lakeheadu.ca.

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specific outcomes. The program uses Catalight's Wellbeing Scales to measure progress – a one-of-a-kind industry gauge validated by statistical analysis that monitors a person's happiness and life satisfaction through surveys. In the Compass B pilot, clients consistently - and excitingly

- reported improvements in their overall sense of wellbeing, regardless of the specific elements they chose to work on. Just seven people of the more than 200 participants dropped out.

Compass B embodies personalized care for neurodivergent individuals. It stands as a testament to the idea that when people are given the tools and support to

steer their own course, they not only meet their goals but also experience a profound sense of personal growth and fulfillment. Catalight's initiative is a step toward a more inclusive approach to behavioral health. We're very much looking forward to this introduction to a broader audience and, ultimately, helping more people find their path to wellbeing.

Doreen Samelson, EdD, MSCP, is the Chief Clinical Officer of Catalight, a non-profit that provides access to innovative, individualized care services, clinical research, and advocacy — so people with developmental disabilities can choose their path. Samelson leads the organization's behavioral health research team, focusing on promoting families' overall well-being.

Active listening, expressing empathy,

and validating another's emotions assures them that you want to understand what they are going through, allowing them to



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