

AUTISM SPECTRUM NEWS

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INFORMATION, ADVOCACY, AND COMMUNITY RESOURCES

SUMMER 2024

VOL. 17 NO. 1

Supporting Autism Service Providers

Reducing Staff Turnover Among Autism Service Providers

By Georgia Efthimiou, MA, BCBA,
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and Howard Savin, PhD
First Children Services

Autism service providers have the unique challenge of helping the individuals they work with achieve meaningful and sometimes life-changing outcomes while managing their own mental and physical exhaustion. The burnout rate among Registered Behavior Technicians (RBTs) and Board Certified Behavior Analysts (BCBAs) in the field is high. Direct care staff working with individuals with developmental disabilities have burnout rates as high as 70.7%-77% per year (Mitchell and Braddock 1994; Seniger and Traci 2002). Combating staff turnover through support programs within Autism provider organizations is paramount for retaining good staff while providing quality and effective services. Burnout among direct care staff is due to several factors, including inconsistent hours, complexity of caseloads, family dynamics, or a lack of support and



training. Autism service providers often recruit and hire staff with varying degrees of experience. For some, it may be their first time in the field. Regardless of experience, all staff should receive continued training and support from their organization. Training should be ongoing to ensure

providers stay updated with the most effective and ethical practices when delivering autism services. Support from within one's Autism services provider organization is essential to retaining quality staff.

Different organizations in our field support providers. Those providing ABA-re-

lated services, such as Board-Certified Behavior Analysts (BCBAs) and Registered Behavior Technicians (RBTs), have guidelines for supervision that must be followed. These can be found in the Ethics Code for Behavior Analysts and the RBT Ethics Code. These guidelines come from the Behavior Analyst Certification Board, founded in 1998 (Sellers et al., 2023). It is a certifying body for credentialing all BCBAs and RBTs. Shortly after the Board was founded, they put out the Guidelines for Responsible Conduct for Behavior Analysts in 2001 (Sellers et al., 2023). It was from there that our Ethics Code evolved.

ABA practitioners are held to standards stated in our ethics code, including our responsibility in practice, responsibility as a professional, responsibility to serve our clients in a meaningful way, responsibility to adhere to our research, responsibility as supervisees, and more (Behavior Analyst Certification Board, 2020). Behavior Analysts assess skills and create goals for clients to make a meaningful change in their lives and those of their caregivers and loved ones. The Behavior Analyst Certification

see Staff Turnover on page 22

Supporting Autism Service Providers: Challenges, Solutions, and Collective Action

By Vladimir Kogan
CEO
Illinois Autism Center

Alex, an early intervention specialist, begins his workday at the community's autism support center, where he's scheduled to work with Mia, an eight-year-old girl on the autism spectrum. Mia, who is non-verbal, has shown a keen interest in participating in activities through visual aids. Alex plans to combine a visual communication system with sensory play to develop Mia's ability to express her needs and desires in a supportive, understanding environment.

Alex's approach requires patience and a deep understanding of the individual needs of children like Mia. Progress can often be challenging, marked by gradual headway, the occasional setback, and the need for continuous strategy adaptation.

After weeks of persistent work, one of Alex's most rewarding moments is when Mia finally hands him a picture card, signaling her wish to participate in her favorite sensory activity. Though it may seem small, this achievement represents a significant step forward in Mia's communication skills,



showcasing the impact of one-on-one support and the potential for further improvement in Mia's communicative skills.

The important role of dedicated professionals is highlighted in the work of early intervention specialists like Alex, who teach fundamental skills using techniques

based on research. Despite the modest compensation many of these individuals often receive, their creativity, patience, and ability to adapt to each child's needs are priceless skills. Along with helping youngsters like Mia overcome communication challenges, they also provide the ground-

work for the children's future growth and independence in each facet of their lives. All of this points to a fundamental truth: investing in these service providers benefits society. Ignoring the issue can lead us to dark days, indeed, and it seems they have already arrived.

In addition to meeting current needs, we should lay the groundwork for individuals on the spectrum to make significant future contributions to society by providing them opportunities to develop and thrive. The growing demand for autism support service people, driven by an increase in diagnoses and a shortage of skilled providers, highlights the pressing need for a more extensive support system.

Challenges Faced by
Autism Service Providers

Securing service providers for children on the autism spectrum poses significant challenges across various settings, including schools, clinics, and home-based services.

In educational settings, integrating specialized support services often bumps against budget constraints and limited

see Collective Action on page 24

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Deadline: December 4, 2024

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Improving Physical and Emotional Wellness

Deadline: March 5, 2025

Summer 2025 Issue

Understanding the Impact of Stigma

Deadline: June 11, 2025

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Coordinated by Fred R. Volkmar, M.D.



Interdisciplinary Approach to Obtaining a Medical Diagnosis For Individuals With a Complex Behavioral Profile

By Lauren Carter, MEd, BCBA, LABA, Emily Chin, PT, DPT, Maria Wizboski, RN-C, BSN, CDE®, and Mary Jane Weiss, PhD, BCBA-D Melmark

Individuals with complex behavioral and medical profiles require a multidisciplinary approach due to multiple specialized areas of need. This approach allows interdisciplinary teams to efficiently address multiple presenting needs simultaneously and comprehensively (Boivin et al., 2021). This collaborative process requires trust, respect, clearly defined and equitable roles, commitment, and accountability. It requires each discipline to have comprehensive knowledge of their specialty, as well as an understanding of other team members' roles, including training, experience, and scope of practice (Boivin et al., 2015; Brodhead, 2015; La-France et al., 2019; Slim & Reuter-Yuill, 2021). In theory, all clients benefit from interdisciplinary collaboration. In some instances, however, such collaborative care is essential. When the needs of the individual require specialized expertise from multiple disciplines, a collaborative team approach is needed. It is important to focus on the values of the team approach, the roles and responsibilities of each mem-



ber, and the quality of interprofessional collaboration and teamwork (Slim & Reuter-Yuill, 2021).

This article highlights the importance of an interdisciplinary approach to obtaining a medical diagnosis for an individual with a complex behavioral profile related to an underlying medical condition. The individual was a 20-year-old male with diagnoses of autism spectrum disorder and attention deficit and hyperactivity disorder. They were non-verbal and uti-

lized an AAC device to communicate their wants/needs throughout their day. This individual attended a residential and school program (Melmark), where the primary methodology is applied behavior analysis. Due to a challenging behavior profile, the individual was taught using a 2:1 staff-to-student ratio for their school and residential days. The individual received allied services in speech and language pathology, occupational therapy, and physical therapy.

Regarding their behavioral profile, the individual engaged in inappropriate use of materials (i.e., throwing, swiping, crumpling), displayed difficulty remaining seated during academic instruction, demonstrated inappropriate and/or unsafe behaviors when moving from one area to another or when seated near peers, minimizing opportunities to participate in group instruction, and engaged in kicking towards walls, dropping to the floor to engage in head directed self-injury, hitting head to walls, and attempting to access unsafe areas. Historically and currently, this individual engaged in high rates of challenging behaviors (e.g., aggression, self-injury, drooling, property destruction [e.g., throwing objects], and ritualistic behaviors), which limited access to some environments, social interactions, and academic programming. They also demonstrated resistance in the form of aggression and self-injury when access to preferred activity/items and ritualistic behavior was restricted and/or blocked and demonstrated limited safety awareness during transitions (e.g., kicking dangerous items, knocking over items, climbing on furniture). This individual did not demonstrate awareness or understanding of risks to the individual's self or others when engaging in these

see Interdisciplinary on page 26

Establishing and Promoting Self-Care Within a Human Service Agency

By Katie Salvatore, MEd, BCBA, LABA Executive Director Melmark New England

In an industry faced with post-pandemic staffing shortages, the question of how to promote self-care and decrease burnout among autism service providers has become more critical than ever before. Burnout can be defined as a work-related illness that results from ongoing psychological stress (Leoni et al., 2020), and it is widely believed to lead to other illnesses and injuries. Given the potential impact of this work-related illness, significant research has been done on the factors contributing to it and what can be done to mitigate these. However, many identified factors that seem to lead to staff burnout and turnover, such as challenging behaviors and relatively low wages, often seem immovable (Leoni et al., 2020). In response, many autism service providers have increasingly focused on promoting self-care among their employees.

Self-care as a concept, though, is often difficult to define, let alone implement effectively, as an organization. One way to conceptualize self-care is as a collection of actions designed to promote physical and mental well-being (Dorociak et al., 2017). On an organizational level, autism service providers and other agencies often seek to enhance their employees' self-care through various wellness initiatives. These



initiatives may include various topics, such as yoga, mental health, and hydration. In some cases, wellness campaigns may be designed to increase awareness and provide connections to outside resources, while in other cases, companies may invest directly in employee health by subsidizing gym memberships and other health benefits. In addition to these health and wellness initiatives, many employers also invest in incentives or events designed to serve as rewards or "reinforcers," increasing employee morale and decreasing burnout. Perhaps the most well-known of these

types of rewards is the almost ubiquitous staff pizza party.

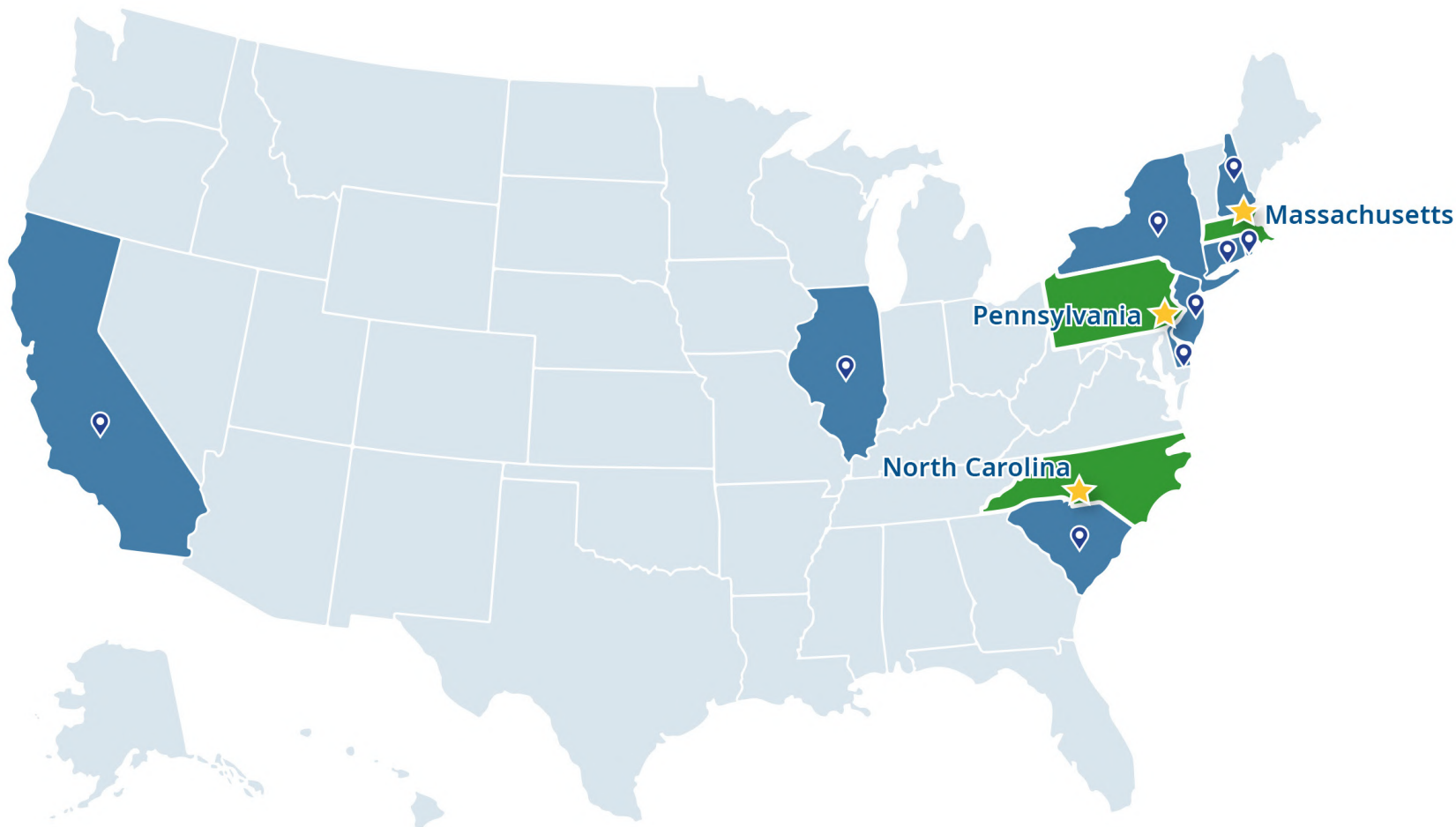
While this article is certainly not an indictment of pizza parties or yoga workshops, it is an invitation to reconsider the factors affecting burnout and the concept of self-care through the lens of motivation. In behavior-analytic terms, motivation describes the degree to which a particular outcome is reinforcing and the factors that establish that reinforcer as effective in the first place. A simple example often used is that food is particularly reinforcing to someone who is hungry, especially when they like the

food being served. Human beings are complicated, though, and often have complex and competing motivations that are more difficult to detect than those related to basic human states, such as hunger.

In the workplace, where financial motivation and reinforcement often provide only a superficial lens of analysis, this is certainly true. Many studies have shown that what we assume is most reinforcing in the workplace, including increased compensation, is not always effective (Kuvaas et al., 2017). Some researchers in economic psychology have described this phenomenon by observing that intrinsic motivation appears to be more powerful than extrinsic motivation in improving job performance and decreasing turnover (Kuvaas et al., 2017). As a radical behavior analyst, though, I am hesitant to stop at the assumption that something is simply "intrinsic" and internal and, therefore, cannot be explained or addressed. Luckily, Acceptance and Commitment Therapy (ACT) provides an essential behavior analytic framework to understand intrinsic motivation as a matter of value alignment.

In the ACT framework, values are defined as deeply held beliefs which serve as guiding principles (Paliliunas, 2021). An individual whose goals are closely aligned with their short- and long-term values feels a greater sense of purpose and motivation. They also find it easier to engage in

see Self-Care on page 27



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Autism Treatment Should be Guided By Recent Research Reflecting the Expansion of the Diagnoses



By Tracy Gayeski, PsyD, MBA
Chief Health Officer
Catalight

When I first began working as a behavioral interventionist while pursuing my undergrad psychology degree in 1996, we treated children with autism in much the same way many providers do today. Over the past three decades, we've learned a great deal about autism. So, why are many still relying on outdated research? As autism prevalence continues to rise and our understanding evolves, our approach to autism care must evolve with it.

There needs to be a change to our approach to providing care – prioritizing the wellbeing of individuals we support and their families.

Using 46 studies published in the past 10 years and our own real-world data, we've discovered that, when it comes to autism treatment, there is a lack of evidence for a robust 'dosage effect' when looking at interventions based on applied behavior analysis (ABA). That is to say, more hours of care alone doesn't mean a better result. While some guidelines for ABA call for 30 or more hours of weekly treatment, I am happy to report that recent evidence shows children are meeting their goals with far fewer hours and shorter lengths of stay.

Catalight researchers spent a year and a half putting together the [Catalight Practice Guidelines](#) and publishing them in March, and it became clear that there were diminishing returns in ABA treatment after 15 hours in most cases. Lower hours resulting in better outcomes are excellent news for clients, families, health insurance payers, and the industry as a whole. At Catalight, we strive to help all in our care to achieve greater wellbeing – that's our greatest outcome measure.

Recent studies highlight the benefit of parent-mediated care – where a practitioner teaches caregivers ABA methods to use in everyday life. This approach not only improves the care of children with autism but also provides more flexibility and conve-

nience in a natural, everyday setting, making it less intrusive.

Providers who subscribe to the theory that high hour treatment leads to better outcomes often rely on studies conducted more than 15 years ago, including a [study](#) published in 1987 that focused on a treatment group of 19 autistic children, of which nine showed positive results.

In contrast, Catalight – with our wide provider network – cares for 17,000 individuals with intellectual and developmental disabilities every day. With such a large census of people, we can gather valuable insights from the data for diagnoses on various complementary treatment plans to see how effective they've been. It's rare that we see high hours of ABA as a medical necessity. Catalight's Vice President of Clinical Excellence, Dr. Lindsey Sneed, [published a study following 107 clients in November](#) that showed children made significant progress with just 9 hours of ABA treatment a week.

When research was published in the 80s, autism prevalence was about 1 in every 1,000 – reflecting a homogenous population and similar traits. Today, that number is 1 in 36 with a diverse population and differing needs.

How can we rely on an almost 40-year-old study to address children on the spectrum today, especially with the increase in diagnoses? Comparing the two populations is like comparing apples to oranges. It's surprising that so many providers overlook recent studies that emphasize the need for greater flexibility and individual care while pointing to dated research that's questionable in so many areas.

Recognizing recent research, it's clear that – when caring for such a diverse number of unique individuals – there is no 'one size fits all' treatment that can possibly meet the needs of everyone. While there may be a small sub-population of children who still benefit from high-hour ABA, more are seeing impactful outcomes with additional treatment options like parent-mediated care that take into account the full family dynamic. At Catalight, we offer a variety of treatment options and tailored care so that individuals and families

see [Autism Treatment on page 26](#)

Innovative Recruitment Campaign Launched in NY State To Address Direct Support Professional Workforce Shortage

By Willow Baer
Acting Commissioner
New York State Office for People With
Developmental Disabilities (OPWDD)

Direct Support Professionals (DSPs) provide crucial services for more than 125,000 New Yorkers with developmental disabilities, including autism spectrum disorders, all across the state. The important roles that DSPs serve cannot be understated; I see it every day in my interactions and visits to programs at our hundreds of service provider partners throughout New York. DSPs are passionate people who enjoy empowering people and making a difference in their lives while bringing smiles to their faces.

Unfortunately, the positive impact DSPs make in the lives of people with disabilities has been negatively affected by mounting workforce challenges across all human service industries. In response, Governor Kathy Hochul, the New York State Legislature, and OPWDD have launched extensive initiatives aimed at professionalizing this vital workforce, promoting public awareness of direct support careers, providing advanced educational opportunities, credentials, and career ladders for DSPs, and enhancing their wages.



A direct support professional working with a smiling young woman

One important and very visible initiative launched this past Spring is the statewide #MoreThanWork DSP recruitment marketing campaign.

Simply put, #MoreThanWork highlights the essential roles that DSPs play in the lives of people with developmental disabilities and promotes the tremendous value and meaning found within a direct support career. Our team at OPWDD partnered

with Latham-based advertising agency [Vibrant Brands, Inc.](#) to implement this comprehensive marketing campaign and engaged media buying company [OpAD Media Solutions](#) to spread the campaign across traditional and digital media platforms to boost the recruitment efforts of service provider agencies throughout the state. The campaign is providing enhanced visibility and the opportunity to attract mo-

tivated job candidates to the 225 service providers who are taking part. The entire OPWDD service system will benefit from this campaign.

#MoreThanWork is reaching as wide an audience as possible, depicting DSPs in their day-to-day work and the meaningful nature of what they do. To ensure the campaign is accessible to diverse audiences, the campaign's content reflects New York's great diversity and is available in a number of languages.

The website, [DirectSupportCareers.com](#), serves as the campaign's hub for participating agencies to promote their mission and their role in New York communities, as well as the career opportunities they are offering. The agency profiles offer providers the opportunity to highlight what sets their agency apart from others, its unique mission, and any distinctive focus or attribute that will help them stand out as a great place for people to launch a meaningful career.

Agency profiles are categorized by county and displayed in a randomized order to ensure equal visibility. This helps show job seekers the vast opportunities that exist across the state with providers that offer the full range of developmental disabilities services and supports. Job seekers may then connect directly with any developmental

see Recruitment on page 25

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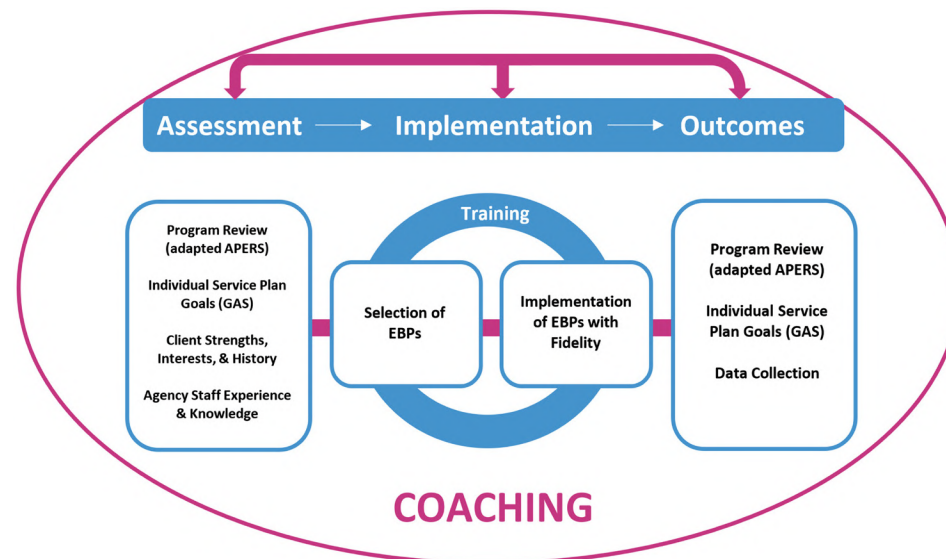
APPLY TODAY! #MoreThanWork



Tailored Professional Development for Licensed Care Staff to Support Community Living for Adults with Autism

By Melina Melgarejo, PhD,
Jessica Suhrheinrich, PhD,
Mary Rettinhouse, MS, BCaBA,
Patricia Schetter, MA, BCBA,
and Tana Holt, MPH

Across the next decade, we can expect a 123% increase in the number of youth with autism transitioning out of school-based services (IACC, 2017). These increases have placed a growing demand on the service systems supporting transition-aged youth and adults and magnified the need for effective and evidence-based programs for adults with autism. The Interagency Autism Coordinating Committee (IACC) has identified service access for adults with autism as a priority, including understanding service gaps and barriers. The IACC Strategic Plan for autism indicates many of the challenges faced in working with adults with autism are related to the lack of a well-trained and motivated workforce (IACC, 2017). Insufficient use of evidence-based practices (EBPs) is linked to poor pre-service training, supervision in the field, and a sense that the use of EBPs is not expected, supported, and rewarded (IACC, 2017). There is a clear need for the development of appropriate interventions for adults with



Adaptation to the National Professional Development Center for ASD Model

autism and effective training practices for their support providers.

The National Professional Development Center for ASD (NPDC-ASD) developed a professional development model to support states in increasing the use of EBPs for autism in public school programs (Cox et al., 2013). The model involves systematic program assessment (Odom et al., 2018), structured evaluation of student progress toward annual goals (Ruble

et al., 2012), and provider training on the implementation of EBPs. The model and resources are associated with increases in overall program quality, use, and fidelity of EBPs and individual student progress (Odom et al., 2013). Resources include the Autism Focused Intervention Resources & Modules (AFIRM), which present the 28 EBPs identified by the NPDC-ASD into interactive online modules with specific steps for teachers and practitioners to plan

for, use, and monitor each practice (afirm.fpg.unc.edu).

One organization that has employed the NPDC-ASD model and resources is the California Autism Professional Training and Information Network (CAPTAIN; Suhrheinrich et al., 2020). As part of a CAPTAIN initiative to scale out the use of EBPs, CAPTAIN piloted an adaptation of the NPDC-ASD resources and training model into adult day programs. Participating adult clients with autism met or exceeded their goals, had a reduced need for individual behavior intervention plans, and had greater access to the program curriculum (Rettinhouse, 2018).

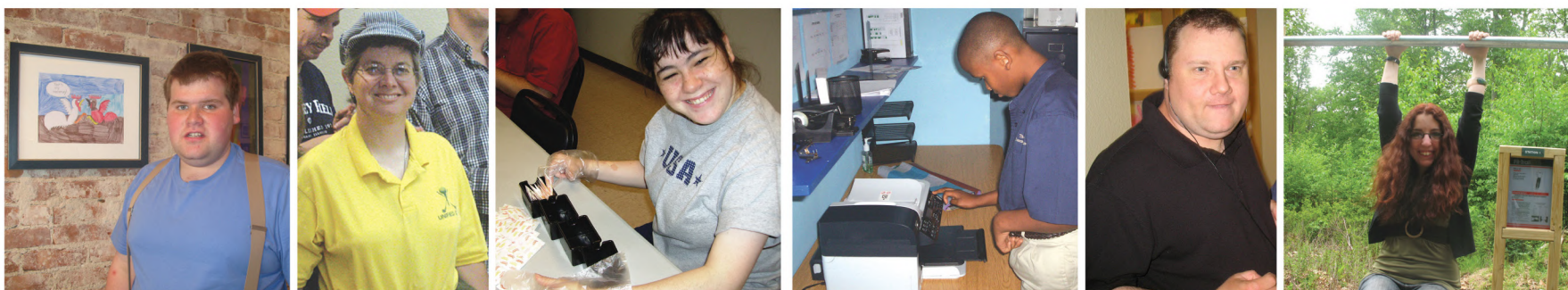
Given the positive outcomes of this pilot program, grant funding was secured to adapt additional resources, expand the training capacity, and evaluate the effectiveness of the adapted model. The current study included three specific aims:

Aim 1: Evaluate staff and organizational characteristics and needs. Which EBPs do staff and administrators at community care facilities report as helpful in meeting the needs of adults with autism?

Aim 2: Adapt NPDC-ASD training resources to support direct service provider

see Development on page 28

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The Increasing Popularity of Telehealth Services for Autism Spectrum Disorders

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

Children and young adults with autism spectrum disorders (ASD) often find it challenging to visit the doctor's office due to a variety of sensory, social, and communication barriers. The sights, sounds, smells, and textures commonly found in a doctor's office can be overwhelming and can trigger anxiety. Many people with autism have difficulties with communication, making it hard for them to express their needs, and they may also struggle to understand instructions from the medical staff. All these different factors, in combination with challenging social interactions, create obstacles that an individual with ASD may find complex to navigate.

Telehealth has played an increasingly important role in improving healthcare delivery, making it more accessible and efficient since the COVID-19 pandemic (American Psychiatric Association, 2020). The APA conducted a survey of its members to understand how psychiatrists' use of telehealth in practice has changed over the course of the pandemic. Prior to the pandemic, 64% of providers said they did not use telehealth to treat patients. In January of 2022, "81% of respondents said that they see 75-100% of their patients virtually" (APA, 2020). Currently, telehealth is a highly regarded tool that allows clinicians to observe patients in a more natural, relaxed setting and offers convenience for families (Ramirez-Moya, 2022).

Telehealth has also played a significant role in the diagnosis, treatment, and management of ASD. Research indicates that telehealth has significantly benefited individuals with ASD and can provide effective and reliable assessments and interventions with accuracy comparable to in-person evaluations. Parents and clinicians report high satisfaction with telehealth, appreciating the flexibility, cost savings, and the ability to observe children in their natural environments. Additionally, telehealth enables regular, consistent therapy and reduces the stress associated with traveling to appointments. These advantages contribute to improved overall care and quality of life for individuals with ASD (Kuhl-Meltzoff Stavropoulos, Bolourian & Blacher, 2022).

Applied behavior analysis (ABA) is a widely studied and utilized treatment intervention for individuals with ASD that has been shown to be effective (Smith & Iadarola, 2015). Using telehealth, therapists can deliver ABA instruction to children and their families via video conferencing to demonstrate techniques and monitor progress. This is particularly beneficial for families in remote or underserved communities where access to specialized care is limited (Nohelty, Bradford, Hirschfeld, Miyake & Novack, 2022). Overall, telehealth has transformed ABA services by making them more accessible, flexible, and efficient, ultimately leading to better outcomes for individuals with ASD and their families.



Telehealth allows individuals with ASD to receive care from a variety of multidisciplinary team members. Speech and occupational therapists, developmental pediatricians, and mental health professionals can be provided remotely, ensuring that children continue to receive consistent intervention despite the physical need for travel (California Telehealth Resource Center [CTRC], n.d.). Virtual meetings can be easily scheduled and conducted, allowing for more frequent and efficient team discussions and case reviews. Telehealth can provide individuals with ASD and their families with comprehensive and holistic care by multidisciplinary teams collaborating to adjust treatment plans in real-time while ensuring that interventions are well coordinated and holistic (CTRC, n.d.).

Telehealth platforms allow for greater involvement of parents and caregivers in the therapeutic process, which can lead to significant improvements in the child's behavior and social skills. Parental training via telehealth has also been shown to help manage disruptive behaviors and support the child's development more effectively (Hopson, 2020). One reason for telehealth's increasing popularity is due to its ability to give an individual more control of their environment. In this way, people with ASD can avoid being subjected to overstimulating medical environments and, instead, can remain at home with more tolerable surroundings. Many parents also appreciate having the freedom to turn off the video camera in the event of a behavioral issue. Providing these options can go a long way in establishing trust between individuals with ASD and clinicians (Ramirez-Moya, 2022). Receiving care in their familiar and comfortable home environment can reduce the sensory overload and anxiety often experienced during in-person visits. This more relaxed setting can lead to better engagement and more accurate assessments.

While telehealth offers many benefits for individuals with ASD, it also presents challenges that can affect the quality of care and the effectiveness of telehealth interventions. Using telehealth to complete a diagnostic assessment may not work for every individual due to differences in

symptom severity, age, and developmental impairment. All these factors will affect how a person with ASD responds to the online platform. One of the biggest concerns is that relying on telehealth to treat ASD will cause clinicians to overlook important subtleties that can be more easily observed in person. It can also be difficult to notice suicidal ideation, other co-morbidities associated with ASD, significant aggression, and signs of abuse (Ramirez-Moya, 2022). In situations like this, a hybrid

method ensures a more holistic approach to treatment. Additionally, not all families have access to reliable internet or the necessary devices to participate in telehealth sessions. This digital divide can limit the availability of telehealth services for some populations. Connectivity issues, poor audio or video quality, and other technical problems can disrupt sessions, making it difficult to maintain effective communication and engagement. Ensuring privacy and confidentiality during telehealth sessions can be challenging, especially in busy households. Sensitive discussions or assessments may be overheard or interrupted. On the provider's end, protecting personal health information during telehealth sessions is a priority. It requires secure platforms and compliance with privacy regulations. Healthcare providers and therapists may need additional training to effectively deliver telehealth services and use the technology efficiently. Lastly, for many families experiencing financial hardships, access to the hardware and software needed to participate in telehealth is still a challenge (Ramirez-Moya, 2022).

Telehealth has become increasingly popular for individuals with ASD and their families due to its ability to enhance accessibility, flexibility, and coordination of care. It has improved parental involvement

see Telehealth on page 15

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Empowering Autistic Job Seekers Through Mentorship

By Courtney Carroll
Manager, Hire Autism
Organization for Autism Research

When it comes to job search and employment, autistic adults may face specific challenges, including difficulties with social interactions, executive functioning, and communication. Additional obstacles include employer bias and a lack of understanding. These issues create significant barriers to finding and maintaining employment and advancing within a chosen career path.

Job search mentorship for autistic adults is an incredibly valuable and often underexplored avenue for fostering success. Autistic individuals bring unique strengths and perspectives to the workplace, and mentorship can provide the support and guidance necessary to navigate challenges, capitalize on assets, and prepare them to thrive in professional settings.

Other numerous benefits of mentorship for autistic job seekers include:

- Enhanced job search materials
- Clarification on career goals: short-term and long-term
- Networking skills and growth of the professional network

Helping Autistic Job Seekers Find Meaningful Employment



- Sense of determination and independence in the job search
- Heightened confidence
- Increased self-advocacy and communication skills

Support and Guidance

Mentorship provides autistic adults with personalized support and guidance tailored to their unique needs and goals, regardless of where they are in their job search. This

may include updating job search materials, navigating job descriptions, and preparing for interviews.

Mentors can also support goal identification, an important beginning step for autistic job seekers. This guidance can help autistic individuals identify their career goals and develop practical strategies for achieving them. A clear roadmap allows candidates to find and apply for job opportunities more closely aligned with their education, experience, and skills. Additionally, mentors can clarify the education, training, and networking opportunities

available to support the candidate's long-term goals and career advancement.

An additional support component includes helping candidates identify necessary interview or job accommodations and practicing disclosure to the employer. The ability to understand and ask for accommodations is a great step to growing confidence and advocacy skills.

Confidence and Self-Advocacy

Providing autistic job seekers with this one-on-one support not only helps them understand the job search but also helps them build confidence in their ability to obtain and carry out employment. Mentors can help autistic individuals recognize their strengths and worth, celebrate their successes, and advocate for their needs. By providing encouragement and positive reinforcement, mentors empower autistic adults to believe in themselves and their abilities. Increased self-confidence has direct implications on their performance in the workplace and how they self-advocate.

Self-advocacy is a critical skill in the workplace, defined by the University of California Santa Cruz as "an individual's ability to effectively communicate, convey, negotiate, or assert his or her own interests, desires, needs, and rights. It involves making informed decisions and taking

see *Mentorship* on page 25

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Tapping Your Strengths for Autism Services Advocacy

By Colleen Burnham, MBA,
Eileen Mendes,
and Sabrina Rando, EdD, BCBA, LABA

When most people think of advocacy, they think of lobbying, lawsuits, or legislation. Legislative advocacy has significantly increased access to autism services over the years. However, if it isn't something you're already experienced with, it's outside of your comfort zone. What you might not realize, though, is that you are likely already engaged in some form of advocacy. In autism services, advocacy takes several forms, including appealing adverse funder determinations, improving provider staff retention, increasing access to care, empowering families and individuals, fostering inclusion across settings, promoting awareness, building bridges of communication, and unifying a collective voice.

Consider this parallel adapted from a sociological discussion of illness (McKinlay, 1979): Imagine you're standing at a river's edge enjoying a peaceful, sunny afternoon. Suddenly, you hear a distressed commotion up the river. You look to see someone in the water, flailing as she drifts toward you. She clearly needs help. You run into the river, swim up to her, use all your strength to grab ahold of her and pull her to the riverbank. As you both begin to



process what just happened, you hear more commotion from up the river. Another person is flailing and needs help. You repeat the brave and exhausting act of diving to retrieve them and bring them to safety at the river's edge. Once again, when you've reached safety, you hear more commotion. You look upriver and are devastated to see several more people in distress.

At this point, you can continue to race into the river repeatedly. However, you realize this is not sustainable. Instead, you go upriver to see what is going on. WHY ARE ALL THESE PEOPLE FLAILING

IN THE RIVER? You arrive at a bridge upriver and discover there is a man throwing people into the river. You approach the man and convince him to stop throwing people in the river. Boom: no more people flailing in the river. This solution made the impossible possible. But what does this have to do with ABA and advocacy?

Think of the common barriers to access to autism services. These can be barriers you face in your daily life as a caregiver, through your work as a provider in clinic, residential, home-based, or school settings, and those that you know from your fami-

lies' or clients' experience: provider staff turnover, insurance funder denials, waitlists for services, etc. These barriers reduce access to services and are the people being thrown into the river.

Let's examine the example of provider staff turnover. As a barrier to access to services, turnover has been thrown in and is flailing down the river. You spend all your energy on marketing, interviewing, and onboarding to get turnover out of the river, just like pulling out the people. You look upstream to realize even more turnover is flailing. Constant marketing, interviewing, and onboarding is impossible if turnover continues to be thrown in. You realize this is not sustainable, so you go upriver and determine that the thing throwing turnover into the river is a lack of quality training. So, you work with your clinical leadership to improve the quality of your training. Boom: no more turnover flailing down the river.

We've already considered common barriers to access to autism services. These barriers are very familiar to us because they impact the daily lives of autistic people, their families, and service providers. It is easy to identify the problems. What we may not realize or readily identify is our strengths related to these barriers. Our strengths, though, are how we stop the guy from throwing barriers into the river.

see *Advocacy on page 27*

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Supporting Autistic Service Providers Through Understanding, Inclusion, and Accommodation

By Danielle Aubin, LCSW
AuDHD Psychotherapist
My Autistic Therapist

When I opened my autistic-centered psychotherapy private practice in 2022, I never imagined that a significant portion of my clientele would comprise other autistic service providers. It makes sense now, upon reflection, since our field's challenges are profound, and many of us are drawn to this work by high levels of empathy and a desire to support our community. This means that autistic service providers offer valuable insights from their own experiences as autistic individuals while also being more susceptible to burnout due to their disabilities.

Many may not realize that numerous autistic individuals provide services to the autistic community in various roles, such as occupational therapy, psychotherapy, medicine, behavioral health, and education, among others. Some may openly disclose their autism, while others may not feel comfortable doing so. So, how can organizations support autistic service providers, regardless of whether they are open about their identity?

As a therapist, one of the primary reasons autistic individuals seek my help is



due to workplace issues. This is unsurprising, considering that many autistic individuals struggle with employment due to various factors, including increased rates of discrimination, as reported by the Harvard Business Review. To mitigate negative outcomes resulting from their autistic traits, autistic service providers may attempt to mask or camouflage their characteristics, which exacts a significant psychological

and physiological toll. Consequently, they may resign or lose their jobs due to a lack of accommodations and burnout.

Clearly, being an autistic service provider poses numerous challenges. So, what can organizations do to address them? First and foremost, they need to educate themselves and others on creating inclusive, autistic-friendly environments. Since some autistic service providers openly disclose

their autism while others do not, assumptions about who requires accommodations must be avoided. Some accommodations that enhance environments for autistic individuals include adjustable lighting, reduced noise levels, quiet spaces for retreat, generous work-from-home policies, flexibility in the acceptance of different communication preferences, and increased education on the diverse experiences within the autistic community to combat discrimination, including discriminatory policies that disproportionately affect autistic workers.

Autism is considered a dynamic disability, which means that an autistic person may be able to do some tasks one day and then be unable to do them the next. This can occur due to a variety of factors, including how much stress the person is under, if they have to mask heavily, or if they are experiencing sensory overload. It's important to create a safe space where autistic service providers feel safe enough to share if they need breaks or a reduced workload to accommodate a decrease in functioning ability.

It's crucial to recognize that autistic individuals are not defined solely by their autism; many have multiple marginalized identities, such as being BIPOC or LGBTQ+, experiencing additional

see Supporting on page 25

What Families with Autism Should Consider When Evaluating School Programs

By Todd Harris, PhD
Executive Director of Autism Services
Devereux Advanced Behavioral Health

One of the greatest challenges parents of children with disabilities face is finding the most appropriate educational program. When searching for a school for a child with autism spectrum disorder (ASD), the task can be complex. Understanding instructional and social variables can help parents make the right decision.

Instructional Considerations

First, parents must determine if the instructional strategies employed by a school are consistent with what they feel will be effective for their child. Ensuring the right fit is critical and can be assessed not only by asking questions but also by touring a program and observing classrooms in action.

When observing a classroom, parents should note the following:

- **Student engagement:** For learning to occur, a student must frequently and appropriately engage with materials, as well as with staff and other children. Observe several students and determine if they are listening to the instructor, following directions, completing work, and engaging with recreational materials.



Ideally, students should be engaged at least 80% of the time.

- **Opportunities to build communication and social skills:** Quality educational programs will arrange their learning environments so students have an opportunity to communicate. For example, at snack time, students may be encouraged to ask for their snacks rather than have the teacher offer snacks to them. There should also be opportunities to learn and practice social skills, ranging from greeting others and taking turns

to saying "please" and "thank you" and engaging in conversations.

- **Opportunities to increase independent living skills:** Look for evidence that students are being taught academics, as well as self-care, motor, recreational, domestic, and employment skills (for older students). Ask about the level and intensity of a school's community-based instructional program. For optimal progress, most students should receive systematic instruction in the community at least weekly.

- **Motivational systems, preferred materials, and visual supports:** When observing structured teaching, make sure a motivational system is in place (e.g., a point system or token economy) and that staff is using preferred materials and visual supports (e.g., visual schedule pictorial reward cards, word/picture prompt cards, social stories) to enhance understanding. Ask how staff are trained to implement different strategies. Determine if the teaching methods and interventions are supported by scientific research.

- **The school's philosophy regarding behaviors:** Inquiry about the school's philosophy regarding the reduction of unwanted behaviors, and ask questions, such as, "Are functional behavior assessments used for program planning?" Or, "Are these plans designed to teach appropriate alternatives to replace challenging behaviors?" Consider how staff members respond to unwanted behavior. Are they calm, or do they show frustration?

Social Considerations

While it is crucial to consider the instructional aspects of a school, the social climate is equally important. Parents should pay attention to the frequency and quality of staff-to-student interactions and note the following:

see School Programs on page 30

Preparing Autism Service Providers for Natural Disasters and Other Emergencies

By Kelly Bermingham, MA, BCBA, Michael Wasmer, DVM, DACVIM, Kristen Koba-Burdett, BCBA, LBA, CDP, Maria R.S. Solis, MA, BCBA, Dallas Star, MBA, CDE, Jessica Brown, LCSW, and Veronica Glickman, MA, MS, BCBA

When confronted with an emergency, people with autism spectrum disorder are at a greater risk for injury or death than their neurotypical peers. Many autistic children and adults lack safety awareness or the ability to follow basic safety rules. Even if they have these critical skills, each autistic individual has a unique profile of strengths and challenges that may impact their ability to safely respond to a natural disaster or other emergency.

In the 2021 National Autism Indicators Report: Family Perspectives on Services and Supports, approximately 40 percent of families said they hadn't discussed emergency planning with their support teams (Roux et al., 2021). Qualified autism service providers are uniquely positioned to assist families in preparing for such events.

According to the Federal Emergency Management Agency (FEMA) 2023 National Preparedness Report, the United



States faces increasing frequency and severity of climate-related disasters (FEMA, 2023). Autistic clients and their caregivers may face significant challenges, such as client skill regression, following disasters due to the temporary or permanent closure of autism service provider organizations. Indeed, one in four businesses do not reopen after a disaster. (FEMA, 2018). This makes it essential that autism service provider organizations have disaster preparedness and continuity of care plans.

A **disaster preparedness plan** for autism service provider organizations should be detailed and tailored to address the specific types of natural disasters most likely to occur in your geographic region, such as earthquakes and wildfires in California and tornadoes in the Midwest.

At a minimum, a disaster preparedness plan should include:

- Identification of a crisis planning, training, and response team.

- The location of a collection of emergency basics (e.g., first aid kit, flashlight, radio, batteries, food, water).
- A complete and up-to-date staff contact list that includes mobile phone numbers.
- A means to maintain communication during the disaster in the event of cell phone outages.
- An evacuation plan with a designated post-evacuation meeting point for staff.
- Regular verification of functioning early warning devices (e.g., smoke alarms).
- A detailed inventory list to assist with filing insurance claims, if necessary.
- A current backup of critical organizational data (e.g., service data, vendor contracts, tax documents, and other financials).

Continuity planning helps ensure that an autism service provider organization can continue to deliver essential services with minimal downtime in the wake of a disaster. A **continuity of care plan** must consider both the client's and provider's readiness to resume services.

see Emergencies on page 29

Telehealth from page 11

in sessions, reduces stress and anxiety preparing for doctor's appointments, and offers greater access to a multidisciplinary team. While telehealth can present some challenges, like technical issues and ensuring privacy, it can also help to overcome geographical barriers, offer flexible scheduling, and facilitate real-time support in natural environments. As a result, telehealth continues to be a valuable and widely adopted approach, meeting the diverse needs of the ASD community. The future of telehealth appears to be promising and holds great potential for improving access to care, personalizing treatment, and enhancing the quality of life for individuals on the spectrum and their families.

Jill Krata, PhD, CLC, is the Owner of *Evolve Autism and Family Coaching*. For more information, please email DrJill@evolveautismandfamilycoaching.com.

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What I'd Like to See Change in the Disability World Over the Next 50 Years

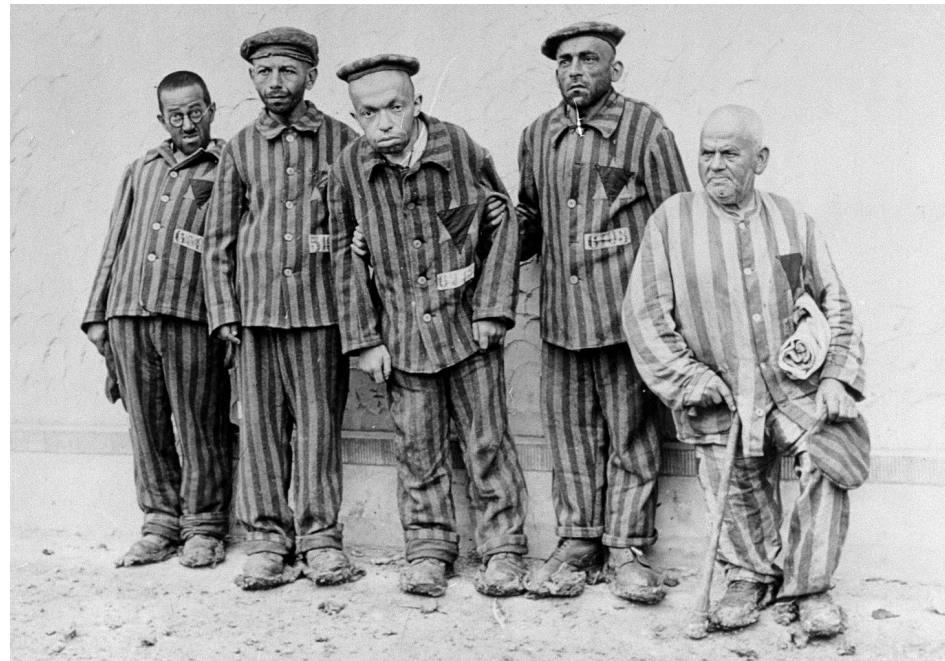
Part 2: Know and Teach the REAL History

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

Occurring all across Western culture is a deep reckoning with the historical treatment of people of African descent. And assisting mightily in this process is the concept of *unlearning*. Without unlearning, we now know that we will continue to sanitize and apologize for our ancestors. Unlearning represents not just more extensive research on the subject, it's a necessity to the most basic learning by putting a separate lens on why our prior teachers needed to lie about the legacy of slavery, Tulsa, Jim Crow, and George Floyd.

People with disabilities/disabled people need to cheer, support, and also take notes. When I mentioned "*society's insecure demand to be able to 'exclude,'*" in Part 1 of this series, "*Let's Change How We Define 'Disability,'*" I may not have been as over-reactive as you thought.

Cut to the chase: Ancient Greeks took us into the woods and chopped us up. The Spanish Inquisition of the Catholic Church drowned or lit us on fire. Europeans from the Middle Ages throughout the first half of the twentieth century used us for scientific experiments without permission or



Five handicapped Jewish prisoners, photographed for propaganda purposes, who arrived in Buchenwald, Germany after Kristallnacht.

Credit: [Wikimedia Commons](#)

anesthesia. The Nazi "final solution" included us. Until the 1972 discoveries with in Staten Island's "Willowbrook" facility, US residential institutions neglected our nutrition, our sanitary needs, allowed us to

often die from treatable diseases, and repeatedly raped (mostly) female residents.

Globally, it is not hard to discover pockets of such eugenics. As late as 2010, California's prisons were still sterilizing (what

were almost exclusively non-white) female inmates in exchange for early release.

All throughout this soul-crushing history, families were encouraged not to love their disabled children as, for centuries, under the "religious model" of disability, we were interpreted as punishments from God for the perceived sins of the parents.

Did we improve that much through the centuries and into the 1960s-1970s, when parents of autistic children were told, "Put him in a home and forget you ever had him?"

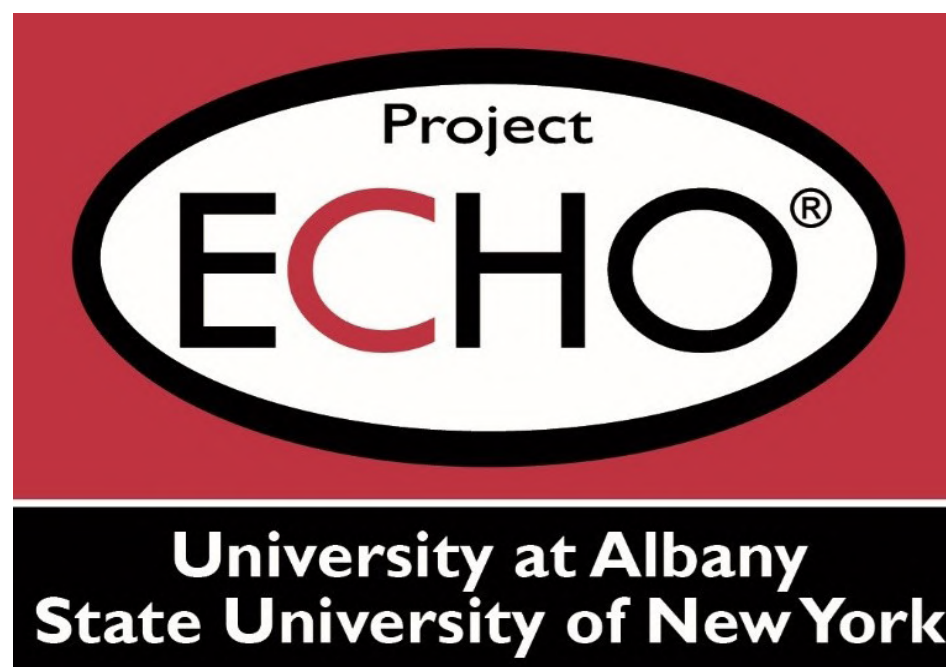
There are many "models" of or ways you can look at disability. There's the social model, the economic model, the aforementioned religious model, and the medical model. And under the medical (or deficit) model of disability, we are defective. Disability itself is perceived as a failure, and it is this model that, in particular, has been used to support the aforementioned horrors. Even the American Psychological Association, normally a haven for cold-thinking (if not heartless) intellectuals, writes, "*The medical model suggests that professionals with specialized training are the 'experts' in disability. Persons with disability are expected to follow the advice of these 'experts.'*" And lastly, many current autism institutions that profess love and respect for

see *REAL History* on page 31

ECHO Autism for Mental Health Clinicians: Creating Access to Specialized Care in Local Communities

By Dan Magin, BA,
Hanna Kent, BS,
Krista Drapalik, MA,
Melissa Rinaldi, PhD,
and Kristin Christodulu, PhD
Center for Autism and Related
Disabilities at the University at Albany

The growing population of individuals on the autism spectrum who have co-occurring mental health conditions necessitates a workforce of mental health professionals who are competent and confident in working with these individuals. Unfortunately, the current research depicts a large gap between that demand and the current state of the field. Evidence-based mental health treatments like Cognitive Behavioral Therapy have been validated and adapted in the treatment of anxiety, depression, and trauma in autistic individuals (Steinbrenner et al., 2020; Walters et al., 2016; Stack & Lucyshyn, 2019). Yet, many mental health providers report receiving little or no training to adapt mental health treatment to the unique needs of individuals on the spectrum (Williams & Haranin, 2016). Related to this lack of autism-specific training among mental health care professionals, many mental health providers experience low levels of self-efficacy in working with this population (Crane et al., 2019).



This lack of training and lack of confidence in treating this population presents a major barrier for autistic individuals seeking mental health services. In a recent study of 462 parents of autistic children with a mental health condition, 32% of parents reported a mental health crisis within the past month, and 25% of parents reported that their children did not receive mental health treatment to address this cri-

sis (Vasa et al., 2019). Statistics like these reflect the dire need for the elimination of barriers to treatment, including accessibility to a competent and confident workforce of mental health clinicians capable of treating individuals on the spectrum.

One model that has been used to effectively and efficiently address this gap is the Project ECHO model. Project Extension for Community Healthcare Outcomes is a

flexible model of education developed by the University of New Mexico (Zhou et al., 2016). It was initially developed to disseminate information from experts to community-based health professionals in rural areas through teleconferencing technology (Zhou et al., 2016). It follows a hub and spoke model in which a team of expert specialists, the hub, collaborate with a group of community-based health professionals, the spokes, in an "all teach all learn" format (Komaromy et al., 2016). This format includes a brief didactic lecture by a specialist and an individual case presentation by the participants of the program (Moody et al., 2020). Project ECHO has been expanded and modified to be used not only with physicians but also with other health professionals, teachers, and even parents (Moody et al., 2020).

The University at Albany has used the Project ECHO model to disseminate information and best practices regarding the treatment of co-occurring mental health concerns with individuals on the autism spectrum. Participants in this program ranged from licensed clinical social workers to doctorate-level clinical psychologists. Preliminary data indicate that this use of the model is a feasible and acceptable approach to helping clinicians access information related to treating autistic clients.

see *ECHO Autism* on page 30

Service Providers Need Enhanced Autism Education from the Autistic Community

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

When I was finally diagnosed in late 2000, public awareness about the autism spectrum, especially the milder variants such as Asperger Syndrome as it was then known, was at best minimal. In particular, the vast majority of mental health professionals (the service providers most likely to address issues facing autistic individuals) knew very little about autism and virtually nothing about Asperger Syndrome if they had even heard of it. I can even remember when a common reaction to the name of my condition (while speaking to mainstream audiences) was one of laughter because the name sounded like “ass-burger.” I actually resorted to using the correct German pronunciation to avoid such responses. Such limited awareness on the part of the general public, and particularly among the service providers that autistics were often dependent on, did not serve our community well at all.

In the two decades since that time, autism awareness has improved dramatically, to the point where it even became part of our popular culture. While this has done an effective job of portraying some more common autistic traits and behaviors, even



if in an exaggerated or less-than-accurate manner, at least there is more widespread knowledge of the challenges faced by those on the autism spectrum. Many common media depictions of autistics, such as technology entrepreneurs, scientists in academia, and brilliant surgeons, are greatly misleading, considering the alarmingly high unemployment rate in our community (even among very talented and sometimes

gifted individuals). As an electronics engineer who had a career in research and development, I am considered exceptionally successful when compared to most of the autism community, even though I was never promoted during my nearly 30-year career (largely by choice) and was hardly a tech billionaire! As for behavioral traits, their representations are a little better, even if they still leave much to be desired. In any

case, despite all the misconceptions, at least there is much wider awareness about the autism spectrum among society in general and among service providers in particular.

Educating Service Providers About Autism

There are two principal categories of service providers, regardless of specialty: those who specifically work with the autistic population and those who serve the general public. The first category, which was minuscule in number when I was first diagnosed, is largely quite knowledgeable about our challenges and behaviors. They are likely to have had formal education and/or training about the autism spectrum, not to mention far greater experience in dealing with a variety of autistic individuals. As such, they are familiar enough with most autistic issues to effectively serve our community. Thanks to the increase in autism awareness over the past two decades, their ranks have increased considerably, even though there is still a great need for many more of them.

However, the situation is somewhat different for those who serve the general population. Although increased public awareness has helped to improve this, there are still enough misconceptions, along with

see [Education on page 29](#)

Autistic Lived Experience: A Song Request at a High School Dance That Backfired

By Sam Farmer
Neurodiversity Community Self-Advocate,
Author, and Public Speaker

Had I known then what I know now, the DJ calling the shots at this dance would not have heard this request despite how much I loved the song in question. It comes down to the fact that context matters, as do the hidden rules of the social situations in which we find ourselves. These realities often eluded me at that point in my life as an autistic individual who didn't know it yet.

I could not believe my eyes when I walked up to him and noticed that he had the album on hand and in plain sight. And I could not believe my ears when he actually decided to honor my request for a song off that album. I felt listened to, that what I had to say mattered, and overjoyed so much so that I ran out onto the dance floor with my quirky, less than stellar dance moves on display the instant I heard it. Unfortunately, I was out there dancing alone, not only with respect to not having a partner but alone, on the floor, surrounded by classmates, faculty members, and whoever else, standing on the sidelines while staring at me, thinking God only knows what, until the DJ saw what was going on, stopped the song after maybe 10 seconds in and abruptly moved on to something else.



Sam Farmer

Back in the '80s, when I was in high school, the expectation at school dances was to hear Top 40-esque Pop/Rock hits of that era, which had a rhythm and a beat that could easily be danced to. A Jazz vocal group, not so much. Imagine songs by the likes of Phil Collins, Madonna, Michael Jackson, Whitney Houston, Tears for Fears, Journey, and Frankie Goes to Hollywood being complimented with one performed by [The Manhattan Transfer](#).

Oops! Not the best choice for this particular circumstance. It didn't matter that the song I requested, [Another Night in Tu-](#)

[nisia](#) off The Manhattan Transfer's critically acclaimed album [Vocalese](#) (1985), features a multi-Grammy Award-winning vocal ensemble joined by the iconic Jazz singer [Bobby McFerrin](#), a multi-Grammy Award winner in his own right. Or that it embodies all the ingredients of a true musical masterpiece. What did matter is that context is paramount.

As a Jazz pianist, the [Dizzy Gillespie](#) classic [A Night in Tunisia](#) (of which [Another Night in Tunisia](#) is a vocal ensemble arrangement) was a favorite of mine to play. A revolutionary composition for its time, it helped fuel the nascent [Bebop](#) movement in Jazz and the beginnings of the Modern Jazz era. I immersed myself in this music from the start, and it wouldn't take long for it to become core to my identity as a musician.

One day, my older brother, also a Jazz musician at the time, brought [Vocalese](#) home and played [Another Night in Tunisia](#) while I was hanging around. I was immediately swept away by the adaptation, having never imagined that [A Night in Tunisia](#) could sound anything quite like this. The Manhattan Transfer was now on my radar, and seeing [Vocalese](#) at the dance provided the bait that I simply could not resist.

And then humiliation set in, although thankfully only briefly because the song didn't play for long, and nobody gave me a hard time. My classmates and teachers knew me pretty well, including my social

idiosyncrasies and worse crimes have been committed, so luckily, this turn of events fell short of being traumatic in any way.

Unidentified autistic individuals are particularly vulnerable to trauma, largely because of stigma, pronounced sensory and emotional sensitivities, and the fact that many of our behaviors, for which there are no explanations in the absence of a diagnosis, are at odds with societal expectations. In retrospect, I was most fortunate that night, having been able to move on from this incident mostly unscathed.

In many respects, my unusual song request made perfect sense. The hidden rules of social situations were all but non-existent to me back then, largely due to a strong preference common among autistics for that which is explicit, factual, apparent, and does not need to be read “between the lines.” As such, I often depended on visual cues to help guide my decision-making, and it was not as if there were signs posted at the dance which said, “No requests for Jazz.” The visual cue I did encounter was the one that ultimately led to embarrassment: the [Vocalese](#) album cover, sitting there next to the DJ, waiting to be picked up, even at a high school dance governed by opposing expectations.

All in all, I found myself in the middle of a perfect storm within which I couldn't

see [Lived Experience on page 28](#)

Pulling It All Together: How to Create a Multidisciplinary Team for Your Child With Autism

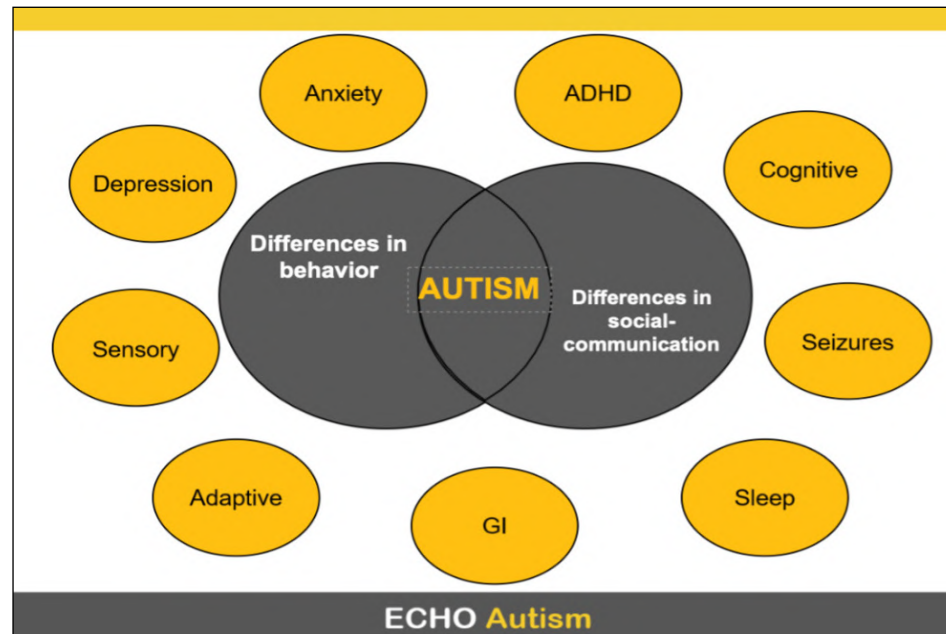
By Amy Kelly, MBA, MNM
National Director of Family Engagement
Devereux Advanced Behavioral Health

When families receive an autism diagnosis for their child, they may not realize they are also likely receiving a diagnosis for other medical and behavioral health conditions that have not yet been identified.

Autism is a chronic condition that requires ongoing treatment and support. Certain medical and behavioral health conditions are more likely to coexist with an autism diagnosis and require more frequent monitoring. Some of these conditions include anxiety, attention-deficit/hyperactivity disorder, behavioral differences, seizures, sleep disturbances, and gastrointestinal concerns.

Ideally, every child diagnosed with autism would be seen at a clinic with subspecialists available to conduct a multidisciplinary evaluation (an evaluation performed by various specialists who come together to look at a child as a whole from their expert viewpoints), which could identify any coexisting conditions.

Unfortunately, this is not always possible. Instead, you may need to build your own multidisciplinary team, which could



include the following subspecialists:

- Developmental and behavioral pediatricians
- Psychologists and psychiatrists
- Neurologists
- Gastroenterologists
- Sleep specialists
- Speech-language pathologists
- Occupational therapists

Finding these subspecialists (as needed) contributes to creating a comprehensive team that includes school specialists, teachers and staff, and other behavioral

health professionals.

Sometimes, a case manager is assigned to a family (through insurance or behavioral health services) to locate these professionals and, perhaps, even connect with them. However, in most cases, the parents or family need to create and connect this team.

When “connecting” team players, make sure you:

- Bring copies of reports from other disciplines to each appointment for other team members.
- Ask those team members to be copied on any electronic communications.
- Create a shared drive through Google or another platform to upload and store any documentation (e.g., reports, visit summaries, therapeutic notes) and allow access for all team members

While it is not an easy task to search for specialists, attend all of the appointments, and connect with your child’s team members, it will be well worth the effort and can make a significant and positive difference in the long run for your child’s progress and your peace of mind.

see *Multidisciplinary on page 31*

The Impact of Professional Networking for Autism Service Providers

By Mary Ann Hughes, MBA
Certified Special Needs Divorce Coach
Special Family Transitions LLC

It is often said “it takes a village” to provide support to families impacted by autism. Parents of autistic children may find that to be true, especially when looking for resources to support their children and for themselves, but it also applies to professionals looking for ways to connect with those who could benefit from knowing about their services.

As someone who was inspired a few years ago to start a business to support divorcing parents of children with autism and other disabilities, I had to not only learn how to start a business and get certifications and additional knowledge to effectively support the clients I hoped to serve, but I had to get out there so that families, as well as professionals, could learn about me and my services.

I am told by many parents and fellow professionals that I am “everywhere,” and I am seen as a thought leader in the field of special needs divorce coaching. Visibility in the marketplace was certainly one of my goals as a new business, and I am proud of the work I have done to reach and support families and professionals. I will share in this article some of the things I do to raise awareness of the services I provide, my company, and myself.

Social media platforms are certainly



a great way to get visibility in your local community, as well as to gain a broader geographic reach. Facebook, Instagram, and LinkedIn are popular platforms to post and interact with family members and professionals. Not only are professionals who post valuable content seen as authorities in their field, but people who follow their content may develop a parasocial relationship with them, meaning they may feel like they know the professional on a personal level, even though they have never met in person. This is an important way to develop the

Know-Like-Trust factor so people can feel comfortable doing business with someone or entrusting that professional with the care and guidance of their child or family.

Joining organizations, associations, or groups of professionals in your field or area of interest is a great way to get to know like-minded professionals with whom you can develop relationships collaborations, and even become referral partners. Take advantage of the opportunities to get to know and learn from other members, whether these are in-person or online.

Another important way to network with professionals is to participate in in-person events. Post-COVID, many events and meetings have gone online, but there is still a lot of value in meeting people face-to-face. One of my favorite types of events to attend is Resource Fairs, especially those put on by local school districts. Not only do you get to meet families looking for information and services, but you can and should take the opportunity to meet fellow vendors who are present. Often, these are the organizations and representatives you will see at other events and can also follow up with to become collaboration and referral partners. When given the opportunity, also take advantage of presenting and sharing information in front of a live audience to demonstrate your expertise and establish your credibility in your given field.

In the words of Henry Ford, “Coming together is a beginning. Keeping together is progress. Working together is success.” So, make and take opportunities to meet fellow professionals and do great things together.

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Enhancing Dental Care for Autistic Individuals: Strategies and Collaboration

By Mecca Slocum
and John Timothy Hansford, DMD
Athens Area Pediatric Dentistry

For individuals on the autism spectrum, navigating dental care can present significant challenges, often resulting in long waits and apprehension. In such instances, the partnership between dental practitioners and professionals who work with individuals on the autism spectrum becomes not only beneficial but essential.

Personalized Care

Dental environments can be overwhelming for those on the autism spectrum due to sensory sensitivities, communication barriers, and anxiety. Dr. John Hansford, Pediatric Dentist and Dental Anesthesiologist at [Greenpoint Pediatric Dentistry](#), emphasizes the importance of personalized care tailored to each patient's specific needs.

Dr. Hansford states that both autism and anesthesia are assessed based on their location along their respective spectrums. Thus, personalized evaluation and customized treatment are crucial. Conducting phone consultations or non-treatment office visits with patients and caregivers can align



doctors, staff, and healthcare teams on triggers, calming techniques, and patient comfort levels. Once a comprehensive understanding of patient expectations and behaviors is established, a treatment plan can be devised to accommodate their comfort levels, ranging from behavior management strategies to sedation and, when indicated, general anesthesia to ensure humane, high-quality dental care.

Community Collaboration

Collaboration between dentists and professionals experienced in autism spectrum disorder is crucial for meeting the diverse needs of individuals on the autism spectrum. Professionals such as speech-language pathologists, occupational therapists, behavior analysts, and special education teachers play vital roles in

informing individuals on the autism spectrum about dental care providers capable of catering to their unique needs.

Martha Ranson, Speech-Language Pathologist at the Clarke County School District, underscores the necessity of community collaboration in dental care for individuals on the autism spectrum. She emphasizes the importance of inclusive dental services and healthy oral structures, which are essential for speech development.

Speech-language pathologists are often among the first professionals children encounter post-autism diagnosis, making access to inclusive dental services crucial for parents. Martha states that healthy oral structures, including aligned teeth and proper tongue function, are essential for speech development, underscoring the importance of dental health. Having a dentist capable of working with children with special needs, particularly autism, is vital. Many parents may overlook dental care due to anticipated challenges, such as sensory and communication difficulties their child may face during visits and procedures.

Training and Innovative Approaches

Comprehensive training for dental professionals is essential for providing

see Dental Care on page 32

Unspoken Injuries: Supporting Health Professionals Coping With Client Loss

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

I was delighted to get my first consultant job working in an in-patient [psychiatric] unit... In my second week, I had my first patient die by suicide. In my third week, I had my second patient die by suicide. In my third month, there was a very distressing...death by suicide on the ward...[P]art of me died. How could I have had three deaths like this? It must have something to do with me (Gibbons, 2023).

My reaction to the above statement is that no health professional is omniscient. Violence against self or others is a concern with which all human services providers are familiar, whether serving the psychiatric population or people with developmental disabilities, and exceptions to "doctor-patient" confidentiality agreements underscore those situations. Helping professionals ask their clients about suicidal thoughts and actions, but some cling to the omnipotent belief that they have special powers of insight into others' minds and the ability to predict what someone will do in the future.

Unfortunately, there is also widespread anxiety in Western society that frank discussions of self-harm and death both encourage suicidal thoughts and behaviors and normalize them.



Suicide Statistics

According to the Centers for Disease Control and Prevention, "more than 48,000 people died by suicide in 2021. That is 1 death every 11 minutes. 12.3 million adults seriously thought about suicide" (Suicide Data and Statistics | Suicide Prevention | CDC).

In the developmental disabilities sector, which includes autism, the stigma of odd behavior is exacerbated by decreased awareness and understanding of what makes people tick. People with major mental illnesses are at greater risk of self-

harm or suicide than the general public, and autistic people are at a higher risk of suicide than those with mental illness. Rigid thinking, difficulty adapting to change, social isolation and loneliness, lack of coping strategies, and oversensitivity to stimuli all increase the risk of suicide in autism (Shtayermman and Fletcher). "Combining data across studies, prevalence of suicide attempts in ASD was estimated to be 7 to 47%, and suicidal ideation was 72%" (Hedley and Uljarević, 2024).

In her article, *6 Reasons Autistic People Are at Greater Risk of Suicide*, Claire Jack

references research suggesting that over 50 percent of people who had attempted suicide scored above the cut-off point for likely autism as measured on the Autism Spectrum Quotient (Jack, 2023)

Undiagnosed ASD and Suicide Risk -

More and more adults – many of them women – are seeking autism assessments, suspecting they fell through the cracks in the system during childhood. Some have long histories in the mental health system, with long lists of difficulties such as problems with employment, relationships, and mental health issues, including suicidality.

Personally Affected - This author was officially diagnosed with Autism and ADHD in 2021. I initially entered the mental health system in first grade, re-entering it in my early 20s after achieving an MA in clinical psychology. I was confused, depressed, and angry that, despite a large volume of theoretical knowledge of human behavior, I was unable to apply any of it in a clinical setting. Due to undiagnosed sensorimotor impairments, I couldn't even keep jobs in retail sales or fast food restaurants.

I self-injured numerous times. My depression reached the point where I begged one psychiatrist for a lobotomy. I felt entirely alone, wretched, and unvalidated – in part because my doctors agreed that none of my many diagnoses was a "textbook case"

see Coping with Loss on page 31

How to Create a Safe and Engaging Sensory Experience at the Pool

By Maggie Achenbrener, OTD-PP, OTR/M
Concordia University Wisconsin
and Alysha Skuthan, PhD, OTR/L, ASDCS
Shenandoah University

The pool is a great tool to use to cool down and engage individuals with autism spectrum disorder (ASD) over the summer. Not only can water exploration in the pool provide socialization opportunities in a natural environment, but water can meet essential sensory needs as it provides deep pressure to calm the body, resistance to build strength and provide sensory input to the body, and gross motor movement to help regulate the body (Torres-Ronda & Schelling i del Alcázar, 2014). Additionally, individuals with ASD enjoy swimming more than individuals without ASD (Eversole et al., 2016), supporting the integration and exploration of the pool to provide leisure activity engagement. There are many things that can be done to prepare for the pool to create a safe experience and meet the sensory needs of individuals with ASD.

Tapping into the Sensory System

In order to meet an individual's sensory needs, it is important to consider what those sensory needs are. Below are some examples of how to create the best sensory pool experience.



Movement Seeker/Adventurous Explorer: If an individual with ASD enjoys crashing into objects, jumping off of surfaces, spinning, and/or desires frequent movement, consider providing opportunities to jump into the pool, climb/pull out of the pool, or swim laps for the trained swimmer. The resistance of the water (Torres-Ronda & Schelling i del Alcázar, 2014), along with the rote movement of swimming laps, can be calming and provide the needed movement that is often

desired on land. Additionally, while swimming laps, the corpus callosum, or middle of the brain, sends messages between both hemispheres of the brain (Goldstein et al., 2023). This communication between both sides of the brain encourages tracking across the midline of the body or integrating both the left and right sides of the body (Goldstein et al., 2023), a skill that helps to prepare an individual with ASD to read, engage in math, and have more awareness of their body.

Movement Avoider/Cautious Explorer: If an individual with ASD is cautious with movement, avoids various textures, or selectively engages in sensory activities, provide opportunities to interact with water outside of the pool first. Throw or set objects into the pool to see how they float; scoop water out of the pool into other containers to observe the movement of the water, which can be visually calming and/or regulating; throw toys into the pool and encourage retrieval of the objects from the side of the pool; and/or even dip a sponge into the water and encourage washing hands, arms and/or legs with the sponge. Never force water participation, but rather encourage curiosity and exploration in a way that promotes comfort while still interacting and enjoying water. Once an individual with ASD is ready to enter the pool, allow them to hold onto you or the side of the pool so they feel anchored to an object. Once they feel comfortable moving away from the edge of the pool, engage them in rhythmic swaying or rocking, as this can be calming and regulating for the sensory system.

Safety

While swimming provides many social, leisure, and sensory opportunities, it is important to prioritize safety, as drowning is

see Pool Safety on page 32

Promoting Quality Applied Behavior Analysis Services Through Nonprofit Accreditation

By Erick M. Dubuque, PhD, LBA, BCBA-D
Director
Autism Commission on Quality

Individuals with autism demonstrate persistent differences in social communication and interactions as well as restricted, repetitive patterns of behavior, interests, or activities (American Psychiatric Association, 2013, 2022). Autism exists on a wide spectrum, and there is a great deal of variation in how it affects individuals and their families. According to surveillance data reported by the Centers for Disease Control (CDC) (2023), childhood prevalence estimates of autism have increased dramatically over the last two decades from 1 in 150 in 2000 to 1 in 36 in 2020.

For decades, applied behavior analysis (ABA) has been widely recognized as an effective treatment for autism by numerous independent, government, scientific, and professional bodies (Larsson, E.V., 2021). Unfortunately, there are numerous barriers creating variability in service quality that are preventing patients from accessing the care they deserve, including, but not limited to, unqualified providers falsely claiming expertise in ABA (Dubuque, Yingling, & Allday, 2021); training programs failing to adequately prepare providers (Dubuque & Kazemi, 2022); poor distribution of qualified providers across the country (Yingling,



Ruther, & Dubuque, 2022); low and variable reimbursement rates across funding sources (Maglione et al., 2016); overleveraged companies prioritizing profits over patient care (Batt, Appelbaum, Nguyen, 2023); inexperienced clinical providers working with minimal oversight (Behavior Analyst Certification Board [BACB], n.d.); and demand for services far outweighing the supply of qualified ABA providers (BACB, 2023).

Compliance with industry standards developed and enforced by a known and trusted accreditation body is needed to address these barriers. Alongside other quality

control mechanisms (e.g., professional certification, licensure), accreditation can help stabilize the industry by promoting standards designed to address meaningful issues preventing access to quality ABA services.

Accreditation offers numerous benefits to individual organizations by verifying and keeping their focus on quality improvement, patient safety, risk mitigation, consumer satisfaction, and professional development. More importantly, widescale adoption of accreditation has the potential to benefit the industry by serving as a stabilizing force that fosters a culture

of professionalism, ethical behavior, and continuous improvement. Unfortunately, while these benefits are significant, they may not be strong enough to incentivize the industry to invest the time and resources necessary to pursue accreditation on a large scale. Instead, widescale acceptance and adoption of accreditation is likely to be achieved only when financial and regulatory incentives are created that make it more expensive for organizations to opt out of accreditation than to opt in. Funders are uniquely positioned to create financial incentives to promote the widescale adoption of accreditation by recognizing trusted accreditation bodies. Recognition could come in multiple forms, including limiting access to funding streams, offering preferred rates, expediting the credentialing process, or eliminating administrative burdens for accredited organizations. Funders must be careful when they create financial incentives for organizations to pursue accreditation. Many ABA provider organizations have never gone through an accreditation process and will need adequate time to align their operations to industry standards. Creating incentives that require accreditation too quickly could serve to limit access to services instead of improving access to quality services. Fortunately, funders can mitigate this issue by giving enough notice

see Accreditation page 21

The Case for Acceptance Commitment Therapy for Sensory Processing in Autistic Young Adults

By Priya Winston, PhD, LMSW
Transitions

In my career as a clinical service provider for Autistic young adults, I have seen how understanding the senses can impact one's emotions. It is so important to be aware of how Autistic people learn, communicate, and think with all of their senses. Recently, The DSM-5TR has included "sensory symptoms" in the diagnosis of Autism Spectrum Disorder. In other words, it is a sensitivity to sounds, sights, smells, tastes, and textures (Patil & Kaple, 2023). There are many questions I urge clinicians, therapists, and multiple mental health service providers to consider relating to this when they work with Autistic People.

What is the environment of your office like? Are there peaceful but stimulating designs and colors? Are there items with soothing textures and sounds? What lights or moving items are in place? How do you communicate with those that you work with? Do you offer any visual components? Are there images or videos to explain what you are discussing with someone when you are speaking? How do people with Autism communicate with you when they are not audibly speaking? How are you communicating non-verbally with body language or



other methods that they may be picking up on? I recently did a presentation at an event about teaching self-advocacy to Autistic young people. My favorite part was when a teenage boy and his mother approached me after the conference. The boy pulled out a tablet from his device. He wrote a message on his tablet to thank me for the presentation and to say that he related to what I spoke about. This message would have been lost if his mother or I focused

on having him speak out loud at that moment. This is not to say that working with people on their audible speech) is wrong or unimportant (shout out to speech-language pathologists). I simply mean to convey that we must be attuned to people.

Movement can be another part of sensory processing or communication. Are the people you work with able to stand or move when they meet with you in your office? If you have experience with working

with Autistic People, you may be familiar with the term "stimming." Stimming refers to actions that are repetitive in motion and sound. Most experts agree that it is a response to sensory stimulation that serves to regulate their emotions (Rudy, 2023). Are you accepting of the sensory sensitivity yourself? Do you encourage Autistic people who you work with to embrace the idea that their sensory sensitivity may make them different from those who do not have Autism? The stigma in our society with this can be difficult.

Unfortunately, we also live in a world where actions related to sensory sensitivity may hinder the achievement of goals of Autistic people. In my humble opinion, this needs to be prioritized over changing how the world sees Autistic people. For instance, if someone wishes to go to college and obtain a job in an office setting after graduation, they will have to learn to manage constantly needing to move or shake their body. Stimming will likely not be possible in their college classes or in the office settings where they work. Should college administrative professionals and employers consider ways that they can be inclusive and accommodating to this? I would say absolutely! I firmly believe this, as I am fortunate to have the opportunity

see *Therapy on page 30*

Accreditation from page 20

to providers before these financial incentives are established to ensure organizations have enough time to prepare, apply, and participate in the accreditation review process.

For funder recognition to work, the relationship between funders, provider organizations, and accreditors must be mutually beneficial with appropriate checks and balances coming from all sides. This can be achieved by ensuring that funder concerns about quality, safety and efficiency are addressed within an accreditor's standards and review process. Accreditation bodies can appropriately balance and incorporate standards that address funder concerns by relying on independent committees comprised of industry experts and representatives from the diverse groups involved in receiving, delivering, supporting and funding services. Accreditation bodies can also appropriately balance provider needs by partnering with state professional and consumer associations who are better equipped to understand the local service landscape and how accreditation can be most beneficial to the providers working within in it. Accreditation bodies can also work together with funders to help align their policies with industry standards, which ultimately should help reduce the administrative burden providers face when trying to comply with the patchwork of policy requirements across different funders.

For recognition to work, it is critical that funders ensure that they do not inadvertently recognize accreditation bodies with known and unknown financial conflicts

of interest that compromise their ability to regulate the industry. For example, accreditors should not be involved in selling the organizations or services they regulate. Accreditation bodies perform an important societal function by setting and enforcing industry standards. When these bodies are structured as nonprofits they are better equipped to fulfill this function because they are created to serve the public good and are required to adopt additional safeguards to ensure they remain transparent, accountable, and trusted by the communities they serve. For example, nonprofit status helps ensure an accreditation body is not concealing its sources of financial support or any agreements made to secure that support from unknown sources. The integrity of an accreditor is not guaranteed by its nonprofit status; however, this status and the additional safeguards it brings are designed to help prevent financial conflicts of interest and unethical behavior.

Widespread adoption of accreditation for ABA service providers is an important step the industry needs to take to address the numerous barriers preventing families from accessing the care they deserve. Funders can help promote this adoption by creating financial incentives that encourage organizations to pursue accreditation from trusted nonprofit bodies.

Erick Dubuque, PhD, LBA, BCBA-D, is the Director of the Autism Commission on Quality (ACQ), a nonprofit accreditation body for organizations offering applied behavior analysis as a healthcare service to individuals and families affected by autism. ACQ is backed by the Council of Au-

tism Service Providers (CASP), a known and trusted trade association with over 350 organizational members serving over 125,000 individuals with autism. More information about ACQ and CASP can be found at <https://autismcommission.org> and <https://casproviders.org>.

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The Neuro-Strength-Based Support Framework: A Collaborative, Strength-Focused Approach to Autism Interventions

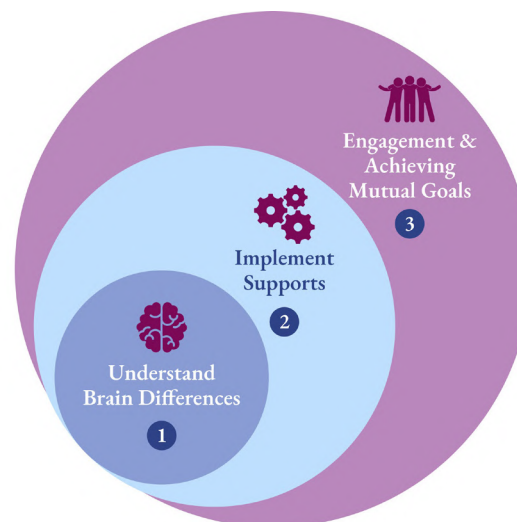
By Susan Golubock, MEd
and Staci Neustadt, MS, CCC-SLP
Making Sense of Autism

Autism remains an enigma to some despite decades of research and a plethora of interventions aimed at addressing its myriad facets. Historically, interventions have been crafted to mitigate perceived developmental, sensory, and behavioral deficits without a solid foundation in the bio-neurological underpinnings of autism or consideration of co-occurring conditions. Such an approach often neglects the essential insights that could be derived from the very individuals it aims to help—those on the autism spectrum.

The inclusion of autistic individuals in the design and evaluation of intervention strategies is a rare occurrence. Yet, their involvement is crucial to ensuring the interventions address their real needs and preferences. A more profound understanding of the neurological differences in autism could facilitate more effective coordination between various approaches, including behavioral, developmental, educational, therapeutic, medical, and family-based strategies.

The Neuro-Strength-Based Support Framework

The Neuro-Strength-Based Support for Autism (NSBSA) is a novel framework designed to fill this gap by translating neuroscience research into practical terms that autistic individuals and their support networks can understand. Rather than propos-



ing a completely new intervention method, NSBSA serves as a unifying framework. This framework is applicable across different disciplines, allowing therapists, educators, clinicians, and parents to increase their understanding of autistic strengths and address the desires of the autistic individuals they support.

Development and Objectives of NSBSA

Developed by an autistic occupational therapist, Susan Golubock, drawing from both professional and personal experience, NSBSA focuses on utilizing the strengths of autistic individuals to provide necessary supports that enhance their functional abilities. The effectiveness of the NSBSA framework was researched via a structured training program for service providers working with autistic clients, with three primary objectives:

1. Feasibility and Acceptability: To evaluate how feasible and acceptable the NSBSA training program was among service providers.
2. Satisfaction with Intervention Goals: To measure changes in service providers' satisfaction with their intervention goals for autistic clients before and after the training.
3. Goal Writing Focus: To assess shifts in service providers' goal writing, from focusing on remediating deficits to achieving milestones to emphasizing the use of autistic individuals' strengths and supports for enhancing desired functional abilities.

Training Program and Evaluation

The NSBSA training program consist-

ed of eight modules, followed by weekly virtual meetings with researchers for questions and discussion. The topics covered in the modules included:

1. Introduction to NSBSA for Autism
2. Interpreting and Supporting Autistic Behaviors
3. Sources of Autistic Motivation
4. Autism Neuroscience Research on Attention to Input
5. Autism Neuroscience Research on Processing and Recall of Input
6. Autism Neuroscience Research on Body and Emotional Self-Awareness
7. Developing Goals that Target Desired Function
8. Developing a Program Plan for Implementing NSBSA Goals

Participants underwent pre- and post-training evaluations. The pre-training phase involved a Goal Satisfaction survey and a Goal Writing assessment. After completing the training, participants filled out a Post-Training Goal Satisfaction survey, a Post-Training Goal Writing assessment, and a Course Satisfaction Survey.

Results and Implications

The data analysis, using paired t-tests to

see Framework on page 23

Staff Turnover from page 1

Board supports behavior analysts by giving free access to peer-reviewed publications and academic journals to ensure we are up to date on research and knowledgeable about best practices in ABA. Additionally, BCBA's are required to provide consistent and ongoing supervision, train RBTs and stakeholders in best practices, and ensure interventions are being implemented with fidelity. The aim is to promote autonomy for our clients.

Along with the BACB providing resources to support practitioners, BCBA's and RBTs support each other within the field. BCBA's have gotten together to create organizations such as Applied Behavior Analysis International (ABAI), the Association of Professional Behavior Analysts (APBA), state organizations, and more. These organizations hold conferences where practitioners from different areas of the field can collaborate, share their work and research, and offer tools to help increase the quality of direct services. They also provide continuing education units, which BCBA's must obtain to ensure they stay up to date on research and best practices in the field.

Supervisors within ABA provider groups should meet with BCBA's weekly to provide support in areas such as case reviews,

RBT supervision tasks, and data-based intervention decisions. They should also provide guidance and advice when staff are taxed from productivity requirements and caseload complexity. Providers can also survey their employees periodically to ask what additional support they feel will be helpful as they carry out their services daily. As supervisors create schedules, they should consider details such as drive time, staff preferences in setting, and appropriateness of staff-to-client ratio. This all contributes to minimizing burnout and cultivating a group of professionals who feel supported, motivated, and passionate about their profession.

In addition, professional development opportunities are the greatest resource for our Autism providing partners. Staff from a behavior technician level all the way up to a director should have access to professional development opportunities. This helps providers keep up with the research, data, and developments in ABA. Compassionate and trauma-informed care have surfaced as priorities in our field and should be at the forefront of treatment. Assuring that our Autism providers are fully versed in these domains should be standard practice. It helps provide and encourage staff to be more empathetic providers.

It is also especially important that staff

have opportunities to share their interest in training topics they would like to explore. School districts and clinic-based providers can especially use this as a tool for gearing training toward specific topics. It also enables the staff to find time to share their experiences on what is working and what they need more support with. By providing staff with opportunities to share and learn, we can assess and work towards reducing staff burnout. When we reduce burnout, we are cultivating a work environment geared towards effective services that are ethical and compassionate.

Providers can also benefit from mentorship opportunities and peer review of their direct and indirect work. Having access to a peer to provide feedback encourages flexibility in a permanent product of work and the ability to gain new experiences in thought processes and strategic development of treatment. This ensures the quality of services and creates meaningful goals for the clients we serve.

Georgia Efthimiou, MA, BCBA, is Sr. Director of School Based Services, Lisa Radil, MA, BCBA, is Assistant Director of School Based Services, Brandon Sierchio, MA, BCBA, is Director of Quality and Training, and Howard Savin, PhD, is Clinical Advisor at First Children Services.

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Value-Based Developmental Disability Care Driven by Innovation Can Efficiently Battle Rising Healthcare Costs

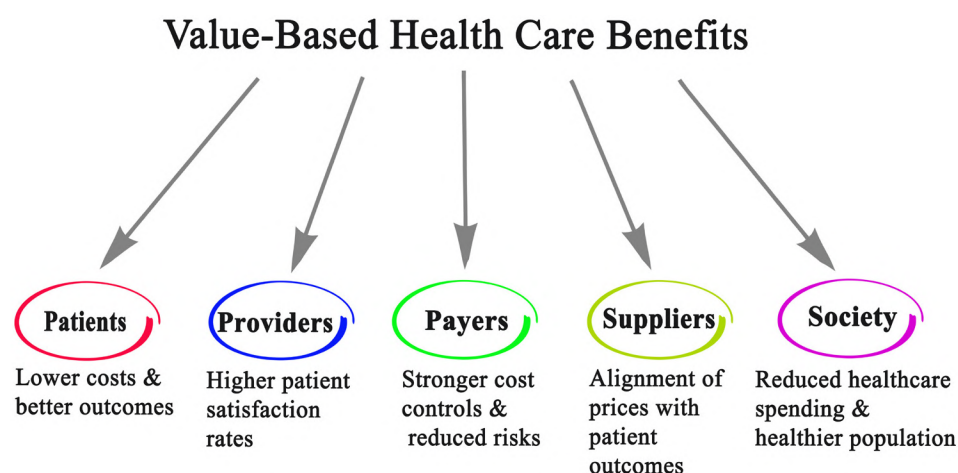
By Trent Iden
Chief Growth Officer
Catalight

There's a fundamental truth that often gets lost amid the complexities of behavioral health insurance costs: the paramount importance of outcomes.

The call for value-based care across all healthcare is becoming louder, signaling a desire to shift from the traditional fee-for-service model to one centered on results. With the increasing rates of autism, that transformation is critical in the behavioral health space, where rising costs and fragmented care underscore the urgent need for innovation.

Catalight has been working under a pioneering value-based care system in partnership with its largest payer since 2018. Through extensive research and a decade's worth of evidence-based practice, our clinical team is strong in the belief that lower hours of applied behavioral analysis (ABA) – especially in the form of parent-mediated care – is just as effective if not more so, than the standard, high-hour ABA.

Value-based care redefines success not by the volume of services rendered but by the quality of outcomes achieved. It's a departure from the unsubstantiated notion that more equals better, instead focusing on what truly matters: improving the lives of clients and their families. Catalight's core 'value' is creating greater wellbeing. We're able to create that value in as few as 8 hours a week in ABA compared to standard models that call for more than 30. Shifting to customized care presents hope for tackling



the burgeoning crisis of escalating costs in behavioral health.

The biggest factor in implementing value-based care is innovation. Led by clinical indication, Catalight has been relentlessly looking at the situation differently.

Intellectual and developmental disability care defies the standardized treatment approaches all too common in fee-for-service models. Our mentality is "one size doesn't fit all." We fully embrace that each person we serve is unique with differing family dynamics; put together, the population, as a whole, is drastically more heterogeneous than it was when high-hour ABA became the standard in 1987. By tailoring treatment options for each client and giving choices, we seek to provide flexibility and freedom to families. When children achieve greater wellbeing through lower-hour ABA and telehealth options, parents are able to use that time for the betterment of their family holistically – enhancing the quality of life for all members. We're looking to do

more than just deliver care – we're reimagining it for efficiency and effectiveness.

Giving a choice in one's care is important not only to achieve outcomes faster, which is a critical component of succeeding within a value-based environment, but also to eliminate waste and inefficiency. When there's wasteful spending, families lose.

Catalight published a study in March that noted a diminishing return after 15 hours per week of ABA. In the fee-for-service system, more hours billed means more reimbursement without a cap or financial reason not to provide more care. Families are paying out of pocket for unneeded hours. In turn, it's costing insurers more to cover the cost of behavioral health benefits – forcing them to increase premiums.

When treatment is more efficient with far fewer hours, not only is a family saving time that can be spent elsewhere, but they're saving tangible dollars in cost share. By prioritizing outcomes over sheer volume, payers in value-based care are

demonstrating this model is not just a theoretical concept but a pragmatic solution with proven benefits.

Payer motivation remains the chief hurdle to greater adoption of value-based care in behavioral health. Billing systems, authorization for services, and general 5-year plans are all built around fee-for-service. A transition to a value-based model requires a concerted effort to recalibrate incentives and align interests toward the shared goal of improving patient outcomes.

While such a long-term change will be complicated and arduous, the benefits to families and the behavioral healthcare industry could be monumental.

At the heart of value-based care lies a commitment to the client experience. It's about empowering families with choice, flexibility, and convenience while sparing them from unnecessary burdens of time, stress, and financial strain. By streamlining care delivery and eliminating wasteful spending, value-based models offer a lifeline to families.

As healthcare costs spiral out of control, the need for sustainable solutions becomes increasingly more pressing. By embracing value-based care, we're not just reimagining behavioral healthcare; we're reshaping lives, one outcome at a time.

Trent Iden is Chief Growth Officer at Catalight, a nonprofit that provides access to innovative, individualized care services, clinical research, and advocacy - so people with developmental disabilities can choose their path. Samelson is a licensed clinical psychologist and leads the organization's behavioral health research team with a focus on promoting the overall wellbeing of families.

Framework from page 22

evaluate changes in Goal Satisfaction and Goal Writing, showed significant improvements post-training. This was indicative of a positive shift in how service providers perceived and wrote their intervention goals, now focusing more on the strengths and desired outcomes of autistic individuals.

The training program received high marks from participants, with 100% recommending the NSBSA training for other therapists and stating that the length of the training was just right. Additionally, all participants agreed that the training helped them make meaningful changes to their current strategies with clients.

Emphasizing Strengths Over Deficits

The traditional deficit-based model of intervention has often focused on what autistic individuals cannot do, aiming to "normalize" their behaviors and abilities. This approach can be both limiting and stigmatizing, reinforcing negative perceptions and often overlooking the unique strengths and potential of autistic individuals.

The NSBSA framework shifts this perspective by recognizing and harnessing the inherent strengths of autistic individuals. This strength-based framework not only

fosters a more positive self-image among autistic individuals but also encourages them to leverage their unique abilities in ways that enhance their quality of life.

For instance, autistic individuals often exhibit exceptional attention to detail, strong memory skills, and a deep focus on specific interests. By designing interventions that build on these strengths, therapists and educators can help autistic individuals achieve greater success and fulfillment in their personal and professional lives.

Integrating Neuroscience into Practice

One of the core innovations of the NSBSA framework is its foundation in neuroscience. By incorporating the latest research on how autistic brains function, the framework provides a more accurate and nuanced understanding of autism. This scientific basis helps demystify the condition and offers practical insights into how best to support autistic individuals.

For example, research on sensory processing differences in autism can inform more effective strategies for managing sensory overload. Understanding the neural mechanisms behind autistic individuals' unique ways of processing and recalling information can lead to better educational techniques that cater to their learning styles.

A Collaborative Framework

The development and implementation of the NSBSA framework underscores the importance of collaboration among all stakeholders involved in supporting autistic individuals. This includes not only professionals like therapists and educators but also family members and, crucially, the autistic individuals themselves. The tools and strategies offered in the NSBSA framework are ones that anyone, professionals, parents, and autistics, can use and benefit from.

The NSBSA framework involves autistic individuals in the design and evaluation of interventions, ensuring that their voices are heard and their preferences are respected. This collaborative framework fosters a more inclusive environment where autistic individuals feel valued and empowered.

Moving Forward: The Future of Autism Support

The positive outcomes of the NSBSA training program highlight the potential for this framework to transform how autism interventions are conceived and delivered. By focusing on strengths rather than deficits, grounding approaches in neuroscience, and promoting collaboration, the NSBSA framework offers a comprehensive and compassionate way to support autistic individuals.

As we move forward, embracing frameworks like NSBSA can foster a more inclusive and effective support system for autistic individuals. This framework holds the promise of not only enhancing their functional abilities but also empowering them to lead fulfilling lives aligned with their personal goals and strengths.

Conclusion

Autism is complex to non-autistic individuals and requires education to foster understanding. The NSBSA framework represents a significant shift in how we understand and support autistics, moving away from deficit-focused interventions to a strength-based, neuroscience-informed framework. By involving autistic individuals in the process and fostering collaboration among all stakeholders, frameworks such as NSBSA provide a promising path forward. This framework not only respects each person's unique neurological makeup but also ensures that their voices are heard and valued in the creation and evaluation of interventions designed to assist them.

Susan Golubock, MEd (retired OT), is the Founder and Staci Neustadt MS CCC-SLP is CEO of Making Sense of Autism. For more information on our research go to makingsenseofautism.com/nsbsa-research.

Collective Action from page 1

awareness and training among general education staff, making it difficult to provide adequate support within schools. The rapid evolution of autism research makes it imperative that service providers remain current on the most effective treatments and interventions. To address this issue, these specialists must participate in continuous professional development. However, this necessity poses challenges, demanding considerable time and financial investment.

Burnout and staffing challenges also significantly impact the field of autism support services. The demanding work environment, sometimes characterized by close, intensive interactions with others, high caseloads, and the emotional toll of the job, contributes to high turnover rates among staff. Such turnover disrupts the continuity of care for individuals with autism, undermining their progress and stability. The remaining staff are left to manage increased workloads, exacerbating stress levels and potentially compromising the quality of care. This cycle of burnout and turnover underscores the need for systemic changes to support the well-being and retention of these service providers.

Autism clinics and private practices face challenges, including funding issues, adequate staffing, or insurance limitations that can restrict service availability or the scope of support offered. Advocating for their client's needs is often hampered by bureaucratic obstacles and constraints on which services are covered by insurance.

Another primary hurdle is the shortage of qualified professionals, a situation exacerbated by the growing prevalence of autism diagnoses without a corresponding increase in trained specialists. This discrepancy leads to long waiting lists and limited access to services, particularly in areas lacking healthcare infrastructure or rural regions where specialists are few and far between.

When families are already struggling to manage the intricacies of autism treatment, these "service deserts" cause further stress by delaying assistance during critical developmental times. The limited access in these areas is compounded by logistical challenges, including the need for travel to distant clinics or the lack of specialized services within their community. Given the current state of affairs, focused initiatives must be launched to increase the accessibility and quality of autism support services for children, regardless of their geographic location.

Further challenges arise for community-based services, which assist in less formal, more accessible environments. These can include a lack of funding for public programs, insufficient training for community workers, and a shortage of programs that fully include children with high needs. As a result, families often find it challenging to access support that is not only close to home but also attuned to their children's social and emotional growth.

Home-based services, while potentially providing a more personalized and less disruptive option for families, face their own



Vladimir Kogan

problems. Issues such as securing funding for in-home therapy, finding qualified providers willing to offer services in a home setting, and coordinating care among various therapists can complicate the delivery of these services. Because of the personal aspect of assisting in the home, those providing this service must have extensive training in autism therapies but also be sensitive to adapting to the unique dynamics of each family's household.

A Call for Collaborative Solutions

Addressing the widespread accessibility challenges in schools, clinics, community, and home-based settings calls for a multifaceted strategy that provides more funding, enhanced provider training, and innovative solutions to ensure every child receives the necessary support to succeed. Enhancing support for autism service providers demands concerted efforts across society, requiring individuals to dedicate their time and resources, businesses to commit to inclusivity, and policymakers to enact meaningful changes.

At the individual level, contributing through volunteering or donations can have a profound impact. Volunteering enhances service providers' abilities and deepens their awareness of autism. Financial contribution empowers providers to broaden their services and fund research that can lead to innovative support methods. One of the most important things people can do to help create a more receptive atmosphere for autism care is to speak out in favor of autism services and to call for policy changes.

Businesses can make a difference by partnering with other service providers to expand and improve the services offered. Ensuring that individuals with autism have equal access to inclusive workplaces and employment opportunities encourages personal growth and values their unique perspectives.

For policymakers, the challenge lies in crafting legislation that tackles the root issues affecting autism services. This includes ensuring sufficient funding, increasing insurance coverage for therapies, and supporting educational initiatives. Thoughtful policy reforms have the potential to considerably boost the service landscape for autism, expanding access to these critical therapies. Such changes can

also cultivate supportive ecosystems for individuals with autism and their families.

Remember that refining support for individuals with autism, like Mia, is a responsibility we all share, whether it's by volunteering, donating, or advocating for better policies; every bit of effort counts. Engaging with local organizations, supporting fundraisers, or pushing for policy changes are all ways you can help professionals like Alex provide the best care. Regardless of how large or small your contribution is, it goes a long way toward building a more inclusive environment where individuals with autism can rely on a more robust support system that allows essential services to reach them.

People with autism and developmental disabilities rely on a wide range of specialists who fill several roles in a variety of environments. In academic environments, special education teachers adapt curricula and teaching strategies for students with developmental disabilities, while school psychologists focus on assessment and interventions to support educational and emotional needs. Behavior analysts implement Applied Behavior Analysis (ABA) therapy to improve social skills, communication, and academic performance. Speech therapists address language development and speech disorders, including those associated with autism. Occupational therapists help students develop fine motor skills and adapt to sensory inputs, and paraprofessionals provide direct, hands-on assistance to foster inclusion and personalized learning.

In clinical settings, clinical psychologists specialize in assessing and diagnosing autism and providing therapeutic interventions. Occupational therapists in these settings focus on enhancing daily living skills and sensory processing abilities. Speech and language pathologists offer therapy to improve communication skills, while board-certified behavior analysts design and oversee ABA therapy programs. Registered behavior technicians, under supervision, implement daily ABA interventions, directly teaching skills and documenting progress.

Community settings involve social workers who support families by helping them navigate services and access resources. Registered behavior technicians and ABA therapists use community outings to generalize treatment goals. Music and art therapists utilize their mediums as therapeutic tools to facilitate communication and expression in non-verbal ways.

Home-based services include ABA therapists and registered behavior technicians who deliver personalized interventions in the child's home, focusing on improving specific behaviors and skills in familiar settings. Early intervention specialists work with young children and their families to address developmental delays as early as possible. Family counselors specialize in providing guidance and support to families, helping them understand autism and manage its challenges.

Vladimir Kogan is CEO of the Illinois Autism Center.

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- Kowalczyk, Liz (2023, December 9). Thousands of Mass. children diagnosed with autism are becoming adults. Many families find the state unprepared to help. *The Boston Globe*. <https://www.bostonglobe.com/2023/12/29/metro/massachusetts-adults-autism/>

Recruitment from page 9

disabilities agency whose opportunities interest them to learn more and apply for specific positions.

One thing that makes the #MoreThanWork campaign stand out is its engaging and authentic content. Its video interviews offer testimonials with real DSPs using their own words, and the static ads show photos of real DSPs at work supporting real New Yorkers with developmental disabilities. These images are being featured widely across digital and social media. In addition, traditional advertising spans billboards, bus shelters, subway car displays, gas pump toppers, bus tails, and more and can be seen in every county of New York. All of these ads and videos point job seekers to the central website DirectSupportCareers.com to learn how they can start their own rewarding career as a DSP.

The campaign, which launched in mid-March 2024, has already generated:

- 13,638 “click-throughs” to provider agency websites from job listings on the #MoreThanWork website,



Willow Baer

- 155,405 total website visits,
- 52.7 million total ad impressions and
- 12.5 million complete video views.

We are looking forward to seeing even

greater reach and activity as the campaign moves forward.

As efforts continue in the digital media, social media, and earned media space, we are confident the campaign will attract diverse and qualified job applicants and support the development of future committed leaders in the developmental disabilities field. In this way, #MoreThanWork will help establish a more robust support system for people with developmental disabilities across the state of New York and, in doing so, serve as a model for similar initiatives to be introduced across the country.

OPWDD is committed to addressing the significant DSP workforce crisis that is affecting those with developmental disabilities throughout New York. #MoreThanWork is but one of many initiatives we have underway, each one making important strides in how the world views and respects the tremendously valuable work of direct support professionals. I'm thrilled that the #MoreThanWork campaign is visible in our communities and successfully engaging the public with our mission. I'm excited to see its impact in

New York State and across the nation as others work to build their direct support workforce. But, most importantly, I'm so hopeful for how it will undoubtedly support the development of a caring, committed and talented direct support workforce to empower people with developmental disabilities.

And that is, after all, why everyone in this field does the work that we do.

Willow Baer is Acting Commissioner of OPWDD. To learn more about #MoreThanWork, visit DirectSupportCareers.com and the campaign's social media platforms across [Facebook](#), [Instagram](#), [LinkedIn](#), [TikTok](#), [Snapchat](#) and [YouTube](#). To learn more about OPWDD's other DSP workforce initiatives, visit OPWDD's webpage at www.opwdd.ny.gov/supporting-and-strengthening-direct-support-workforce.

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The Arc New York 2024 Budget Advocacy Info Sheet, Feb. 2024. thearcny.org/wp-content/uploads/2024/02/2024BudgetPrioritiesKG2824.pdf

Mentorship from page 12

responsibility for those decisions.” While certain aspects of self-advocacy in the job search and workplace may be daunting, such as differing communication styles, navigating social situations or norms, or asking for support, the outcomes are beneficial. Mentors can help empower job seekers to advocate for accommodations and communicate their needs to an employer to support their success. Additionally, mentors can assist job seekers in understanding common intricacies of the workplace and develop strategies for managing sensory sensitivities and communicating effectively with colleagues.

Self-advocacy is not easy; it requires practice and self-reflection. Through mentorship, autistic candidates can advocate for themselves in big and small ways. For example, they propose the time and day for their scheduled calls with their mentor, request feedback before meetings, ask questions, clarify their learning preferences, etc. In turn, this grows their confidence in self-advocacy and helps them see the positive outcomes that can occur when they express their needs.

Long-Term Implications and Networking

Mentorship can also facilitate profes-



Courtney Carroll

sional development for autistic adults by providing access to networking opportunities. Mentors can introduce mentees to influential contacts, connect them with peers and professionals in their field, or share job openings they think might be a good fit. Over time, these connections and relationships can open doors to new career opportunities, collaborations, and professional growth.

In summary, mentorship for employment among autistic adults is a valuable resource that provides tailored support, builds confidence and self-advocacy skills, helps navigate the workplace, fosters skill development and career advancement, and offers long-term support and networking opportunities. By harnessing the power of mentorship, autistic adults can overcome barriers to employment and thrive in the professional world.

Hire Autism Navigator Program

The [Organization for Autism Research's \(OAR\) Hire Autism Navigator program](#) is a unique mentorship program specifically designed to help autistic job seekers find meaningful employment. Navigators serve as trusted advisors and advocates, offering guidance and encouragement as mentees navigate the job search.

Through the Navigator program, OAR offers job seekers the opportunity to work with a virtual mentor on various aspects of the job search, including resume, cover letter, and interview preparation. The mentor can also provide additional resources and answers to employment-related questions such as disclosure, accommodations, and job identification.

As members of their mentee's village of

support, Navigators meet job seekers where they are in their job search and provide a do-it-yourself teaching style to continuously promote learning and self-advocacy.

Mike G., a previous Hire Autism job seeker, shared his experience with a Navigator, saying, “My Navigator helped me with my resume, interviewing skills, choosing the right jobs to apply to, and provided resources to continue guiding me through the job search. Going through the navigator program has significantly increased my confidence in myself and how to present myself and my skills to employers. It has removed much of the mystery around different aspects of job seeking. I feel well prepared for interviews and am confident my resume will stand out.”

Interested in working with a free Hire Autism Navigator? Follow [these steps](#) to get started!

Interested in volunteering as a Hire Autism Navigator? [Apply now!](#)

Courtney Carroll is Manager at [Hire Autism with the Organization for Autism Research](#).

Reference

[Empowering Success: The Art of Self Advocacy in the Workplace](#)

Supporting from page 14

psychosocial stressors, or having co-occurring diagnoses. Given the uniqueness of each autistic individual, we must listen to them and create safe spaces for expressing their needs. When in doubt, ask the autistic person directly using their preferred method of communication. Offering choices and listening to the unique needs of each individual is the best way to accommodate them. Assuming that all autistic individuals need silence or dislike social gatherings overlooks the varied sensory and psychological needs within the autism spectrum.

As an organization, it is important to review the policies currently in place regard-

ing accommodating autistic people. Are there autistic people in leadership positions? Are autistic-friendly communication styles accepted (such as conversations/meetings done in written format, captions during Zoom meetings, ample time given for processing prior to answering)? Are more direct communication styles seen as equally valid? These are just some small examples of how an organization can begin to see themselves through the eyes of autistic service providers and notice what may need to change.

In conclusion, autistic providers have unique needs because of the gift they provide with their invaluable lived experience as autistic people while also the challenges

they face while working as disabled people. Autistic service providers need environments that offer them access to accommodations to support their sensory needs, communication style, and way of thinking without running the risk of being discriminated against.

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hbr.org/2021/12/autism-doesnt-hold-people-back-at-work-discrimination-does



Danielle Aubin, LCSW

Interdisciplinary from page 6

topographies of challenging behavior.

Other aspects of their daily routine and health were examined to better understand the individual. The individual, at times, showed decreased sleep patterns, illness, or injury due to self-injury. During these times, interventions were modified to ensure the safety of the individual. For example, during decreased sleeping patterns or illness, the individual was given opportunities to nap during the day. During times when the individual had sustained an injury (i.e., fracture, hematoma, concussion), modified intervention protocols were written and trained with all staff working with the individual to ensure the individual's and staff's safety to ensure healing and no further injury.

Medical History

The individual's baseline presentation (before noticeable changes in presenting profile) supported referrals to and ongoing services from occupational therapy, physical therapy, and speech and language pathology. The occupational therapist noted left-hand dominance with equal upper extremity use, shoulder complex, and fine motor skills. The physical therapist noted a symmetrical gait pattern (equal step length, step height, heel contact, and toe clearance), midline trunk and reciprocal motion of hip/pelvis, variable gait pattern directly related to interfering behavior of reaching/kicking or attempts to gain access to items/areas while walking. The speech and language pathologist noted a typical swallow pattern with no signs of distress or aspiration. These evaluations assisted the team in understanding the individual's complex needs and ensured a consistent approach across providers and disciplines.

In September 2022, the individual's presenting profile noticed noticeable changes. The occupational therapist noted significant atrophy of the right upper extremity muscle bulk, decreased active range of motion and strength within the right upper extremity, and increased muscle tone within the left wrist and fingers. The physical therapist noted decreased control of the right side, leading to an ataxic variable gait pattern with right-sided foot drop, an increase in needed external support (leaning on staff) only on the left side (most intact side), and less tolerance for walking (with increases in flopping behavior, unclear if for pain). The speech and language pathologist noted coughing after the intake of thin liquids and wet vocal quality when asked to sustain the vowel /a/ after swallowing thin liquids.

Various evaluations and appointments were scheduled to ensure that these dramatic changes in adaptive functioning were fully assessed. Appointments were made with dentists, oral surgeons, neurologists, physiatrists, rheumatologists, and orthopedists. An MRI showed that the

brain stem was smaller on the left than on the right. A physiatrist ensured that aquatic PT could be consistently given. Seizure activity was also noted, and anti-seizure medication was begun. Issues with wisdom and chipped teeth were fixed, reducing the potential for infection or pain contributing to the individual's distress.

Diagnoses and Follow-up

Motor deterioration was evident and may have been secondary to abnormalities in brain structures and seizure disorder. The following are protocols/services that were put into place to decrease the continued decline in motor movements. Physical therapy, occupational therapy, speech therapy, and nursing worked collaboratively to develop a checklist to assess the client's presentation each morning. All staff working with the individual were trained on the use of this checklist and on when to alert therapists/nurses if a change was noticed. This checklist assessed the individual's ability to follow motor imitation with their face, arms, and walking gait. Due to weakness in the right extremities – hand/arm/leg – the individual was fitted for a leg and wrist brace. Given some behavioral concerns with toleration, the BCBA collaborated with the physical and occupational therapists to ensure that systematic toleration programs were implemented to gradually build stamina and tolerance. The individual's environment was also modified to allow for a more open area to sit and move around, with a student desk and chair available for completing seated work tasks. The individual also began wearing a hard-sided helmet with a face shield in 2021 due to head-directed self-injury. This helmet continued to be worn to ensure no further injury to the head. Adaptations to current therapy services occurred. Physical therapy was added to the individual's Individualized Education Plan (IEP). This allowed physical therapy to implement and monitor exercise programming and stretching toleration. In addition, aquatic therapy was recommended and implemented through a local.

Through all of the assessments, medical appointments, and inter-professional collaborations, the consulting psychiatrist closely monitored the individual through consultation/review of the current medication regime, review of behavioral data/graphs, and videos of presenting symptoms. This was vitally important when the individual displayed movements that could be attributed to seizure activity but which needed to be examined to rule out any psychiatric medication side effects.

As with all biological and behavioral interactions, the combined expertise of all disciplines ensured adequate oversight. With a focus on using evidence-based interventions compatible with existing procedures, new approaches ensured that there was support and direction to address the changes within the individual (Newhouse-Oisten et

al., 2017). The more complex the individual's needs, the greater the need for interdisciplinary care (LaFrance et al., 2019).

Conclusion

Individuals with disabilities often encounter barriers to access to care. These barriers include the individual's inability to communicate, persist, and advocate for their needs (Malik-Soni et al., 2022). Given this, they often require others to serve as their advocates. Such advocacy becomes even more essential when complex needs and/or the individual's medical and behavioral profiles change. Other barriers include limited training for medical professionals in providing services to individuals with disabilities (Bruder et al., 2012). Collaboration across all disciplines helps to ensure proper advocacy for appropriate evaluation and access to comprehensive care under these conditions. Within this case, all disciplines provided summaries of relevant information to caregivers when they could not attend appointments. Perhaps most vital to this approach, all disciplines were integrated into every assessment checkpoint, ensuring comprehensive and thorough evaluation.

Partnership with the family was also essential and helped ensure family members advocated directly for their loved ones. Given that multiple individuals within this organization were on the team, it was important to ensure that all members communicated with each other and that one member was identified as the point person for contact with parents to ensure efficient and accurate delivery of information as well as to provide ways for the parent to advocate. Many parents do not have the resources and/or know what to advocate for; this family requested staff assistance. To ensure successful visits to each appointment, proper staffing was always secured. In addition, a team member attending the appointment brought the individual's medical record to appointments and worked to limit the need for unnecessary imaging. This staff member could also reference the medical record to answer questions about previous appointments, test results, etc.

Organizations must embrace an interdisciplinary model for individuals on the spectrum, especially when their needs are complex, and there is a clear interface between biological variables and behaviors. Creating openness to an active, collaborative partnership across disciplines helps ensure adequate assessment and treatment and that the individual, the family, and the staff are supported in their advocacy and care for clients.

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Autism Treatment from page 8

can choose what works best for them.

Over the past three decades, autism care has transitioned out of the educational model to a medical one. I can't think of any medical field that wouldn't place a

higher value on the more recent and more relevant data and research over old methodology. As an industry, we must do better by being more progressive, recognizing the needs of individuals, and focusing on the overall wellbeing of the people and families we serve. The success of out-

comes should be measured by the positive impact on lives, not just the number of treatment hours provided.

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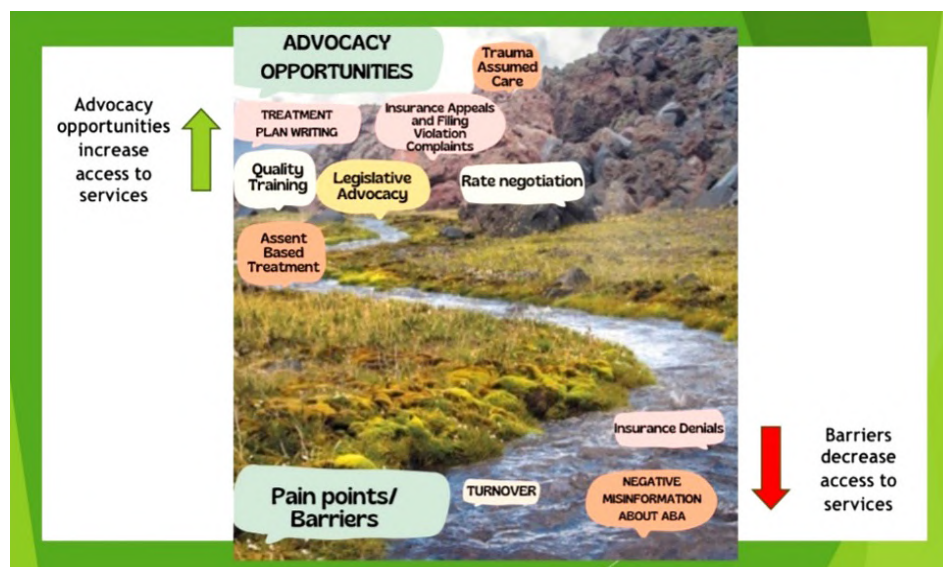
ualized care services, clinical research, and advocacy - so people with developmental disabilities can choose their path. Samelsson is a licensed clinical psychologist and leads the organization's behavioral health research team with a focus on promoting the overall wellbeing of families.

Advocacy from page 13

Consider your strengths related to autism services. What would you feel confident training others or presenting on right now? Are you a BCBA who really connects with RBTs during training to achieve those lightbulb moments? Are you a parent who knows how to translate the ABA jargon with families new to a diagnosis? Are you an administrator who writes well and spends time putting together detailed appeal letters?

What if the strengths you identify don't relate to the barrier being thrown into your river? Consider who else at your organization might have the strength that's needed. Connect with your state or national resource groups, such as your local Arc, state and national trade and professional organizations, or parent-led advocacy groups. Find the folks who have the strength needed to stop your identified barrier from being thrown into the river.

Let's return to legislative advocacy. There are some fierce trailblazers in autism services who possess strengths related to legislative advocacy and apply those strengths to legislative barriers. They push through legislation that has changed lives for the better and significantly increased access to services over decades. But it starts with imperfect blurbs written up to convey what's needed to tackle an identified barrier by people who might feel intimidated by the legislation process (like you!). It can



take years. Examples of this include:

- Meaningful Autism coverage in all 50 states took 18 years (Autism Speaks, 2020)
- Implementation of Medicaid coverage in all 50 states occurred over the course of more than seven (7) years following a guidance notice issued by the Centers for Medicare and Medicaid (CMS) reminding state plans of their obligations under Early and Periodic Screening Diagnosis and Treatment (EPSDT). It is, therefore, a benefit only available until age 21 in most states, with advocates taking action to expand that coverage beyond 21

(“Clarification of Medicaid Coverage of Services to Children with Autism,” 2014)

We take a strengths-based approach with our children or clients every day. We should do the same with ourselves and advocate for autism services. Take your identified strengths and apply them to the barriers – stop that guy from throwing barriers into the river! Once you realize which strengths you're already applying to advocacy, shout it from the rooftops! Boast about your new and improved quality training program and share it with your colleagues. Create a presentation of your organization-changing training process and sign up to share it at

Self-Care from page 6

psychological flexibility when challenges arise. (Paliliunas, 2021). Individuals who engage in ACT actively work to identify and articulate their values to align their goals accordingly and decrease their burnout and associated avoidance behaviors. When seen through this lens, intrinsic motivation occurs when actions and goals align with an individual's values.

Recently, researchers in the field of behavior analysis have pointed to this framework as a possible starting point in suggesting a value-based approach to self-care. Paliliunas (2021) suggested that while traditional self-care tools such as meditation may be useful in addressing burnout, people will ultimately experience less stress when living lives that align with their most closely held values and beliefs. The article suggests that the current focus on self-care as a restorative practice misses the opportunity to focus on what we can do proactively to reduce the occurrence of burnout and the need for many other self-care strategies in the first place.

What does all of this mean for organizations in regard to burnout and self-care? What role do organizations play in ensuring that individuals live value-driven lives? The answer, I believe, is quite a lot, especially in the field of autism services. First, we can and should have a vital role in providing value-driven work environments. This requires us as autism service providers to ensure that we are clearly articulating our mission, vision, and values at an organizational level. This goes beyond providing a statement of purpose or an organizational mission, which has become an established practice. Instead, a well-articulated mission includes not only a statement

of purpose but the specific investments the organization is making to ensure that mission comes to fruition.

Once an organization clearly articulates its mission, vision, and values, it is important to consider how these are expressed and integrated at every level. A mission-driven organization is one in which every element of the organization's strategic plan is aligned with the autism service provider's mission and vision. Just as importantly, all of the action steps and goals that are set as part of the execution of that plan should be aligned with the values and core commitments of the organization. This key element can be in danger of becoming lost, in which the ends are allowed to justify the means. In a truly mission-driven organization, decisions at all levels should be made according to the articulated values of the company.

One way this is accomplished is by integrating the organization's mission, vision, and values into the daily operations. At Melmark (a human service agency serving children and adults with autism across multiple states), for example, we begin every meeting throughout the organization with Mission Moments, in which we recognize recent examples of our Core Commitments. This has several functions, the first of which is keeping our mission and our commitment to it at the forefront of everything we do. The second important function is to provide concrete examples of how individuals can uphold the mission through our Core Commitments. Lastly, it allows us to highlight individuals or departments by celebrating how their actions exemplify our organizational values.

Creating a mission-driven focus as an autism service provider informs the organizational culture and places values front and center in every arena, including recruitment

and onboarding. In fact, this is where the next crucial step to prevent burnout occurs, right at the beginning of the employee life cycle. If aligning your life with your values is the best way to practice self-care and decrease stress, as Paliliunas (2021) suggests, then hiring employees whose personal and professional values most closely align with your organization's is one of the best ways to proactively preempt burnout in your workforce. Again, the only way to accomplish this is by leading with the mission first in all conversations and framing discussions of roles with new or potential employees according to the core commitments of the organization.

Honesty and transparency are key to this process's success. For example, one of our Core Commitments is a Highly Skilled Workforce, and we are open with staff from the beginning about the degree of rigor in our training, the amount of feedback they will receive, and the high standards we set and maintain. Sometimes, this deters potential staff from pursuing interviews, accepting job offers, or even continuing in orientation, but this is simply part of the process. If becoming highly skilled in Applied Behavior Analysis is not a strong value for that new or prospective staff, then they would likely experience burnout in the long term due to the demands of the position. These hiring and onboarding principles are also especially important to consider for key leadership positions since these individuals will play a role in upholding the agency's mission and recruiting and supporting individuals who will thrive in that environment.

As leaders of agencies providing autism services, we have a unique opportunity to set our workforces up for success. Our own science has given us the framework to ap-

proach self-care proactively, showing us that we experience less burnout when we align our goals and our daily lives with our core values and that doing so constitutes a profound form of self-care (Paliliunas, 2021). By providing mission-driven workplaces whose values are clearly articulated and diligently upheld and recruiting employees whose values align with our own, we give our workforce the best chance for a value-aligned life in the workplace. Personally, I will never turn down a pizza party or a yoga workshop, but neither of those is what gets me through the toughest days. What drives me is this form of radical self-care, in which the work itself is not something that needs to be escaped from, but which feeds my soul, keeping the mission first for every individual every day.

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proach self-care proactively, showing us that we experience less burnout when we align our goals and our daily lives with our core values and that doing so constitutes a profound form of self-care (Paliliunas, 2021). By providing mission-driven workplaces whose values are clearly articulated and diligently upheld and recruiting employees whose values align with our own, we give our workforce the best chance for a value-aligned life in the workplace. Personally, I will never turn down a pizza party or a yoga workshop, but neither of those is what gets me through the toughest days. What drives me is this form of radical self-care, in which the work itself is not something that needs to be escaped from, but which feeds my soul, keeping the mission first for every individual every day.

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Development from page 10

(DSP) knowledge and use of EBPs for autism. How can training resources be selected and adapted to fit the needs of staff working with adults in community care facilities?

Aim 3: Assess the effectiveness of the adapted model and resources in three developmental disability service agencies supporting adults with autism. How effective is the training program in increasing staff knowledge of EBPs? How did staff and agency participation impact progress on client goals?

Aim 1: Evaluate Staff and Organizational Needs

A survey was distributed to community care facility administrators, DSPs, and parents and caregivers of adults with autism and intellectual disabilities. A total of 88 individuals completed the online survey, including 13 DSPs, 73 facility administrators, and 2 parents. We asked about the top areas of need of adults with autism living in group homes. Behavior was reported as the top need (n=52, 22.4%), followed by adaptive skills (n=43, 18.5%), mental health (n=36, 15.52%), and social skills (n=31, 13.4%). We also asked about the EBPs that would be most helpful in targeting these areas of need. Antecedent-Based Interventions were the top EBP reported (n=26, 19.7%), followed by Functional Behavior Assessment (n=17, 12.9%), Reinforcement and Differential Reinforcement (n=15, 11.4%), and Prompting (n=8, 9.1%).

Site assessments for ten local area care facilities were completed to evaluate which EBPs were currently in use. During site assessments, evidence-based teaching practices were not being used to address existing goals across nine out of 10 facilities, and support was largely provided in a “do-for” manner, meaning that direct support professionals would complete activities of daily living for the clients residing in their care rather than supporting them to complete activities independently.

Aim 2: Adapt NPDC-ASD Training Resources

Two EBPs were selected based on data gathered from the survey and site assessments, as well as the level of technical skill required of providers and the utility of the practices, such as Prompting and Visual Supports. The modules for these two EBPs were adapted to include content relevant to staff working with adults. For example, video content for the Prompting module includes both adult actors and scenarios relevant to adult clients. Modules include video clips of professionals explaining how they have used both visual supports and prompting strategies in ways that are most effective with older learners. Both modules are hosted on an interactive platform (PlayPosit) that allows users to

view the video presentation and digitally complete activities and content questions. Participants received feedback in response to content questions to support enhanced learning, and pre/post-tests were embedded into each presentation to assess trainee knowledge gain.

Aim 3: Assess the Effectiveness of the Adapted Model and Resources

We implemented the adapted resources and training program in three community care facilities. Seven staff and one parent participated in the training activities and seven clients agreed to participate in the project. The training program consisted of an initial half-day interactive didactic training workshop. Together with the staff and administrator, the trainer helped to develop relevant and appropriate goals for each participating client, considering their strengths, interests, and history. Each facility received a start-up kit of materials to prepare Visual Supports related to the individualized client goals. Additionally, staff participated in weekly virtual coaching sessions with the trainer to discuss progress toward the goal and the implementation of EBPs. The total length of the training program was five weeks, with a follow-up interview with each community care facility administrator.

Prior to training, providers were asked about their confidence using Visual Supports and Prompting. A majority of participants rated their confidence using both Visual Supports and Prompting in the low-moderate range. Providers also completed a pre-post knowledge assessment for each EBP. Post-test results indicate increases in knowledge for both EBPs, with an average score of 65% (35% at pre-test) for Prompting and 76% (65% at pre-test) for Visual Supports across all participants. The trainer report indicated a high level of engagement during training for all participants.

Each community care facility was assessed for overall quality, including site structure, organization, and use of visual supports. Results indicate notable improvement for all sites. Post-intervention, administrators reported finding Visual Supports, Prompting, and the training program to be accessible, fitting, easy to use, and applicable to their setting.

At the client level, goal progress was monitored using Goal Attainment Scaling (0 = original level of performance, 1 = less than expected progress, 2 = expected level of progress, 3 = somewhat more than expected, and 4 = much more than expected; Ruble et al., 2012). The majority of client goals targeted self-help/adaptive skills (66.7%), such as preparing meals, laundry, morning routines, and showering. Social skills (16.7%), such as staying on topic and engaging in leisure activities (16.7%), were also targeted. By the end of the training program, all clients but one had reached their expected level of progress, and almost half (46.1%) had exceeded their expected level of progress.

Discussion

Our results show that a short-term intensive training program can produce positive outcomes at the staff and client levels. Staff also felt more comfortable and competent in implementing evidence-based practices, as indicated by our pre- and post-training surveys. Since increases in self-efficacy have been shown within other service systems (Yost, 2006) to increase staff retention, this type of training program could have significant implications on workforce retention in a field that is plagued by staff shortages and high turnover rates. The majority of adult client participants improved their self-help/adaptive and social skills. These skills will improve their quality of life by increasing their independence as well as their ability to engage in the community. Our findings are promising, and ongoing funding would allow the intervention to be implemented across a larger sample as well as replicated in other types of agencies like day programs, vocational programs, and family homes.

An additional goal related to the development of these tailored resources specifically for adults within community-based services was to increase the interest in EBPs by community service agencies and by those funding them. The resources developed for this project are publicly available through the CAPTAIN website (www.captain.ca.gov). We have additional plans to disseminate our findings to stakeholders throughout the state, including the agencies who fund adult services as well as parents, self-advocates, and those who can assist with advocating for high-quality, evidence-based care for this population.

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Lived Experience from page 17

help but do something impulsive and off-the-wall. On the plus side, I did manage to imbue the evening with a touch of the

unexpected, of true artistry, albeit for just a few seconds. No harm done!

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Education from page 17

deficiencies in education and training, that need to be remedied.

Service providers often serve distinct communities (ethnic, racial, religious, etc.). They can either be members of that community themselves or learn about it through formal or continuing education or by immersion to better appreciate its cultural differences (along with other issues that it might face). This is very helpful, if not essential, for serving that community. Usually, such communities are distinctly identified and either live largely in the same geographic locales or urban neighborhoods (as with some ethnic groups) or regularly congregate in specific locations (as with religious groups).

In the case of autism, however, the population is evenly distributed (not to mention often unidentified); as such, it is rarely concentrated in any location or even region, and most members need to be served on an individual basis. Still, however, service providers need to be aware of the needs, challenges, and other issues facing the autistics that they are assisting.

Unusual Issues Concerning Autistics

Unlike most other communities, autistics often have a host of unusual issues not as common in other populations. There is also much more variation in the needs and challenges among members of our community than is the case for others. The old saying that “if you have met one person on the spectrum, you’ve met one person on the spectrum” applies in this instance as much as in any other, if not more so.

For instance, sensory sensitivities are nearly universal among autistics, but different individuals will experience these with different senses – for example, some will have auditory sensitivities, some will have visual sensitivities, and so forth, with some having such in two or more senses. Also, with the same sense, different individuals may be sensitive to different stimuli, such as diverse types of sounds (e.g., high-pitched whistling or sudden booms) for those with auditory sensitivities. Even



Karl Wittig, PE

when service providers are aware that autistics can have these sensitivities, they have no way of knowing which will affect a particular individual; they will need to determine, on a case-by-case basis, which ones each person is susceptible to so that they can be avoided.

Other issues can involve instructions that need to be followed. Autistics are known for being very literal in their understanding of language. They are also known for being resistant to changes in personal routines. These considerations both come into play in situations where instructions given by service providers need to be followed correctly. Consequently, providers have to be aware that both of these issues are common with autistics, to state things in such a manner that there is as little room as possible for misinterpretation or misunderstanding, and to follow up to make sure that directions have been followed correctly.

One well-known instance of following directions involves patients taking prescription medications, particularly psychiatric medications. It is known that patients with certain psychiatric conditions refuse to take a prescribed medication. In such cases, conventional wisdom is that they feel they do not need it, do not like how

it makes them feel, or simply do not want to take it. I should point out that, not having any medical or healthcare background, I only know about this from personal and anecdotal accounts given by others.

In the case of an autistic, following a prescribed treatment of any kind, if it interferes with existing personal routines or habits, may very well be resisted. In such cases, the service providers have to be aware of this possibility. They also need to make sure that directions are as explicit and unambiguous as possible and that the necessity of their being correctly followed is made exceedingly clear. Assistance with incorporating such instructions into personal routines may be indicated as well. Subsequent follow-ups to make sure that all of this has happened are also called for here. One potential bright spot is that because autistics are known for being very diligent in maintaining routines, once these have been properly established, they will likely continue to be followed without further intervention.

This very same adherence to regular routines, however, can, in some cases, be problematic in itself. I have personally known instances where an individual who took a large number of prescription medications made a daily ritual of consuming them without considering their actual necessity at the time. In particular, they might continue taking medication indefinitely, even after the condition for which it was prescribed had subsided. This led to overmedication, duplication, and even adverse drug interactions. In these cases, regular monitoring is needed to make sure that such situations do not happen. Once again, my knowledge about this is limited to individuals that I have personally known, either through my involvement with the autism community or in my personal life.

In all these cases, an understanding of the distinct types of situations that can arise when working with autistics but may not otherwise be common is needed on the part of service providers in their dealings with the autism community. This is probably best done by educating providers as extensively as possible (or feasible) about the autism spectrum.

Autistics Can Help Educate Service Providers

Perhaps the best resource for educating service providers about the needs, challenges, and other issues of the autism community can come from autistics themselves. Because of the wide variety of autistic experiences and challenges, groups consisting of a variety of autistics who can recount experiences and describe challenges that are applicable or relevant to the service being provided can be enlisted in this effort. This is not just an instance of “nothing about us without us”; legitimate as that may be, the compelling reason for this is that autistics, by sharing the knowledge they have about the condition they live with, can make substantial material contributions in improving the quality of services that are essential to their community.

As part of my participation in AASET (Autistic Adults and Other Stakeholders Engaged Together – www.autistichealth.org), I have served on the Community Council of stakeholders, which includes autistic self-advocates who provide our own perspectives for a number of projects. Parts of these efforts involved the preparation of materials for service providers who will be working with autistic individuals. This may be a good model for what could be done in the future to further educate providers in a wide variety of different capacities for helping the autistic population.

For example, this may take the form of videos, printed materials, and other media that can be readily delivered to providers who work with our community. Members of the community will, in turn, need to be recruited for these efforts. This can be done by impressing upon them the importance of and need for their participation, as well as (when appropriate) financial or other inducements.

The bottom line is that however this is done, service providers who work with any members of the autism community need to be educated about the needs, challenges, and characteristics of the individuals on the spectrum that they will be serving.

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Emergencies from page 15

Client considerations should include:

- Did the client or caregiver(s) sustain any injuries that would impact service delivery?
- Are the client’s basic needs being met (e.g., food, water, shelter)?
- Can services be provided where the client typically receives services (e.g., the client’s home or school)?
- Did the client have to relocate to a temporary shelter? If so, is this an appropriate location to deliver services, or does an alternative location need to be identified?
- Does the client need additional support as a result of the disaster, such as referral to a qualified mental health care provider?

In addition to client factors, an organiza-

tion’s continuity of care plan must consider individual providers’ readiness to return to work after experiencing the trauma of a widespread natural disaster or other emergency. Organizations should identify an internal or external trauma response team to perform employee assessments and provide support. That can include paid time off or a leave of absence, mental health referrals, temporary reassignment to a different position, and removal from trauma response efforts.

Federal, state, and local entities—including FEMA, the American Red Cross, the Salvation Army, and state and county government agencies—offer resources to help organizations develop disaster preparedness and continuity plans.

The Council of Autism Service Providers (CASP) is a non-profit trade association of autism service provider organizations that have demonstrated a commitment to promoting and delivering evidence-based services. Several CASP members were impacted by Maui’s deadly wildfires in August 2023. These experiences highlighted the need for practical, autism-specific re-

sources to help providers deliver safe, effective services when they themselves are also victims of natural disasters.

Recently, CASP created a working group to provide recommendations for sustaining functional business operations and service delivery following a natural disaster. CASP’s *Community Emergency Guidelines: A Resource Guide for Autism Service Provider Organizations* will include checklists, customizable templates, and brief narratives in a user-friendly format. The resource is expected to be released in Q4 2024 and will be freely available on the CASP website at casproviders.org

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School Programs from page 14

- **Rates of verbal praise:** Praise should be varied and delivered in an enthusiastic manner. Pay attention to the frequency of corrective feedback and how it is delivered. If instruction is designed carefully, error rates will be low, and the use of corrective feedback will be minimized. For every instance of corrective feedback, there should be three to five statements of praise.
- **Happiness of students and staff:** Are students and staff smiling? Do the activities seem exciting? Are students allowed to make choices during each activity? Research shows that using preferred activities during instruction and providing students with opportunities to make choices can lead to higher rates of learning and fewer behavioral challenges.
- **Staff-to-staff communication and family involvement:** Determine what mechanisms exist to allow staff to develop activities, discuss specific child/classroom challenges, and meet with families, clinicians, and other staff. Find out if there are formal mechanisms in place to solicit parent feedback about school components and future development.
- **School policy regarding the observation of students:** Inquire about the school's policy regarding the observation of students. Determine if there is a way to observe students from outside the classroom, if there are time constraints placed upon observation, and if prior notification is required.
- **Intervention education for families:** Most schools offer training sessions open to families seeking to learn how to implement interventions at home. However, not all educational programs invite parents into the classroom to practice techniques or visit the home to show parents how to implement interventions. Good schools recognize that learning does not end when the school day is over and that continuity across school and home greatly benefits children with ASD.

Remember, finding the best education program for your child may not be easy, but it is worth the effort and will ultimately enhance their overall quality of life.

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Todd Harris, PhD

ECHO Autism from page 16

In the three sessions that have been conducted, on average, 94% of participants found the didactic presentation useful to them, 91% of participants found the case presentation portion of the program useful to them, 89% of participants reported that they had better knowledge upon which to base their actions in their clinical setting, and 89% of participants reported that they would be able to use their new skills in their setting. While this data is self-reported and from a small sample of clinicians who participated in this program, it suggests that, at the very least, the majority of clinicians who participate in an ECHO Autism session feel better equipped to work with an individual on the spectrum as a result of the program.

While there is still quite a bit of research that needs to be done to determine whether this increased confidence translates to better mental healthcare outcomes for autistic individuals, spreading awareness of programs like these is the first step towards beginning to eliminate barriers to mental healthcare access amongst autistic individuals. The convenient collaboration with other healthcare professionals made feasi-

ble by Project ECHO can not only enhance the care of autistic individuals but also offer great support to providers. Through public health programs like Project ECHO, we can begin to work towards ensuring that the clinicians working with this population are well-trained and confident in their abilities.

Dan Magin, BA, Hanna Kent, BS, and Krista Drapalik, MA, are Graduate Assistants, Melissa Rinaldi, PhD, is Clinical Investigator, and Kristin Christodulu, PhD, is Director at Center for Autism and Related Disabilities at the University at Albany. For more information on programming and training opportunities at the Center for Autism and Related Disabilities at the University at Albany, please visit the Center's [website](#).

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Therapy from page 21

to provide training to colleges, universities, and businesses on this topic. The world should learn to accept people who act differently. However, clinicians providing services to Autistic people transitioning from childhood to adulthood should prioritize supporting a client's goals as an individual. For instance, can the clinician work with their client to identify what causes the stimming? What purpose does it serve for them? Can the clinician suggest alternative strategies to regulate emotions that will work effectively in a college class or work setting if that is their goal? I was fortunate to receive training on Acceptance and Commitment Therapy (ACT), which utilizes this approach (Glasofer, 2024). ACT is an evidenced-based method of therapy (Gloster, 2020). I encourage all mental health professionals to learn more about it. I believe it is highly effective for those who are supporting Autistic people with the transition from childhood to young adulthood. ACT therapy focuses on accepting all emotions as they are experi-



Priya Winston, PhD, LMSW

enced. ACT therapy also teaches people to make choices and decisions that align with their goals or values (Glasofer, 2024). In the transition from childhood to adulthood,

the focus becomes more on your goals and values than those of your parents' or guardians' wishes. If mental health professionals help parents or family members identify this in childhood, ideally with early intervention to work on alternative strategies to stimming, they can begin the work ahead of time. Perhaps they can consider a new goal if this is impossible in adulthood. For example, they could consider a more hands-on career like a trade or job that requires a lot of moving. A goal related to one's strengths can be more empowering than an unrealistic expectation.

Overall, sensory sensitivity can be helpful if it leads one toward one's goal. However, it can be a detriment if it does not lead someone to the life that they want. Mental health service providers that use the ACT therapy approach can help people navigate it. I encourage them to receive training, education, or information on the methods.

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REAL History from page 16

their spectrum “colleagues” can fool you (i.e., we want to learn respectful language from you so that we can learn how to hide the fact that we’re crappy people). I resigned within hours from [Drexel University’s Autism Research Institute this past January when their head, Diana Robins, Publicly admitted and defended \(almost as a throwaway line\) their use of the Medical Model of Disability.](#)

But it is only here, in this figurative, nasty space we call “the history of disabilities,” where the combining of people with all these hundreds of diagnoses under one definition...makes sense or has any leitmotif... People with disabilities are all and only united as a grouping for whom peo-

ple without disabilities find either too uncomfortable to accommodate, unworthy of their own opinions regarding their worth, if not incapable of humanity.

And as in slavery, our ancestors who did not have disabilities, had little if any objection to these horrors.

The horrible attitudes haven’t gone anywhere. We just now have laws that prevent their owners from pursuing those instincts to their full satisfaction.

Stay tuned for “What I’d Like to See Change in the Disability World Over the Next 50 Years - Part 3: Change Our Culture.”

Michael John Carley is the Facilitator of the “Connections” program at New York University for their worldwide autistic students, and he also has a private, Peer

Mentoring practice. In the past, he was the Founder of GRASP, a school consultant, and the author of “Asperger’s From the Inside-Out” (Penguin/Perigee 2008), “Unemployed on the Autism Spectrum,” (Jessica Kingsley Publishers 2016), “The Book of Happy, Positive, and Confident Sex for Adults on the Autism Spectrum... and Beyond!,” (Neurodiversity Press 2021, where he recently became the Editor-in-Chief), and dozens of published articles. His many other current posts include being the Neurodiversity and Leadership Advisor for the League School for Autism, and he is Core Faculty for Stony Brook University’s LEND program. For more information on Michael John or to subscribe to his free newsletter, you can go to www.michaeljohncarley.com.



Michael John Carley

Coping with Loss from page 19

of any particular mental disorder.

I was asked frequently about thoughts of self-harm and suicidal gestures. I answered honestly but superficially. For me, thoughts and acts of self-harm were impulsive and transitory.

Impact on Professionals

General practitioners, psychiatrists and psychologists, social workers, occupational therapists, disability support workers, and more all work with autistic people. In Canada, much of the available support is community-based, with funding often allocated for families to hire an independent or agency-based worker. Many of these service providers are Developmental or Disability Support Workers (DSWs) (Spruyt, 2021).

COVID-19 spotlighted an urgent demand for DSWs to assist individuals with diverse abilities, spurring investment by the Ontario government into its Care at Home mandate and creating new care-services opportunities.

DSWs complete a program such as social work, child and youth care, psychology, or other social science/health care courses at a college or university. It is, as yet, an unregulated profession; however, their role is to support individuals with developmental disabilities, including autism, to participate fully in their communities. They’re also responsible for implementing behavior management strategies to reduce

challenging behaviors (Spruyt, 2021).

The Ontario government asserts a commitment to patient care in the community, and DSWs often work in Group Homes or their clients’ homes, where they’re left to their own devices to manage their client’s behavior. Aggression and outright violence are serious problems among self-conscious, frustrated young adult Autistics.

A DSW’s Experience - “Ellie” is a DSW who works for my family. She told me that there’s little to no support for workers like her. “You’re on your own,” she explained, to cope with the violence, anxiety, and daily uncertainty about what the day might bring. Ellie has been hit, kicked, punched, and concussed by her early-20s male client, who is far taller and stronger than she is.

Ellie acknowledges the hazards of her job. She knows she could walk away – and perhaps should – but then, “who would the family find to care for him?” She knows his triggers and tries to protect herself by anticipating potential trouble.

I’m one of the few with whom Ellie shares her experiences and feelings. Many professionals, trained to maintain an outward demeanor of strength, are reluctant to open up about their distress and vulnerability. Client-on-therapist violence may result in the client being denied important services – and/or they may find themselves entangled in the justice system.

But if a client, feeling like they have nothing to live for, dies by suicide, their provider (or caregiver) may feel they failed.

“Why didn’t I see it coming? I could have prevented it.” For people whose responsibility is to make sure the person within their care is safe and healthy, the trauma is gut-wrenching.

Empathic Listening by Peers

Talking to an empathic listener is the hallmark of most therapies. After experiencing trauma, it’s vital that “Helpers” give themselves permission to talk openly about self-harm, suicide, and, more generally, death. Many organizations employing board-certified MDs, PhDs, MAs, and others with related qualifications provide opportunities to debrief and/or to seek counseling through a confidential Employee Assistance Program.

AIDS Bereavement and Resiliency Program - There are a number of structured programs designed to target workplace trauma. Having worked at an AIDS/HIV organization at a time when many clients were dying, I received training from the AIDS Bereavement and Resiliency Program of Ontario (ABRPO). The program provides AIDS/HIV workers – administrators, front-line workers, volunteers, and peer workers – customized training to support them through the loss of clients, as well as training them to work with service users who experience loss (“Essential Tools for Support and Stability - ABRPO,” 2021).

ABRPO’s key skills include identifying the emotions impacting workers and prac-

ticing Emotional First Aid. Among the facilitated communication skills is the willingness to risk expressing one’s feelings of anger, fear, and sorrow to peers who have endured similar traumas.

Battle Buddies - The US Army Battle Buddies Support Program was adapted for healthcare facilities during the COVID-19 pandemic. Designed to support workers experiencing anxiety and stress under the “battlefield conditions” of the pandemic, Battle Buddies are partners who understand daily workplace challenges, provide each other with additional/alternative perspectives, support resilience, and, if stresses and anxieties increase, encourage their Buddy to reach out for more in-depth help (Albott et al., 2020).

Uniting for Suicide Postvention - The US Department of Veterans Affairs provides similar programs. Uniting for Suicide Postvention is a resource for providers who have been affected by the suicide loss of a patient. It acknowledges the difficulty of processing loss while maintaining one’s professional duties. Recognizing the impact of loss is a vital step towards healing, at work and in one’s own life (“Uniting for Suicide Postvention - Providers - MIRECC / CoE”).

New Challenges

Western culture has long kept death relegated to hospitals, long-term care, and

see Coping with Loss on page 32

Multidisciplinary from page 18

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Pool Safety from page 20

the number one cause of death for children with ASD (Drowning Prevention & Facts, n.d.). First, always make sure that you are watching and at a safe distance so that you can assist as needed – think an arm's length for the novice swimmer and within two arm's lengths for those more experienced. Additionally, make sure to swim at pools and beaches with certified lifeguards for additional safeguards. If a personal flotation device is needed to create a safer environment for the individual with ASD, make sure that the personal flotation device is Coast Guard-approved. If an individual with ASD has choked on water while swimming and continues to cough hours afterward or spikes a fever, consult a medical professional.

Before Entering the Pool

To prepare for the pool, set expectations and rules for everyone who will be entering or interacting with the water. These rules can include asking for permission from a caregiver before entering the pool or always holding hands on the pool deck. If routine change is challenging, consider



Maggie Achenbrener, OTD-PP, OTR/M

providing social stories or watching a video to help with understanding the steps and expectations of the pool. Providing verbal cues or narrating what is happening can also be helpful. If needed, contact the pool manager and provide the lifeguards and/or staff with information about the individual with ASD so they can take extra precautions. Additionally, providing the individ-



Alysha Skuthan, PhD, OTR/L, ASDCS

ual with ASD pictures or a tour of the pool and surrounding area can be very helpful.

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Dental Care from page 19

compassionate and effective care to patients on the autism spectrum. Understanding sensory sensitivities, effective communication strategies, and behavior management techniques enables dental practitioners to better meet the needs of patients on the autism spectrum. By enhancing their knowledge of autism spectrum disorder and implementing appropriate strategies, dental practitioners can provide more accommodating care.

Gina Williamson, Director of Children's Services at the [Anderson Center for Autism](#), shares insights from her research on sensory sensitivities and positive rein-

forcement techniques. She states that integrating sensory-friendly modifications, comprehensive training for dental professionals, positive reinforcement techniques, and a collaborative approach between caregivers and specialists can help make significant strides in reducing the dental care disparities faced by individuals with autism and improving their overall health and well-being.

Sensory-Friendly Modifications and Positive Reinforcement

Simple adjustments in the dental environment, such as dimming lights, providing noise-canceling headphones, offering

weighted blankets, and allowing patients to bring comfort items from home, can significantly reduce sensory overload and make dental visits less stressful for individuals on the autism spectrum. Positive reinforcement techniques, such as offering praise, stickers, small toys, or breaks after the successful completion of a task, can also encourage cooperation and reduce anxiety during dental visits for individuals on the autism spectrum.

In conclusion, collaboration between dental practitioners and professionals specializing in autism spectrum disorder is paramount for addressing the unique challenges faced by individuals on the autism spectrum in dental care. Through personal-

ized care, informed by comprehensive understanding and assessment, dental professionals can ensure high-quality treatment tailored to each patient's specific needs. By integrating sensory-friendly modifications and positive reinforcement techniques, dental practitioners can create a supportive environment that reduces anxiety and sensory overload during dental visits. This holistic approach not only addresses immediate dental health needs but also contributes to the overall development and well-being of individuals on the autism spectrum, paving the way for a healthier and more inclusive future.

For more information, you can reach Mecca Slocum at mecca.slocum@gmail.com.

Coping with Loss from page 31

funeral homes. "Our reluctance to honestly examine the experience of...dying has increased the harm we inflict on people... [I]f we are unwilling to recognize that... people have unbearable suffering that we can do nothing about...they need...an option where they can relieve that suffering" (Duff, 2016).

Given changes to Medical Assistance in Dying (MAID) law, we're beginning to acknowledge that people with Autism may be in "their right minds" and capable of deciding whether or not they want to continue living. It's more important than ever to have conversations about life, death, and dying – not only in peer groups but with clients and their families.¹

Conclusion

You may always be left asking why the person chose death. Therefore, it's vital to "[h]onor all of your feelings and take... time to grieve, process, and integrate this loss...It is important to do the grief work that we encourage our own clients to do. This is done not only for your own health but also for your future and present clients'

best care" (Hutchinson, 2021).

Annie Kent, MA, spent two decades working in public sector disability, mental health, and infectious diseases advocacy and education. Diagnosed with three closely related types of neurodiversity, a lack of awareness and understanding led to burnout and retirement from the field. She remains an active advocate, learning and engaging remotely with several Autism and ADHD organizations and Forums. For more information, visit her website, www.aspiefemmepress.ca, or email Annie at ajollymo@lakeheadu.ca.

Footnotes

1. In March 2024, a Calgary, Alberta, [Canada] judge issued a ruling that cleared the way for a 27-year-old Autistic woman (not officially diagnosed) to receive medical assistance in dying (MAID) despite her father's attempts through the courts to prevent that from happening. (www.cbc.ca/news/canada/calgary/calgary-maid-father-daughter-court-injunction-judicial-review-decision-1.7154794)

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