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Supporting Parents, Caregivers, and Family Members

Beyond the Autism Diagnosis: Understanding the Multifaceted Needs of Parents

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As the number of children diagnosed with autism spectrum disorder (ASD) increases, so does the number of parents trying to navigate the complexities that accompany an autism diagnosis. Raising an autistic child is challenging for many parents, and many reported higher levels of stress compared to parents of neurotypical children (Estes et al., 2013; Hayes & Watson, 2013; Valicenti-McDermott et al., 2015).

Parents' stress comes from a variety of sources, including medical and behavioral issues, expenses, availability and quality of interventions, and society's attitudes towards individuals with disabilities (Carroll, 2013). Subsequently, it is not surprising that parents raising autistic children experience chronic exhaustion and stress.

While there are numerous intervention services for autistic children, supports for parents is lacking. Understanding the type of supports parents want is a critical first



step towards better assisting parents, and subsequently, improving parents' well-being and family outcomes (Hartley & Schultz, 2014). I conducted a group interview with 26 parents about their child's autism diagnosis and how it impacts their daily life. All parents had at least one autistic

child under the age of 10, with many having other neurotypical children.

Level of Support After the Initial Diagnosis

Parents reported feeling relieved after receiving an autism diagnosis, since

it confirmed their instinct that something was "different" about their child. Despite feeling relieved, all parents felt isolated and lost since they had questions and fears and did not know where or who to turn to. Additionally, after the diagnosis parents reported experiencing a great deal of denial and sadness. Half the parents had support from family or friends and most of the parents were frustrated from the lack of support by their physicians.

The Hidden Stress Many Don't Discuss

Caregiver and family stress typically begins before a formal autism diagnosis is given. Parents reported experiencing reduced support and decreased interactions with family and friends when their child began exhibiting autistic behaviors. Lack of autism awareness was the primary reason parents gave for the negative impact on relationships. Half the parents reported friends stopped requesting playdates, and all the parents reported feeling alone, as though nobody understood their child's

see *Needs of Parents* on page 37

Supporting Latine Caregivers of Autistic Children: Community Needs and Perspectives

By Roxana Rodriguez, MA
and Ana D. Dueñas, PhD, BCBA-D
San Diego State University College of
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Latine* caregivers of recently diagnosed children on the autism spectrum have unique needs and face unique challenges in supporting their children (Blacher et al., 2019). Latine families report feeling overwhelmed, confused, and concerned with information about the incidence of autism, the complexity of the diagnosis, and how to approach advocacy and support. Knowledge and contemporary issues in autism are continuously evolving and recent developments in our understanding of autism could support Latine caregivers. For instance, a vibrant neurodiversity paradigm offers new perspectives about autism and highlights the need for a social paradigm shift towards acceptance and accommodation of autistic people. In part, the neurodiversity movement is a response to the lack of awareness and understanding of how an autistic person thinks, lives, and feels. Although the emergence



of the neurodiversity movement dates to 1999, there is limited awareness of the movement among the Latine community and how this perspective may impact perceptions of autism and child's prognosis. Specifically, Latine caregivers with very

young children may only have exposure to the medical model of disability rather than a neurodivergent lens (Cascio, 2019). Thus, their perspectives may be limited to their child's pediatrician's awareness of autism, limited resources in their commu-

nity, limited public awareness, and cultural stigmas.

What We Know About the Autism
Latine Community in the US:
Risk and Resilience Factors

Latine families are a large sector of the U.S. and are a heterogenous group, representing over 20 countries, speaking diverse languages including: Spanish, Portuguese, and indigenous languages (e.g., Nahuatl). Given the complexity of this group, it is important not to ascribe the same perceptions and beliefs to all Latine people. However, research has highlighted some common themes that emerge in the Latine autism community that may guide practitioners in culturally responsive care.

Some risks factors for the Latine population include limited awareness of autism and how it will affect their child (Rivera-Figueroa et al., 2022). This may be due to many Latine children having an autism diagnosis 2.5 years later than non-Latine children (Lopez et al, 2020). This delay of diagnosis causes parents to experience

see *Latine Caregivers* on page 36

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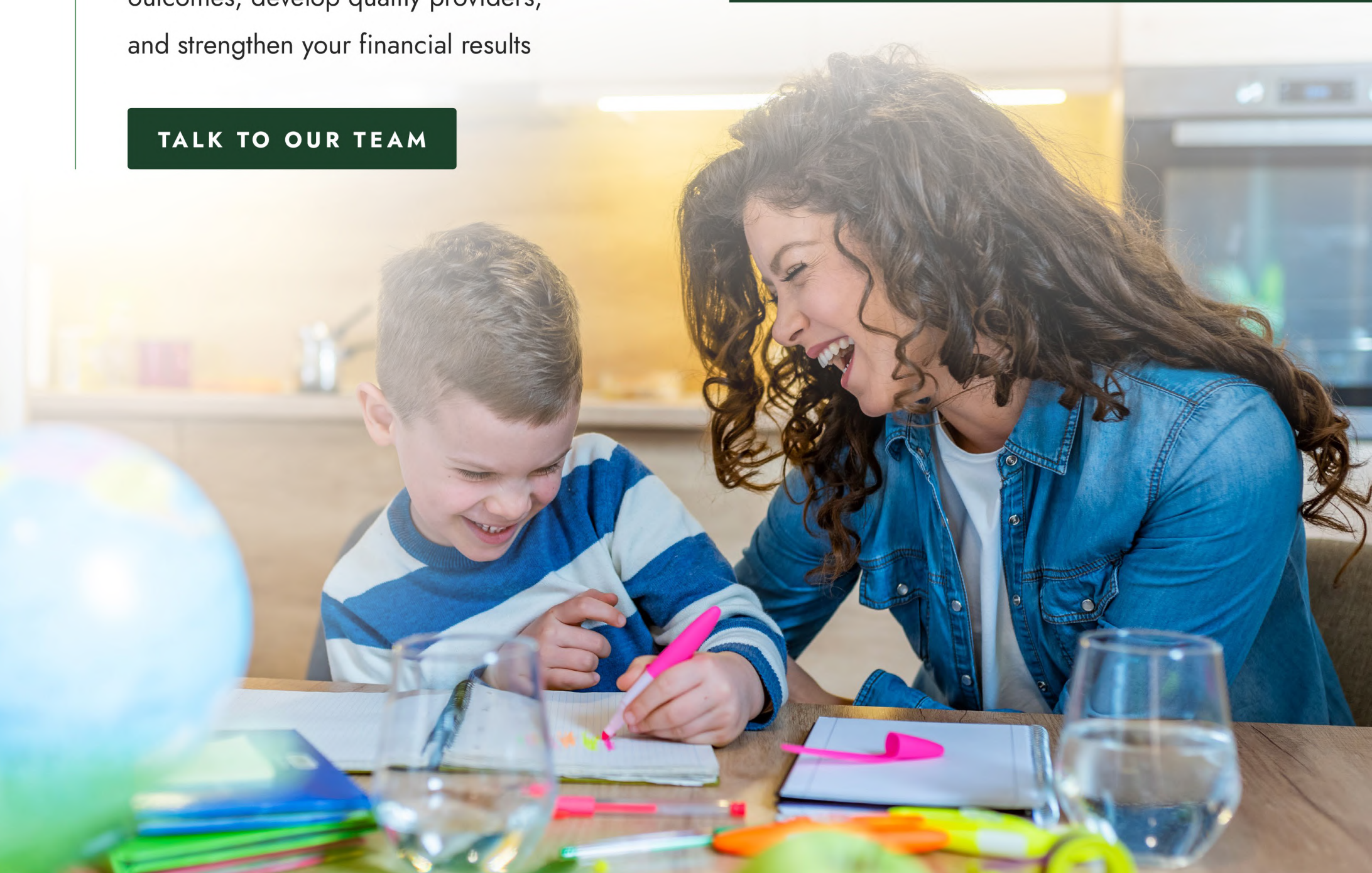


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Navigating the Healthcare System

Deadline: March 6, 2024

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Autism Spectrum News (ASN), published by the 501(c)(3) nonprofit organization Mental Health News Education, was developed to provide the autism community with a trusted source of evidence-based information and education, the latest in scientific research, clinical treatment best practices, family issues, advocacy, and vital community resources.

ASN raises the level of the autism field by serving as a central repository of quality, practical information written by leading professionals in autism service delivery and research, family members, and autistic adults. The publication's trusted content guides autistic adults, parents, and service providers in the right direction from the very beginning.

ASN provides hope through education by collaborating with leading autism organizations and educational institutions that are improving lives every day. The publication serves to unite and improve our evolving systems of care and advocate on behalf of autistic individuals and their families to reduce the harmful effects of stigma in the community.

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A Mother's Journey Advocating for Her Child's Autism Diagnosis and What Fellow Educators Can Learn

By Shelley Hughes, OTR
Director of Portfolio
Management and Delivery
Pearson Clinical Assessment

As a registered occupational therapist (OTR) and Director of Portfolio Management and Delivery at [Pearson Clinical Assessment](#), I have extensive experience working with students who have been diagnosed with a variety of conditions. And as a mom of an autistic daughter, I understand on a personal level how challenging it can be to get the diagnosis that's needed - and why it's imperative that schools join caregivers in their quest for answers.

Advocating for Your Child: The Long Journey When Doors Are Shut

My daughter, who is now 20, was diagnosed with autism at the age of five. While that might seem relatively early - and it definitely is compared with many - I knew from the time she was two that it was a possibility. That instinctual notion set off an arduous journey of speaking with professionals who would suggest she had speech and language needs rather than autism.

It's hard to endure that frustration as a parent: when you are certain your child needs something, and practitioners and other experts push back. But, I remained persistent and eventually got her the specialist care that has helped her flourish and which she still needs today to manage her everyday life.

However, not everyone has the capacity to continue when they feel as though they aren't being heard, and I realize my professional background gave me an advantage. If I hadn't known what to look for and hadn't pushed, she probably wouldn't have been diagnosed until much later, delaying the start of critical support and therapy she needed.

As a parent, we know to trust our instincts because we know our child. It's our role to advocate for them to ensure access to the right supports as early as possible, which will contribute to better long-term outcomes.

Yet, large gaps remain in getting children diagnosed with autism, especially those in specific demographic groups. It's why I'm always eager to speak out.



The Role Educators Have in More Equitable Diagnoses

One of the issues I discovered was that there are multiple barriers to getting a diagnosis in females. These include parental perception, but also lack of information and even clinical bias, where many in the field continue to view autism as a "boy's disorder." Additionally, with less readily available information regarding females and autism, it's more difficult for concerned parents to find out what they need to know.

Taken together, all these factors can lead to delays in recognizing autistic profiles, which, in turn, delays referrals. It's no surprise that [research](#) indicates many girls with autism are not properly diagnosed.

Besides gender, race/ethnicity and socioeconomic factors can contribute to under-diagnoses in certain groups. A [recent study from Rutgers University](#) concentrated in the New York / New Jersey metro area discovered that Black children with Autism Spectrum Disorder (ASD) and no intellectual disabilities were 30% less likely to be identified compared with white children. Those living in affluent areas were 80% more likely to be identified with ASD and no intellectual disabilities compared with children in underserved areas. [Additional research from the CDC](#) finds that Black and Hispanic children are less likely to be identified with ASD than white children, although [that number has recently risen](#). Further recent research [finds](#) underserved populations also often lack access to needed resources.

These disparities in private diagnosis illuminate the critical role schools play. Screening is the first step in the early intervention and identification process, which is vital to begin implementing supports and therapy to facilitate success. Early detection is key in terms of improving both academic outcomes and social needs. Students who are diagnosed later might not thrive to the extent possible, which in turn can impact mental health, social skills, and more.

Early detection also helps families better understand their child's needs and advocate for them, as schools can act as a gateway to the resources and services caregivers need but might otherwise be unable to access or afford.

Autism screening should be included as part of a comprehensive mental health approach, given how the two conditions are intertwined. [Studies show](#) around 70% of children and young people with autism experience one mental health condition, while 41% experience two or more mental health diagnoses.

Assessments and Supports That Can Help Promote Better Outcomes

While the benefits of screening for autism are clear, I know schools are constantly challenged to find funding for any programs, even those with clear benefits. That's why I am proud of the wide array of tools in the [Mental Health Resource Center](#) that Pearson has assembled.

I also believe in the power of staff education and training. Working with autistic

students can be challenging, but the more educators understand, the more support they can provide. A whole host of environmental and interpersonal factors can impact students' participation level, but fortunately, there are ways educators can adjust their physical classroom setup and daily routine to accommodate a wide variety of needs.

Pearson provides a number of assessments that can identify students with autism and their needs, which can initiate the journey to provide the individual supports that will foster success:

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- [The PEDI-CAT](#) can be used to support a key assessment goal of gaining understanding of the support needs required to participate in daily activities.
- [Sensory Profile™ 2](#) offers insight that can help educators make the right accommodations and help autistic students become masters of their own environment.

Focus on the Strengths

By working together, we can make sure the right processes are in place to facilitate screening and make sure it's carried out effectively and efficiently.

The most essential support - as with any area of child development - is to embrace their strengths. Don't spend your energy lamenting what an individual can't do or won't do. Focus on where they thrive - what they can do and what they choose to do.

That's what will set the child up for success within the classroom environment as well as in all other facets of their life. "Focus on the positives" is my mantra, and it can be yours too.

Hughes recommends districts tap into the myriad of free tools Pearson provides. For more resources to support all of your students, check out [Pearson's Mental Health Resource Center](#).

For more information, email Shelley.hughes@pearson.com and visit [Autism Tools | Pearson Clinical Assessments \(pearsonassessments.com\)](#).



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Supporting Families and Caregivers Through a Highly Skilled Workforce: Training with Compassion to Produce Best Outcomes

By Jennifer Ruane, MS, BCBA, LPC, Jennifer Flanders, MEd, BCBA, LABA, and Jill Harper, PhD, BCBA-D, LABA Melmark

Effective ABA services do not occur in isolation. We, as behavior analysts, are part of a larger team including those we serve, stakeholders, and other professionals. In fact, our code of ethics outlines that services provided extend to team members such as caregivers (BACB, 2020). While effective ABA services might result in progress on selected goals and objectives, collaborative practices are necessary to achieve best outcomes. We must learn and teach others a specific skillset that produces coordinated or maybe even integrated treatment plans.

Clinicians often extend direct ABA services by collaborating with families through caregiver training (Blackman et al., 2020). Training members of the larger team such as caregivers promotes the continuation of ABA services well beyond direct service sessions. Consistent support across behavior changes agents (parents, caregivers, and clinicians) enhances outcomes for the individuals we serve. Successful collaboration with caregivers requires clinicians to demonstrate a complex



repertoire integrating technological skills with soft, interpersonal skills (Melton et al., 2023; Rohrer et al., 2021).

Evidence-Based Training

An essential aspect of caregiver training includes utilizing an effective instructional method to teach new skills such as Behavior Skills Training (BST; Dogan et

al., 2017; Parsons & Reid, 2012). Behavior skills training is an evidence-based practice, which includes the use of performance-based and competency-based strategies, during which the trainee practices the skill and demonstrates competent or mastery of that skill (e.g., Harper et al, 2023). Therefore, clinicians must be skilled in the technology of training others as behavior change agents utilizing

such methods. As an evidence-based practice, BST has been successfully in training caregivers to implement a variety of practices with their children (Schaefer & Andzik, 2021).

Parsons and Reid (2012) describe BST as a multistep process, which includes identification of the skill, a written description, demonstration, practice, and feedback. In the case of the family and caregiver training, the trainer would be a highly skilled clinician and the trainee would be the family member or caregiver. Here is an outline of the steps of BST as it would be implemented with a caregiver:

1. The clinician provides the caregiver with the rationale for teaching the specific skill.
2. The caregiver is then provided with a definition of the skill and a written description of how to perform the skill.
3. The clinician demonstrates the skill, step-by-step as written and provides the caregiver an opportunity to ask questions.
4. The caregiver completes the competency check, which means they perform the skill and the clinician provides performance feedback or corrections.

see *Skilled Workforce* on [page 38](#)

Self-Care is Not Selfish: The Important Role Self-Care Plays in Promoting Good Outcomes in Autistic Individuals

By Suzanne Muench, MSS, LCSW
Director of Admissions & Family Services
Melmark

Self-care is one of those buzzword phrases that often goes in one ear and promptly out the other. Well-meaning clinicians, and even the latest podcast gurus, talk about prioritizing self-care in a world that is constantly demanding more and more of your time and energy as a family member. We are in a time and space post-pandemic where attention to the importance of mental health is at an all-time high, and access to available resources is seemingly at an all-time low. In my role as the Director of Admissions and Family Services at Melmark, I hear from family members everyday who are struggling to identify appropriate resources for their loved ones while making do with what little support they are able to drum up. Most of the time parents are picking up the slack to the detriment of their own health and well-being. Families of the children that we serve often have identified needs outside of educational settings, and yet there are significant gaps in the provision of services and providers across the board. This means caregivers are spending a great deal of time exploring any viable options of support for their loved one. But what about support for



themselves? This piece of the equation is often missing, leading to an entirely new series of challenges for caregivers. Helping families understand how self-care is critical to their children's success is increasingly important.

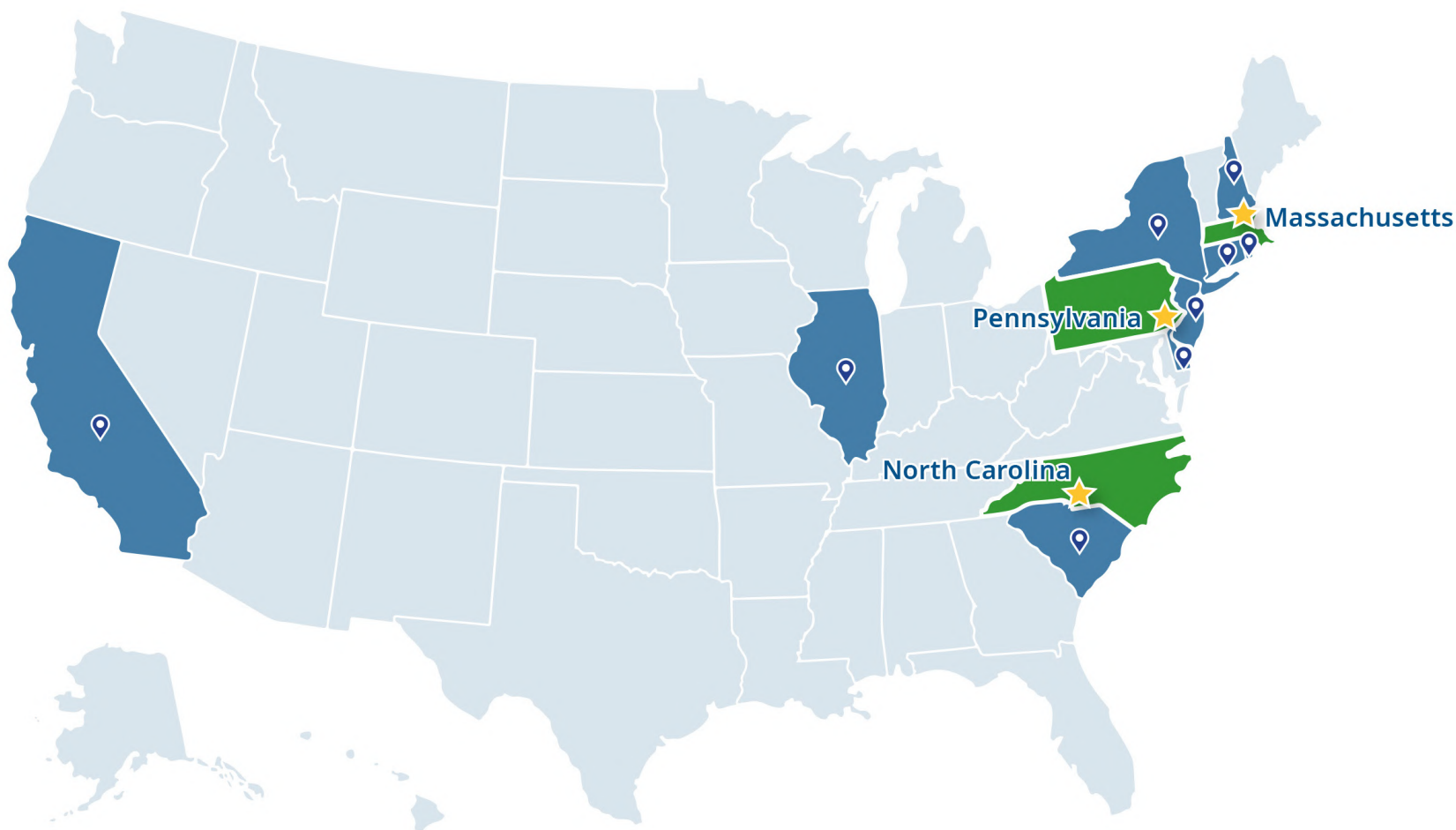
First, what is self-care? There is a multitude of definitions out there; however, I found the one offered by Gorsky (2014) to be simple yet comprehensive. Gorsky identifies self-care as those practices that










include maintaining one's own *health and wellbeing*, actively seeking *support*, and *maintaining some activity apart from one's caregiving duties*. Breaking down self-care into these three parts makes this large idea seem more manageable. How are you supporting your own health and well-being? How are you seeking support? And finally, what does life look like outside of being the parent/caregiver? Perhaps one of these areas is easier to focus on than another, but

all three deserve attention if caregivers are to keep themselves in good enough shape to continue caring well for their children.

In order to get on board with self-care, it's helpful to understand what's in it for you, and to identify how your self-care can be beneficial to your loved ones, including those with special needs. Why would you spend time to care for yourself when there are so many other things that take priority? The answer is rather simple - you cannot give what you do not have. Merluzzi et al. (2011) suggest that improving self-care allows space for parents and caregivers to manage more of the family's needs. When attention is given to supporting your own needs, increased focus and care can be given to the tasks at hand. When you have had adequate sleep or have taken a few minutes to step away and focus on the present situation, you can free up some reserves that may be needed elsewhere. It sounds counterintuitive, but it really works. Many times children are involved in evidence-based programs that are dependent on the interaction and engagement of the parents in order to provide consistency for success (Seymour, et al. 2013). Therefore, one could argue that when you take time to care for yourself, you are actually improving the likelihood that you will have the reserves needed to help your child through

see *Self-Care* on [page 39](#)



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A How-To Guide to Emotional Support for Neurodiverse Couples

By Leslie A. Sickels, LCSW
Clinical Social Worker

In my neurodiverse couples therapy practice in New York City, many central themes are addressed including communication, intimacy, sex, and parenting. However, one of the most consistent themes brought up by neurotypical partners is feeling a lack of emotional support in their relationship. Their neurodivergent partner is often well-meaning and very committed to the relationship, but despite these good intentions, there is a disconnect between what a neurotypical spouse requests and what their neurodiverse partner provides.

Recognizing Differences

When approaching challenges in a neurodiverse relationship, it is important to consider how they may be related to neurodevelopmental differences between partners. Individuals on the autism spectrum experience deficits in Theory of Mind, which is the ability to consider both their own perspective and that of someone else, and then make considerations based on the other person's thoughts and perceptions (Andreou & Skrimpa, 2020). The antiquated view of autism was that individuals on the spectrum were not empathetic. However, adults on the spectrum, along with co-



pious amounts of research, have debunked this and shown that individuals "are capable of recognizing dynamic emotions and the emotional states of others" (McKenzie et al., 2022). Empathy is not as different from their neurotypical counterparts' as previously thought, except for cognitive empathy or Theory of Mind (Greenberg et al., 2018). Thus, we can understand this to mean that other areas of empathy are largely not impacted. However, there are differences related to one's ability to intuitively

see something through another person's perspective, and how to translate that into a way to meet the other person's needs.

Another aspect of difference in neurodiverse relationships is that some people's brains are wired more emotionally, while others are wired more logically. Neurodiverse partnerships often have one person who is skilled in understanding and navigating the emotional experience of an event, while the other partner is skilled in thinking through the logistics or informa-

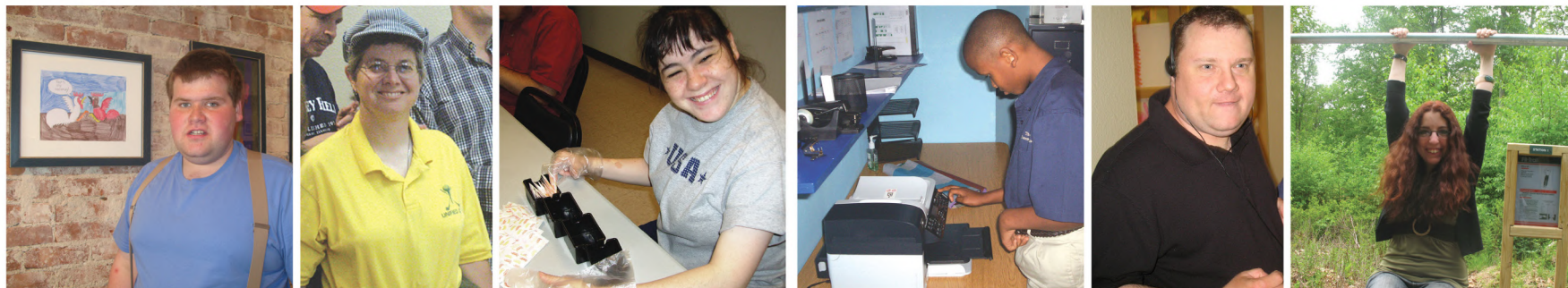
tion needed to have the desired outcome. Both of these roles are important and can make for strong relationships when they are able to complement each other. However, when partners are having miscommunication due to the ways they are perceiving something, either emotionally or logistically, it can also cause stressful interactions. Greenberg et al. (2018) describes "empathizing-systemizing theory" and notes that individuals on the spectrum tend to be more systemizing. While this is an important and useful quality, especially professionally, it does not always help to offer a practical strategy when a partner is only looking for emotional support.

Identifying Emotional Support Needs

Once a couple begins to understand the foundational differences in their neurology, they can have conversations about each of their needs for emotional support. Emotional support varies greatly from person-to-person, so there is not a universal definition that applies to everyone. For all couples, there is a need to operationalize what emotional support means for each person. It is rare that a partner does not want to be supportive, but often what they need to feel supported is vastly different than what their partner may need in the same situation. Clearly discussing

see Emotional Support on page 40

THIS IS WHAT SUCCESS LOOKS LIKE



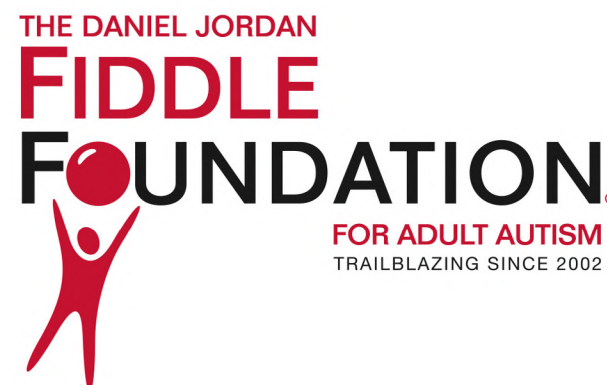
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Navigating Autistic Burnout as an Autistic Parent

By Danielle Aubin, LCSW
AuDHD Psychotherapist
My Autistic Therapist

Being an autistic parent is hard. When your kids are also neurodivergent, this can make life even more challenging when trying to navigate everyone’s complex, often diametrically opposed needs. When we need space, a lot of the time our children need connection and closeness, and we can become overwhelmed and tapped out. When there are days, weeks, or months of this, we can risk entering into autistic burnout territory.

Autistic burnout is characterized by intense mental, physical, or emotional exhaustion often accompanied by a loss of skills (skill regression). I have experienced burnout many times in my life, but as a late-diagnosed autistic, I did not know that was what it was. When I became a parent, burnout became more frequent due to the intense demands (physical, emotional, mental) placed on me as an autistic parent to an autistic child.

Perhaps this is a cycle you are finding yourself in as well. Due to the demands of parenting in a society that has limited support for neurotypical parents, much less autistic parents, we can find ourselves at the end of our ropes. A lot. So how can we deal with this? It requires two steps. The



first is preventing burnout in the first place and when it can’t be prevented (and let’s face it, sometimes it can’t) then we need to learn how to support ourselves in the recovery process.

Preventing Autistic Burnout

In order to prevent autistic burnout, we must design a life that supports our needs as autistic parents. This means that we must incorporate rest into our lives. We

need lives that nourish us and fill up our cups, rather than drain us. To design lives that nourish us, we need to learn what actually nourishes us and what drains us. That means learning what works for you and what doesn’t. It is impossible to design a more supportive life for yourself if you do not know what would feel better.

When asking the question of what works for you, it’s important to look at routine/predictability, your sensory experience, activities, self-care, social connection,

and over/under stimulation. Notice how each of these experiences impacts you and what your “just right” spot would be with each category. Are you being over or under stimulated? Do you like routine or do you need more novelty? What activities do you enjoy engaging in? What frequency/duration works best for you? What level of socializing works best for you? Do you want more or less social connection right now? Are your sensory needs being met? If not, how could you meet your sensory needs better?

After you have started to engage in self-understanding and self-awareness, it is important to ask for help when needed. None of us are entirely independent - we are interdependent and rely on others to help us in one form or another, and others rely on us. Many of us learned to be hyper-independent from childhood as a way to cope with lives that didn’t meet our needs. It may be hard for us to ask for help or to delegate tasks. I implore you to embrace your interdependence with others. Preventing burnout requires that we learn how to ask others to help us. This will look different for each person but generally requires communication.

Recovering From Autistic Burnout

Many autistic parents lack the necessary

see Autistic Burnout on page 41



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S:US' Positive Psychology Approach to Serving People in Crisis and Their Families

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

Since 2016, [Service for the UnderServed's START/CSIDD](#) (Crisis Services for Individuals with Intellectual and/or Developmental Disabilities) Program offers crisis prevention and response services to people who have both developmental disabilities and complex behavioral needs and their families and support system. To participate in the program, the person must reside in Brooklyn or Staten Island in New York, either with family or in a group home; the person must be [OPWDD-eligible](#) and age 6 or over. The participant and their family or caregiver are assigned to work with a START Clinical Coordinator. The Clinical Coordinator works with the person's whole circle of support including family members, advocates, therapists, teachers, doctors, and day habilitation program staff along with additional resources as needed.

The goal of the program is to build relationships and supports across service systems to help people remain in their homes and communities as well as to enhance the ability of their social network and community to support them. Wraparound services are provided to promote stability and help



Lori Lerner, LMSW, RYT-200 hr.

participants stay at home, thereby minimizing hospitalization stay. A full assessment with a biopsychosocial approach, understanding their diagnoses and medication, is done with participants and their team to determine the best ways to provide support. Aminata Sesay, S:US' START Clinical Team Leader shared, "When working with the whole circle and family, staff ask

themselves, 'What can we do to make the situation better to focus on their strengths and not challenges?'" In addition, communication resources are provided to promote ease among the family. Services are recommended based on observations made about the participant and their Care Manager helps the person obtain them.

START/CSIDD clinical coordination is provided for an average of 18 months to enhance the participant's wellbeing and promote stability. The Clinical Coordinator along with their Care Manager will work to get the participant any additional services such as psychotherapy, speech, occupational and/or physical therapy. Therapeutic coaching may also be provided to participants in their home, which promotes de-escalation techniques. The program has a 24/7 crisis hotline. When a family member or advocate calls, staff visits the participant's home as soon as possible to assess the situation, collaborate with the team, and to provide support. The goal is to promote wellbeing and stability and reduce unnecessary emergency services.

S:US also has the Resource Center which offers a respite stay (14-21 days) for a person in crisis with a developmental disability and complex behavioral needs. A person is eligible if they are enrolled in the START/CSIDD program, age 18 or older, and live in their family's home (if they

live in a group home, approval must be obtained first from OPWDD beforehand). The Resource Center can prevent hospitalization or offer respite after being discharged from the hospital before returning home. A planned stay (3-7 days) is also an option to help the participant build their capacity to cope, self-regulate, become more stable, build new skills and interests, and help manage their medication, along with supporting their family with the participant's stay away from home.

The four goals of the Resource Center are to provide "...crisis stabilization, assessment, treatment, and identification of interventions to reduce stress for the person and system."¹ As Cindy Cohen, S:US' START/CSIDD Director shared, "a planned stay at the Resource Center gives the whole family and participant breathing room. Our interventions help the whole circle of support shift their attention away from their challenges towards a re-focus on their strengths."

S:US' START/CSIDD and Resource Center are steeped in utilizing positive psychology and a strengths-based perspective with the participant, their families, and advocates. As Magney Hector-Williams, S:US' CSIDD's Therapeutic Center Director explains, "...the focus is on their

see Positive Psychology on page 44

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Telehealth: Is it Right for Parents and Children?



By Doreen Samelson, EdD, MSCP
Chief Clinical Officer
Catalight

Since the COVID-19 pandemic, the availability of telehealth for autism and other developmental disorders has exploded. Now that we are mostly post-pandemic, many parents are asking: “Is telehealth still the right choice for my child’s treatment?” There is no single answer. Below are several considerations for parents to keep in mind if they are thinking of starting telehealth - or if they are wondering about switching from telehealth to in-person care for their child’s Behavioral Health Treatment (BHT). BHT includes treatment such as applied behavior analysis (ABA) services and non-ABA care.

Is Telehealth Right for My Family’s Collective Wellbeing?

Rather than asking if telehealth is right for their child, I encourage parents to broaden the question: “Is telehealth right for my family’s collective wellbeing?” That’s a subtle, but significant change in perspective. Among parents of children with disabilities, parents of autistic children report some of the highest levels of stress. Telehealth comes with some practical benefits to parents and other caregivers that are often under-discussed, including: less time traveling to and from appointments; less money spent on transportation; less time spent in waiting room; and less disruption to their family’s routine. These non-clinical issues are often overlooked but can be important contributors to the overall wellbeing of a family.

How Does Telehealth Fit with the Type of Treatment My Child Is Receiving?

Another question to ask: “How does telehealth fit with the type of treatment my child is receiving?” BHT for children and youth with autism or other developmental disabilities is provided in two ways. Parent-mediated (also called parent or caregiver-led) or paraprofessional-mediated (also called practitioner-mediated).

In parent-mediated BHT, parents or other caregivers are taught how to implement

their child’s treatment plan. A certified or licensed clinician will coach and support them in this. Parent-mediated BHT has been shown to be just as effective or even more effective than the paraprofessional model of BHT. The advantage of this way of providing treatment is that parents can use what they learn to teach their child or respond to behaviors at any time they are with their child. We sometimes think of this way of providing BHT as teaching parents to parent differently.

In paraprofessional-mediated BHT, a paraprofessional under the supervision of a certified or licensed clinician teaches the paraprofessional to work directly with the child. The paraprofessional often comes to the home a certain number of hours a week but this type of BHT can also be done in a clinic.

Parent-mediated BHT delivered via telehealth comes with some unique benefits. The clinician has the opportunity to virtually observe the child at home in their everyday environment without the disruption or change in behavior that can come when a third-party is in their home - or when the child is in new environment. Some parents use ear buds to receive real-time coaching from the clinician, who can turn off their camera, so the child is not distracted by their virtual presence.

In contrast, paraprofessional-mediated BHT delivered via telehealth may mean increased screen time for the child, which some parents are concerned about. For very young children, paraprofessional-mediated BHT delivered via telehealth may not be realistic or advisable.

What Does the Research Tell Us About Telehealth?

Another important consideration: “What does the research tell us about telehealth?” Research into the efficacy of BHT delivered via telehealth began before the pandemic. Overall, the data show that telehealth is very effective and that many parents find telehealth helpful and easy. A few key points from research published over the past five years:

- A 2018 review of 14 telehealth studies found that telehealth is effective and produces similar results to in-person BHT

see *Telehealth* on page 41

AHRC NYC's Memorial Goldfarb Symposium Highlights Court Rulings' Overlooked Impact on Disability Community

By AHRC New York City

Applying a disability lens to the U.S. Supreme Court decisions makes it clear that recent rulings, including affirmative action, have a significant impact on the community, according to a panel of experts at AHRC New York City's first Memorial Michael Goldfarb Symposium.

"People of color also includes people with disabilities," said Britney Wilson, Associate Professor of Law and Director of the Civil Rights and Disability Justice Clinic, at New York Law School, who was born with Cerebral Palsy. "There's a fear of affirmative action as preferential treatment. 'You're getting something that is different than what I'm getting. You're getting an unfair advantage'...that sounds like accommodation! No, it's actually not fair to treat us all the same, because some people need something else in order to effectively level the playing field."

Kickoff of AHRC NYC's 75th Anniversary

The symposium, "A Call to Action: The Broader Implications of Recent U.S. Supreme Court Rulings for Disability Rights and Protections," kicked off AHRC New York City's 75th anniversary celebration



Photo Credit: Courtesy of AHRC New York City

Panelists, moderators, responders and planning committee members of AHRC New York City's First Michael Goldfarb Memorial Symposium at the CUNY Graduate Center

events. It was a fitting tribute to Goldfarb, who served as Executive Director of AHRC NYC for nearly half of its history. He oversaw the agency for 37 years,

during which time the field of intellectual and developmental disabilities flourished and created the foundation for most of the services and supports that exist today.

"Disability has always been a part of what happens in the courts," said Jasmine E. Harris, a law and inequality legal scholar from the University of Pennsylvania's Carey School of Law, who moderated the panel. "And the courts have always been part of social change in disability. It's not the whole story but it's an important part."

She applied a disability lens to examine *Dobbs v. Jackson Women's Health Organization*, which overruled *Roe v. Wade*. "This is a case that does not have disabled litigants, nor does it implicate disability laws directly," Harris said. "It should be understood through a disability lens with particularly important effects on disabled people."

Rebecca Cokley, Program Officer for U.S. Disability Rights at the Ford Foundation, recalled giving birth to her daughter in 2013. As one of three generations of women with achondroplasia dwarfism in her family, she heard the anesthesiologist telling her doctor "while you're down there, why don't you go ahead and sterilize her because people like her don't need to have any more children."

"People with disabilities should be able to access abortion and reproductive rights because we are people, because we have the fundamental right to bodily autonomy," she added. "That conversation is one that, frankly, I think a lot of people in our community are not comfortable having yet. We're never going to normalize reproductive health care and reproductive justice in the disability space, if we don't talk about what those needs are."

of rights and protections of people with disabilities and other protected classes, the New York State Legislature approved the Equal Rights Amendment for a second time in January, sending the amendment to New Yorkers for ratification on the ballot in November. The ERA would prohibit government discrimination based on a person's ethnicity, origin, age, disability, and sex, including their gender-identity, gender-expression, pregnancy, and pregnancy outcome. It would also protect against any government actions that would curtail a person's reproductive autonomy or their access to reproductive health care. The ERA would, for the first time, explicitly include language to clarify that discrimination based on a person's pregnancy or pregnancy outcome is sex discrimination – an essential clarification given the national trend of criminalizing people for various pregnancy outcomes, as well as the Supreme Court's overturning of *Roe v. Wade*.

Referring to her work for the late Sarah Weddington, lead attorney in *Roe v. Wade*, New York State Assembly Member Rebecca Seawright said Weddington firmly believed that *Roe* had to be protected through state constitutions. "I think passing it here will give more momentum to having it done on the Federal level," said Seawright, Chair of the Assembly's People with Disabilities Committee.

While disability is often overlooked in discussions about the court's rulings and impact, it doesn't lessen their importance to people with intellectual and developmental disabilities.

"It's our responsibility to make sure cases pertaining to disability are being covered to the same extent as other cases, and that aspects of cases related to disability, even if not disability focused, are also highlighted," said Shira Wakschlag, Senior Director of Legal Advocacy and General Counsel, The Arc of the United States. "And it's our job to continually educate the court, so they understand the real-life harms involved and how to remedy them to ensure the promise of our federal disability rights laws can be realized."

Intersectionality and Broadening Partnerships

Where people live, their income, race, gender-identity and other factors impact how people experience disability.

Recognizing that a large section of the disability community lives at the intersection of oppression is critical, said Natalie Chin, Associate Professor of Law and Co-Director of the Disability and Aging Justice Clinic, The City University of New York. While the disabilities rights movement has made major strides, it was considered a largely white, hetero movement led by men with some women, she explained. "Because it was really focused on disability, it kind of forgot that disability isn't a single issue," Chin said. "Disability justice encompasses people with disabilities who are people of color,



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New Yorkers to Vote on Equal Rights Amendment

Fearing the Supreme Court's rollbacks

see Goldfarb Symposium on page 52

Supporting Young Adults: Transitioning to Post-Secondary Educational Opportunities

By **Tara C. Fappiano, Esq.**
Advocate, Mediator, and Litigator

This fall, I dropped my oldest child off for his junior year of college. For our family, this is always a time of excitement, but also one of trepidation. The transition from high school to higher education, from childhood to adulthood, is full of new and evolving challenges. Those challenges are different for students with special needs. Proactive planning, collaboration, and communication, especially between parent and student, are the keys to a successful college journey.

Transition Planning

First, college may or may not be in your student's future. Proper transition planning should begin early in high school, if not sooner. Work with your school district to understand the end goal for your student, with their input. Is a college experience realistic? Is it realistic after four years, or might your student benefit from an extra year of high school, a vocational experience, or skill building? What does your district or community offer that may be appropriate? Does your student intend to go into the workforce, or do they need to explore other supportive services after graduation? These are all issues that can and should be discussed during your student's high school annual review meetings. Setting these goals earlier, even before high school, allows for practical planning over time to put all appropriate supports in place.

While every situation is different, all students should request a final evaluation as they enter junior or senior year to assist with some of these decisions. If the student does intend to go to college, that evaluation will be current and may be used to assist in securing reasonable accommodations. As such, the evaluation should include information to assist with the spectrum of potential requests and needs that may not exist in the school setting.

Choosing a College

The process of choosing a college is daunting for all families. For students with special needs, there are even more factors to consider. Will your student board at school or need to commute? Will they live at school? What do the residential facilities look like? Can your student live independently with their peers? What is the overall size of the school, class size, and student to professor ratio? What supports are available for all students (tutoring services, writing centers, mental health services, counseling, and medical services)? What additional supportive programs are available to students with special needs, and at what cost?

The above questions may all be answered relatively easily. But there are other less tangential aspects of college life, particularly for a student with special needs, which may impact a student's success. One important consideration is how easy it is to



get answers to your questions. Maybe more specifically, the responsiveness of the disability support office and other faculty will be very telling. If it is difficult to get information when applying, it will continue to be difficult as a student. If the school is not supportive of a student with different needs, there are plenty of schools that will be. The overall culture of an institution is best vetted by speaking with students and other parents, not necessarily admission representatives. This is a big decision, and an expensive one, so the choice should feel right from the beginning.

Getting Ready to Go

When your child turns 18, in the eyes of the law and therefore colleges, they are an adult. It is often difficult for parents to view their children this way, so abruptly. As a parent, you are probably accustomed to communicating with your student's teachers, schools, counselors, and other support personnel regularly. In college, that will no longer be the case. In addition, your student is going to feel a new sense of independence that comes from being a college student. They may be more resistant to your help - or help from anyone. They may not take advantage of available resources, or not know how to do so. They may feel they do not need the same level of support that they had before. In college, there is little structure, a lot of free time, and it is easy for a few bad choices or missteps to affect an entire semester.

As a family, you can prepare for these challenges. First, talk to your student about your expectations, and the expectations of the college. Also speak to them about their expectations. Agree as a family on the expected level of communication, and your access as a parent to your student's information, such as grades and schedules. There are various legal documents that may give a parent access to financial information, medical information, and academic information that the institution otherwise cannot share. However, do not expect that a professor will ever communicate with a parent about your student's daily assignments, work product, or interactions with your student. Some support personnel may

be willing to have some collaborative conversations to support the student; but their preference will always be to work with the student directly to foster independence and self-determination.

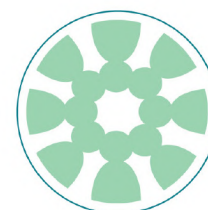
Second, prepare your student for the challenge ahead, and put support systems in place to help. For example, if your student has executive functioning challenges, there is a wealth of technological resources that can help with reminders, organizing assign-

ments, and being in class on time. Consider structuring the unstructured time by doing such things as blocking out time for meals, doing work, studying, and exercise. If your student gets off track, they should know how to get immediate assistance and from where. Speaking from experience, it is very difficult for parents to be that voice. You are now far away. If the only interactions you have with your student are to discuss the "to do" list, or to problem solve, it can have a negative impact on your relationship with your student. Support services on campus, or even outside resources like coaches, can make all the difference.

Finally, your student should apply for accommodations if they need them to succeed. Professors need not modify the curriculum, but a student with a disability has a right to reasonable accommodations that allow them to access that curriculum and the educational facilities. Generally, applications must be made through the disability support services office each semester. But every college has its own rules and processes that may apply, so it is important to familiarize yourself with the process.

It is then the student's responsibility to ask for those accommodations. They must be their own advocate, providing copies of the letters to their professors each semester.

see Post-Secondary on page 26



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Anderson Family Partners: Extended Family, Redefined

By Marybeth Cale
 Founder, Cale Communications
 and Estuary Coaching

For Colleen Contreni, Family Liaison at Anderson Center for Autism, the concept of 'extended family' has long inspired her work.

"I have always been a very family-oriented person, and this role at Anderson is a reminder that by cultivating a spirit of kinship among parents, caregivers, and siblings of autistic individuals, everyone's lives are enriched," said Contreni.

And, as is the case in all families, she says that communication is really the key to navigating challenges, celebrating milestones, and exploring opportunities as an 'extended family.' "Although communication tends to be difficult - or even impossible - for the autistic children and adults served by our programs at Anderson Center for Autism, we know that for their caregivers, having a chance to communicate with one another - and with our team - is everything," she reflected.

To that end, Contreni helps manage a group called Anderson Family Partners (AFP), which was the brainchild of a few parents of Anderson residents and students who felt compelled to build community.

Explained Contreni: "Many moms, dads, relatives, guardians, brothers, and sisters of individuals with autism will say that before



Anderson Family Partners members helping out at the 2023 Anderson Golf Classic; proceeds of the event support Anderson's mission of optimizing the quality of life of individuals with autism. Pictured L-R: Chris P., Julie B., Angela D., Rachele M., and Colleen Contreni (Anderson Center for Autism's Family Liaison)

making the difficult choice to place loved ones in the full-time setting at Anderson, they had long felt extremely isolated and alone. Thanks to AFP, however, they now have the chance to build the kinds of re-

lationships that make life brighter. It is so rewarding to know that this group can provide the sense of belonging that is so desperately needed, and give families a chance to connect with people who share a similar journey in life - one that is hard to comprehend unless you have walked in their shoes."

First established in 2013, AFP is a membership-based group whose mission statement is as follows: "Anderson Family Partners (AFP) is a community of families and guardians of individuals served by Anderson Center for Autism (ACA). We are committed to supporting ACA in their mission of optimizing the quality of life for people with autism. We foster communication, education, and support for the Anderson population, their families, as well as the team members. We also partner with Anderson in community outreach, advocacy, and fundraising efforts."

Said Contreni: "Despite the fact that incidence rates are now 1 in 36 and there are agencies all over the map, I don't believe there are many groups quite like this that exist - and yet this kind of support is so critically important for so many reasons. Through AFP, families have access to informative sessions on our evidence-based approach to therapy, education, and care, along with educational seminars on topics like guardianship and the transition to adulthood. In addition, they learn what our field needs in terms of policy development - the group has even helped advocate for funding increases for organizations like ours, while doing some fundraising on their own (whether it be for Anderson's prom, special outings, or specific needs that some of the residences have). The AFP group also works together to brainstorm solutions when challenges arise - whether it be in an individual or organizational context. And, this group really roots for one another - offering compassion when someone most needs it, and celebrating as milestones are achieved or brighter days come along."

As mentioned, AFP is driven by Anderson Center of Autism's broader mission of "optimizing the quality of life for individuals with autism" - but AFP is simultaneously optimizing the quality of life for their fellow members and even for Anderson's team members who work with their loved ones every day.

"This is all about creating open lines of communication and developing the kind of relationships that allow everyone to reach their potential. Families and team members share resources and knowledge, and engage in the kind of meaningful dialogue that helps us carry out our mission every day. Some of the conversations are difficult ones to have - but they are much less difficult when these relationships are strengthened by this type of ongoing engagement. And the lasting, connected friendships that AFP members have built with one another - and with Anderson professionals caring for their loved ones - keep everyone feeling inspired. We reflect daily on the fact that we are really all in this together, and you can see what that looks like when you attend an AFP meeting."

Anderson Family Partners is open to all families who have loved ones enrolled in Anderson Center for Autism's programs. Dues are \$25 per year (per family), but some will make larger donations to support Anderson's Foundation. "We meet monthly - and the setup is hybrid so it works for all - families who are from as far away as the West Coast, and those who are local to the Hudson Valley where we are based, and everyone in between. We want it to be convenient and accessible to all who wish to participate. And we're always coming up with new topics and programs of interest - for example, one of the upcoming subjects will be 'Autism and Sexuality.' We also recently launched a sibling group, so we are very excited about the response to that."

"Siblings, like parents and caregivers, often feel very lonely in their experience; we hope to empower and enlighten them with tools, knowledge, and a sense that they are valued and supported as well in this unique journey of caring for someone with autism. It has been incredibly rewarding to see them get involved, and I know that it has made a very positive impact on their lives."

Added Contreni, "I have seen so many lives that are enriched by AFP - families who had been so alone who now feel a true sense of community. It really is an extended family here at Anderson Center for Autism - and when families communicate and stay engaged with one another, everyone has a chance to truly thrive."

Learn more about Anderson Center for Autism and Anderson Family Partners at: www.andersoncenterforautism.org/anderson-family-partners.

Marybeth Cale is the owner of Cale Communications and Estuary Coaching. She lives in the Hudson Valley region of New York State and serves as Secretary of the Board of Trustees for Anderson Foundation for Autism. Learn more about her services and expertise at calecommunications.com or estuarycoaching.com.



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The Role of Compassion in Professional ABA Services Relationships

By Howard Savin, PhD
and Michael Reid, PhD, PsyD, QABA
Global Autism Initiative

“Phenomenology or phenomenological psychology, a sub-discipline of psychology, is the scientific study of subjective experiences. It is an approach to psychological subject matter that attempts to explain experiences from the point of view of the subject via the analysis of their written or spoken words” (Wikipedia).

In a world where access to autism services remains uneven, the [Global Autism Initiative \(GAI\)](#) has emerged to offer a beacon of hope for families across the globe. Born out of a commitment to bridge the gap between autism resources and families in need, GAI stands as a testament to the power of education, empathy, and the unbreakable bond between parents and their children on the autism spectrum.

Uniting the World for Autism Support

Autism Spectrum Disorder (ASD) knows no geographical boundaries. Families across continents grapple with the challenges of raising children diagnosed with ASD. However, not all families have equitable access to vital resources and services. This is where the Global Autism Initiative steps in. Created to address the disparities in autism support services, GAI is dedicated to extending education, guidance, and empathy to families who might otherwise be left without the tools they need to empower their children's growth.

Education at the Core

At the heart of the Global Autism Initiative lies a commitment to education. GAI recognizes that empowering parents and primary caregivers with knowledge is key to unlocking the potential of children with ASD. The GAI offers professionally facilitated online coursework that covers a comprehensive range of topics, from the basics of autism to Applied Behavior Analysis (ABA) techniques. Armed with this knowledge, parents are better equipped to foster a supportive and conducive environment for their children's development.

No doubt, people who pursue careers as helpers for special needs individuals mean well and strive to make a positive impact in the lives of the clients they serve. As a corollary, it is generally recognized that to be an effective helper, one must *genuinely* care about the person to be helped. But it's not nearly as simple as it sounds. Once the helper and helpee find themselves in a treatment setting, introductions and a “getting to know one another” dialogue proceed and roles, ideally, begin to diverge. A good helper will adopt a benign, but intense, listening posture thereby making it increasingly comfortable for the helpee to fully share details and history of the issues



Howard Savin, PhD

underlying their help seeking behavior. The non-verbal behavior of the helper as a focused listener is critical, but not sufficient, for the helpee to experience the genuineness of the helper's concern and accurate grasp of key presenting issues. Via a slightly forward body lean, some head nodding and occasional smiling, and the helper's succinct and creative use of paraphrase and summaries, the helpee comes to experience that helper understands critical information leading toward formulation of an intervention plan.

As referenced in [the definition of phenomenology](#) (above), it is somewhere between ideal and essential for professionals supporting individuals with autism to be able to grasp the point of view of the autistic individual and their caretakers and, subsequently, to teach these skills to the caretakers.

The traditional behavior health disciplines of psychiatry, psychology and social work have enjoyed a head start in designing methods for fostering therapeutic relationships, bonding, etc. For example, Carl Rogers, an American Psychologist, was best known for the development of person-centered psychotherapy. This treatment approach flourished in the 1950's and 1960's and largely involved active listening and summarization of the client's thoughts and feelings. Rogers' work led to the objectification of Active Listening Skills. Subsequently, the work of Goldstein, Sprafkin, and Gershaw on Structured Learning Therapy (1976), operationalized key interpersonal and social skills and successfully taught these skills to psychiatric patients.

However, today's graduate level training curricula in Applied Behavior Analysis (ABA) have largely focused on understanding of Autism Spectrum Disorder, methods of intervention for skills development and reduction of maladaptive behaviors and data collection. Techniques for developing effective therapeutic relationships have largely been absent in BCBA and RBT-type training programs leaving this vital area to chance. To address this consequential gap in training, the onboarding process for Behavior Specialists at GAI includes



Michael Reid, PhD, PsyD, QABA

both didactic and experiential training in Active Listening Skills.

Empathy: The Pillar of Connection

Beyond education, GAI underscores the importance of building empathic relationships with children on the spectrum. It's not just about mastering techniques; it's about understanding and connecting with the unique experiences and needs of each child. Active listening, a technique taught by GAI, empowers parents to truly tune in to their

children's emotions and communication styles. This form of understanding becomes the cornerstone of stronger relationships and more effective support systems.

Cultural Sensitivity: Erasing Barriers

Recognizing the diversity of the global community, GAI takes an extra step to ensure that cultural and linguistic barriers are minimized. The Support Specialists are not only highly trained and experienced Qualified Autism Support Practitioners and Behavior Analysts but are also located within the families' own countries. This localization strategy ensures that the support provided is not just professional but also tailored to the specific cultural contexts of each family.

Howard Savin, PhD, is CEO and Founder, and Michael Reid, PhD, PsyD, QABA, is Chief Operating Officer of the [Global Autism Initiative](#). For further information, email hsavin@globalautisminitiative.com.

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The Global Autism Initiative (GAI) collaborates with families globally by providing live, online guidance.

We help parents and caretakers develop effective parenting skills in the context of GAI's reassuring support network.

Through a 12-session program, GAI provides parents and families with specialized knowledge, education, clinical advice, and support.

Our goal is to equip parents with the skills and understanding to effectively manage and support their own child, thereby maximizing positive outcomes for all.

www.globalautisminitiative.com

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The Importance of Residential School-Based Family Support

By Caitlin Sweetapple, EdD,
Arij Abdul-Halim, LMHC,
and Lauren Koffler, MSW
Shrub Oak International School

Providing school-age support for families and caregivers with an autistic child varies based on the school program the student is enrolled in. It is imperative that alongside the programming and support autistic students receive, parents receive similar services. This includes but is not limited to, autism training, support groups, advocacy assistance, future planning, and resources for a variety of evidence-based interventions, not just those covered by insurance or widely known. When schools view their relationship with parents as a partnership, it enhances the overall programming for the child. Currently, there are no federal or even state standards or benchmarks for providing adequate support to families, therefore, schools must transparently offer this level of care, especially in a residential setting. The decision to send a child to a residential placement does not come without years of advocacy from the family. Many families make this decision after experiencing hardship at home or unsuccessful school environments for their child. Rightfully so, when parents make this decision, they need support from the residential school-based team on a variety



Shrub Oak International student engaging in the community

of topics that meet each family's unique needs to truly create a partnership between home and school.

Psychoeducation is a critical component for all families with autistic children, especially those who send their children to a residential program. At [Shrub Oak International School](#), we employ a variety of methods that support parents. First, we provide them with monthly virtual parent training so our families from all over the country and world can engage. Our monthly train-

ing courses cover a wide range of topics that include clinical domains, community engagement, legal advice, financial planning, and life-skills training. This allows families to gain knowledge to support the transfer of skills and after-care support. Additionally, the training supports effective communication with their child, collaboration with staff, and support for the parents themselves as they are a part of a community. Another avenue for support is our robust Parent Liaison program. Every student and their family are assigned a designated parent liaison who communicates progress with families. This program affords the parents the support of a designated individual who knows their child and everything that is occurring in their day to day at Shrub Oak. We believe that supporting parents as much as possible is as important as the work we do with the students directly.

Furthermore, as mentioned previously, it is imperative that we can provide a holistic and transdisciplinary approach when working with our students as well as the family, in addition to receiving parent feedback on which supports are further needed and what can be implemented in the residential setting. It is evident that parents who have autistic children experience a vast amount of mental health stressors, difficulties in time management, deficits in attending to the daily needs of their child(ren), an onerous feeling in addressing family obligations (Bonis, 2016), and poorer quality of life (QoL) (Vasilopoulou & Nisbet, 2016). As a result, it is imperative that further research be conducted, nationally and internationally, on expanding resources such as having more accessible groups for parents on stress management, psychoeducation, and resources to aide in decision-making when it comes to having an autistic child (Bonis, 2016).

For parents who have an autistic child with co-occurring disorders, the profile of students at Shrub Oak, more support is needed in solid, culturally informed, evidence-based practices such as parent support groups that also aid in increasing parent self-efficacy, as well as, enhancing advocacy skills for reducing the stigma that comes with mental health disorders. Additionally, these groups could recommend policy change for autistic children

(Bearss et al. 2015; Liao et al., 2019). Effective parent training and parent-mediated interventions help increase parent psychological well-being, enhance parenting skills to effectively engage their child in times of stress or praise, and strengthens the parent-child relationship to improve family dynamics (Bearss et al., 2015). It is our belief that the stronger the relationship between schools and families are, the more powerful the outcomes for the child are, and as a result, the entire family unit.

Dr. Caitlin Sweetapple is the Director of Research at [Shrub Oak International School \(SOIS\)](#), a private, coeducational, therapeutic day and boarding school for students ages 8-30 on the autism spectrum who face complex challenges. Research at Shrub Oak International School explores, analyzes, and calls attention to a wide range of salient topics pertaining to quality education of autistic students, at Shrub Oak, and globally. For more information, please contact Dr. Sweetapple at csweetapple@shruboak.org.

Mrs. Arij Abdul-Halim is a Licensed Mental Health Counselor and currently pursuing her PhD in Counseling Education and Supervision. She is currently overseeing the Parent Liaison Program at Shrub Oak. She has also served as the Deputy Director for a Functional Family Therapy (FFT) Program at a nonprofit organization affiliated with the Administration for Children's Services. Arij has worked with all age groups and has provided services for clients on the autism spectrum and with varying diagnoses including ADHD, behavioral issues, depression, anxiety, and educational and learning disabilities. She also enjoys using the Community Resiliency Model and is passionate about improving family dynamics and working with children of all ages. For more information, please contact Arij at aabdul-halim@shruboak.org.

Lauren Koffler, MSW, is Head of Admissions, Communications and Client Relations at Shrub Oak International School, a therapeutic day and boarding school for children, adolescents, and young adults on the autism spectrum who face complex challenges and have high personal attention needs. With more than a decade of experience serving the special needs community, first as an educator and then as an administrator, Lauren is committed to providing students on the autism spectrum with an outstanding education in a warm, supportive, family-centric environment. In addition to her full-time role at Shrub Oak, Lauren is currently pursuing a PhD at Thomas Jefferson University. She may be reached at lkoffler@shruboak.org.

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see Residential School on page 42



SHRUB OAK
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A Visionary Approach to Autism Education

www.shruboak.org

Shrub Oak International School is a therapeutic day and boarding school serving children, adolescents, and young adults on the autism spectrum who face complex challenges and have high personal-attention needs.

We offer strength- and passion-based learning supported by a highly individualized, transdisciplinary approach and are located on 127 gated acres less than one hour from New York City. Specialty areas include complex students with behaviors; NVLD; intellectual disability; dual diagnoses of autism and co-occurring conditions including visual and hearing impairments; medically fragile students; and elopement.

The Pines at Shrub Oak (Opening 2024)

New in 2024! Shrub Oak will be opening a new program specifically for autistic students in need of significant psychiatric support and stabilization before transitioning to a less restrictive environment. Students at the Pines will receive psychiatric services in addition to academic and life skills instruction in a safe, supportive environment with a 2:1 student to staff ratio.

For more information, contact Lauren Koffler, MSW, Head of Admissions, at lkoffler@shruboak.org or (914) 885-1995.

Aging with Autism: Innovations for Independent Living to Address the Housing Crisis

By Stacey Ledbetter
Mother and Founder
Nflyte

At the beginning of the COVID pandemic, a friend came down with a particularly bad case of the virus which required emergency transport to the hospital. Laying on the gurney in the back of the ambulance she panicked as they placed the oxygen mask over her face. The EMS workers were frustrated with her as she continued to rip the mask off because she needed to talk to her sister who was accompanying her in that ambulance. She had so many things that she needed to tell her sister. As a mother and sole caretaker to an adult child with autism, she was frantically listing all the care instructions necessary for supporting her son. That was the only thing on her mind at that moment. She was facing the possibility of her worst fear coming true sooner than expected, “What will happen to him when I’m gone?” She made a miraculous recovery and has become an active advocate for autistic adults.

Once our children reach 22 years of age, they encounter the next era of challenges that comes with the “services cliff” which denotes the end of school-based services. Parents think of what it would look like for their children to live independently, and they start the process of researching the options. Sadly, they are faced with the grim reality that resources are limited and the process for applying for assistance programs can be confusing. For many adults with I/DD there are limited options to obtain employment or increase their earning potential. If approved for SSI, the maximum federal payout is \$914/month¹ which puts individuals at 25% below the federal poverty level (FPL).² Waitlists for Medicaid home-and community-based services (HCBS) can reach up to 10 years or more in some states and that funding covers services, not assistance with the cost of housing.³ Where I live in the Charleston, SC area, the fair market value for a one-bedroom apartment is \$1,357/month which is not attainable to an SSI recipient who would need rent to be no more than \$274/month.⁴ This example represents what most are experiencing across the country. The result is that 75% of I/DD adults continue to live at home with family.⁵

The number of autistic students leaving high school has been estimated to reach up to 1 million over the next decade.⁶ With the most recent increase in childhood diagnosis cases climbing to 1 in 36,⁷ the number of autistic students transitioning to adulthood will only increase. The phrase often heard from parents is “I just need to live forever,” accompanied by a chuckle underpinned by hopelessness and fear. In truth, the clock is ticking as caretakers are aging themselves and the question of how long they can continue to care for their child looms. Nationwide, half of caregivers to I/DD adults are older than 50, and 10% are 75 or older.⁸ An added variable is that adults aged 50 years and older often find themselves with



increased caretaking responsibilities for aging parents. Therefore, there is a rising population of people sandwiched between caring for their autistic adult child and their aging parents. The pressure on caretakers is profound.

Fortunately, there are efforts, often led by passionate parents, to pave the way for sustainable person-center communities and tools for supported independence. Just as senior living communities have evolved over time, there is progress away from the institutionalized model of the past to create modern communities that are built to support the continued development of practical life, social, and vocational skills. In addition, there is increasing focus on the need for innovators in technology to create tools supporting people with disabilities. Previously, entrepreneurs have faced difficulty in accessing funding for developing solutions in the disabilities market, but organizations such as [Multiple Hub](#) and [The Disability Opportunity Fund](#) are supporting efforts to make innovation possible.

Modern Housing Options

An excellent source for housing options is provided by [The Autism Housing Network](#) and includes a directory of innovative supportive living communities such as these:

[Oak Tree Farm](#) is an interdependent affordable housing community in Conway, SC for I/DD adults. The community is comprised of 2- and 3-bedroom townhouses or apartments and includes access to transportation, life skills training, an amenities center, a swimming pool, and on-site laundry facilities. While Oak Tree Farm does not provide direct one-on-one care, there are on-site staff members to do daily check-ins and organize group activities and social events. The rent is approximately \$500/month, and the community assists residents with filing for a housing voucher which can cover up to 70% of the cost. Oak Tree Farm will begin moving in the first 75 residents in November 2023 and plans to add an additional building for residents with higher support needs.

[First Place Arizona](#) is a 63-apartment complex in Phoenix, AZ for I/DD adults

who are transitioning to a more independent life. Each resident lives in their own 1- or 2-bedroom apartment and has access to a full suite of services including group life skills training, daily social activities, vocational assistance, and direct one-on-one practical life coaching. The complex includes a training kitchen where hands-on cooking lessons are offered which not only teaches valuable skills but brings the community together. First Place offers a comprehensive activity schedule so that


residents can be as active as they want to engage physically and socially. In addition, they offer a 2-year Transition Academy which is a separate training program for residents that need a more structured transition.

Technology for Independent Living

Technology can play a big part in empowering independence through mobile apps and smart home integrations. To date, most tools available have been designed for K-12 autistic children but that is changing. There are more options coming available to empower autistic adults to live more independently while keeping them connected with their families.

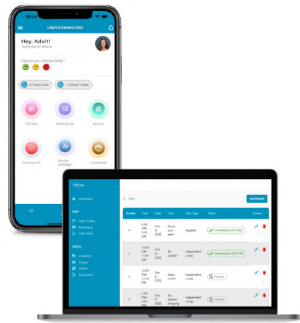
[NFlyte](#) is an all-in-one life skills app for autistic adults who need support living independently that allows families, caregivers, and support programs to provide remote help. Independent adults use the mobile app to create customized visual schedules, keep track of shopping lists, create and share recipes with the NFlyte community, and store documents. Parents and programs log into a web-based dashboard to add tasks remotely and see how their adult child is progressing through the day.

see *Innovations* on page 43




AN ALL-IN-ONE LIFE SKILLS APP FOR AUTISTIC ADULTS





NFlyte supports the transition to adulthood and provides autistic adults with valuable life skills while allowing them to stay connected with their remote caregivers.

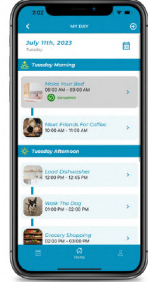


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Notes, Buckets, and Beneficiaries: An Introduction to Special Needs Planning

By Donald T. Brown, ChFC, ChSNC
and Elizabeth Neumann, MA
Special Needs Funding Coach

Having loved ones with special needs requires specialized planning to meet their unique financial requirements. The search for direction about financial assistance (benefits and support provided by government agencies) and special needs planning (preparation for future financial needs) can be especially frustrating for caregivers amidst their other pressing daily concerns. Providing information and resources to help plan for quality of life during a lifetime of care is the primary focus of a special needs financial planner.

Proper financial planning is vitally important so that families and caregivers can plan for their loved ones while preserving their eligibility for government services. Over decades of planning, we've found that families have been concerned about three primary financial priorities:

1. Making sure their dependents always qualify for government support services
2. Answering the question, "What happens when I'm gone?"
3. Maximizing their resources, regardless of their economic status



Strategies to address all three are centered on a few basic ideas.

In most states, Medicaid is the primary source of services for individuals with special needs. While there are multiple ways to remain Medicaid-eligible, most often it is necessary for the person to have less than \$2,000 of assets in their name. Achieving a Better Life Experience (ABLE) accounts allow the individual to deposit \$16,000 per year and accumulate up to \$100,000 without jeopardizing government support ben-

efits. However, they do have a few drawbacks and typically cannot be the main source of long-term support planning (see www.ablencr.org for details). Most importantly, if an ABLE account owner passes away with monies left in the account, Medicaid gets reimbursed for the cost of its services from the account balance remaining. ABLE accounts and special needs trusts (discussed below) have different eligible expenses and restrictions, so using them in conjunction is often most helpful for families. An advisor with special needs expertise can explain the ins and outs of each.

In our opinion, the combination of estate and financial planning remains the most effective way for families to realize their wishes for their dependents. In the estate planning area, using a qualified special needs attorney should be considered critical (they can be identified at www.naela.org, www.specialneedsanswers.com, or www.specialneedsalliance.org). While estate planning encompasses individualized plans that often include additional items, this article will focus on a simple understanding of wills, trusts, and beneficiaries of life insurance, accounts, and retirement plans.

Wills = Notes

Most are aware of the importance of writing a will as a legally binding plan to be enacted upon your death. To simplify, we consider a will to be a note. If someone were going to watch your home and family while you went away for a weekend, you would leave them a note (how to reach you, what's important to know about the house, etc.). Essentially, what a will accomplishes is to legally say what will happen to all of your "stuff," who will become guardian of your dependents, and who will be responsible for these tasks (the executor). A will may have specific references to creating a trust and may also reference a letter of intent, a detailed plan of how you would like your loved ones with special needs to live after you are gone.

Trusts = Buckets

We consider a special needs trust to be a crucial component of a successful financial and estate plan. There are many kinds of

trusts; a special needs trust is a particular type that is imperative to allow individuals with special needs to retain government services eligibility. In simple terms, we consider a trust to be a bucket. What does a bucket do?

A bucket holds things. As your personal legal bucket, a trust allows you to put assets in it, either while you are living or after you are gone. Those assets may be used for dependents with special needs while not having the assets in their names (which would violate Medicaid requirements).

A bucket protects what is in it from outside sources. In special needs planning, it protects the owner of those assets from losing government services eligibility. It also protects them from unscrupulous people or civil litigation, such as divorce. We do not recommend leaving assets directly to a sibling or other caregiver because, once the assets or funds are in that person's name, they can become part of a lawsuit or divorce. Having the funds in the trust (in the name of the individual with special needs) avoids these issues.

A bucket allows you to control how things come out of it. You may pour out a little at a time, dump it all out at once, or anything in between. A trust, particularly a special needs trust, allows the grantor to control assets so they may be used for a dependent with special needs even after you are gone.

The above is a basic overview to help families understand how these important documents make a difference in the lives of their loved ones with special needs. Working with qualified special needs attorneys is critical to the success of your plan. The last thing you would want to happen after your death is for Social Security, Medicaid, or other government agencies to determine that your trust doesn't qualify as a special needs trust because it wasn't properly written. The only things that can correct this problem are time and money... and who will correct the problem after you are gone?

Check Your Beneficiaries

Lastly, knowing that individuals with special needs cannot have more than \$2,000 of assets in their names, here is your easily-done action item: make sure that no individual with special needs is a primary or contingent beneficiary of any relative's life insurance policy or retirement plan like a 401(k), IRA, or pension. Most group life and retirement plans, as well as individual policies, use a default option for contingent beneficiaries that splits proceeds between all surviving children, therefore putting government support benefits in jeopardy. Instead, use special needs trusts and an ABLE account to hold those funds and provide for their future.

Donald T. Brown, ChFC, ChSNC, is a Financial Planner, and Elizabeth Neumann, MA, is a Client Relationship Manager with Special Needs Funding Coach.

see Planning on page 37

Special Needs Planning Quiz

Donald T. Brown, ChFC, ChSNC
dtbrown@nlgrouppmail.com

848.200.7148
www.specialneedsfundingcoach.com

- | Yes | No | |
|-----------------------|-----------------------|--|
| <input type="radio"/> | <input type="radio"/> | 1. Do you have a vision of how your loved ones with special needs will live after you're gone? |
| <input type="radio"/> | <input type="radio"/> | 2. Are you certain that they are not directly named in your will or as beneficiaries? |
| <input type="radio"/> | <input type="radio"/> | 3. Are you confident in your understanding of SSI and SSDI government benefits? |
| <input type="radio"/> | <input type="radio"/> | 4. Have you written a letter of intent? |
| <input type="radio"/> | <input type="radio"/> | 5. Have you established a special needs trust (SNT) to preserve government benefits? |
| <input type="radio"/> | <input type="radio"/> | 6. Have provisions been made to fund the trust most effectively? |
| <input type="radio"/> | <input type="radio"/> | 7. Have you coordinated your special needs planning with relatives? |
| <input type="radio"/> | <input type="radio"/> | 8. Have you established an Achieving a Better Life Experience (ABLE) account? |
| <input type="radio"/> | <input type="radio"/> | 9. Do you understand the uses of and restrictions on ABLE and SNT funds? |
| <input type="radio"/> | <input type="radio"/> | 10. Have you done everything possible to protect your loved ones' financial future? |

If you are not satisfied with all of your answers, please contact
Donald T. Brown, ChFC, ChSNC at 848.200.7148 or dtbrown@nlgrouppmail.com.

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Helping Autistic Individuals Navigate Barriers to Adulthood

By Kenneth Mann, PsyD
Director of Outpatient Programs
for the Developmentally Disabled
Westchester Jewish Community
Services (WJCS)

An adult on the spectrum can accomplish or achieve everything his/her/their cohort who is not on the spectrum has accomplished or achieved, and yet not be rewarded with that same level of independence and autonomy for his/her/their efforts (Cheak-Zamora, Tait & Coleman, 2022). Although young adults are living at home longer than ever after high school graduation, the adult who is on the spectrum does not see an end point in the same way that others do (Furfaro, 2018). Who would not be frustrated and depressed to do what society has prescribed as the path to independence, and yet find oneself stalled in what seems to be a regressed and unenviable position?

Many of us have defined living outside our family of origin, be it on our own, with roommates, or in a relationship as the definition of adulthood. Many of the clients I work with have in common their defining achievement as being the beginning of adulthood. Those clients are, therefore, thwarted in their efforts to become an “adult” as they are defining it and as it is reinforced by our culture. The establishment of one’s own household, in whatever form it may take, has meaning for the individual on the move and for everyone around him/her/them as well.

Reality is unmercifully creating blocks for my clients to achieve this. First, there is the financial reality that is unsurmountable. I have worked with several clients who were employed full-time, were valued employees, yet could not possibly earn what would be required to support themselves. I have also worked with clients who are in pre-vocational training and internships. They are exactly where they should be and they can feel their own progress and development, but they are not earning any compensation for that effort. I also have clients who are on waiting lists for supportive housing. Here, there is hope to achieve the goal of living outside of their family of origin, albeit they have had to cope with being on staggeringly long waiting lists where movement is unpredictable. This brings parents some peace of mind, but it does not help a 25-year-old who feels like they have not left their childhood bedroom, both literally and figuratively.

In consideration of these factors, I have placed an emphasis, when I work with these clients, on an “adultification” of the present. While we cannot create jobs that pay a living wage or turn internships into competitive employment, there are other psychological interventions we can construct that liberate one from childhood. Interestingly, I had a client whose parents set him up in an apartment that they owned in an urban area and they lived several miles away in a suburban setting. He would have been the envy of many of my other clients yet he was miserable. He felt his parents were intrusive and controlling and he lamented, “I might as well move back



home - I live in a bedroom that is 10 miles away from the rest of my house.” The idea of how to live in the world as an adult was even an issue for this client.

One of the most immediate ways to create a different psychological space in the same square footage is to redecorate. Depending on one’s budget this can range from painting the walls to buying new furniture. The question becomes how this space goes from a childhood bedroom to one that reflects an adult sensibility. With one client, with his parents’ support, we worked on thinking of his room as a studio apartment and he went from a twin bed to a couch that opens. Treasures and mementos from the past can be safely stored away and not be on display any longer. Rituals that mark developmental achievements have emotional meaning and it is possible to have a “housewarming” party that unveils the new space to friends and family. Perhaps a party where people bring a gift and alcohol could be served.

It is also essential that the individual seeking adulthood in their childhood home is integrated into helping the household function. Preferably, the role or chore that the individual does is something that others cannot perform. One of my clients who lives with his aging parents learned to change the HVAC filters – a task that his parents found physically challenging. Now his parents joke that if it were not for their son, they would not be breathing in fresh air. To live with others and to not have responsibilities is infantilizing and provides no opportunity for building and strengthening skills that are necessary for future independence and autonomy. I have a young adult client living with his family who is working hard to “be on top of the dishwasher” - his job is to load it, run it, put items away, and for his other family members not to have to worry about it. His mother told us in a family session that although she is certainly capable of handling the dishwasher on her own, it has meaning to her when she sees the effort that her son is putting into mastering this task, and as a result she considers other ways to give him independence and responsibility. Of course, there is no reason why most clients cannot do their own laundry, whether it be somewhere in the house, in the basement

of the apartment building, or the corner laundromat.

Most of the young adult and adult autistic clients I work with who live at home have parents paying for some aspect of their life that is essential in our culture today, such as a cell phone. When these arrangements are made without any link to household contributions and participation, there is a lost opportunity for what I refer to as “adultification.” I worked with a client and his family recently to make this paradigm

shift and to create a system wherein the client’s contributions to daily family life translated to their continuing to pay for his cell phone and video games. Different contributions had varying degrees of power in this system, and it was therapeutic for the client and the family to negotiate what that power should look like at first. The earned power in the system became currency that they would then respect with payment for his cell phone, etc. As the client stated once he accepted this new arrangement, “they are paying for it, but I am the one who is working for it.” The client’s mother wondered, when the client was initially resistant to this change, if what I suggested was too regressive for him as it sounded like the token economy systems that were part of the therapeutic school programs that he had attended for years. We discussed how that was exactly what it was, and that the idea of getting some kind of currency and empowerment for effort was the foundation of the paycheck that adults buy into in the work world. In this way of thinking, this is an adult concept as getting everything that one wants, contingent on nothing, is more the psychology of infancy and early childhood and not indicative of “adultification.”

The cliché that you are as young as you feel has relevance here. We need to consider the subjective experience of being an adult rather than defining adulthood as

see Adulthood on page 52



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Supporting Families in ABA Programs with Compassion and Sensitivity

By Bobbi Rogers
Senior Director of Community
and Industry Relations
Proud Moments ABA

Imagine the feeling of expecting a child. You dream for your child, wonder what they will be like, wonder if they will be funny or smart, outgoing, or quiet. You wonder about a lot of things, but you don't wonder whether they will ever learn to talk. You don't wonder if they will ever have a job or make friends. Will they eat what they need to, sleep through the night, or toilet themselves without help are not the questions that cross your mind. Until one day they are. Until one day you see an evaluation for your child that refers to him/her as being nonverbal, uninterested in their peers, aggressive, self-injurious, and well below their peers in development. No one wants to see their child struggle. To know that the basic parts of life like talking and making friends will have to be learned through intensive therapy sessions is a reality that will literally steal your breath away as a parent. You can't help but ask yourself, what does the future look like? Will my child be ok? For me it started a fire under my feet. We needed to get busy, and get busy fast.

Enter Applied Behavior Analysis (ABA). Joey was two years old when we started ABA. Many days I want to go back



in time to those days and hug him and hug the younger version of myself who was scared for him. It was intense all right. ABA was a game on approach to teaching Joey all the things he deserved to know. It required a huge commitment on my part to revolve our life around his therapy schedule. I had to learn what his behavior meant and how to respond to it. I had to coordinate team meetings, call therapists with questions, take data, and understand the basics of what the programs were so

that I could follow through at home. I was already exhausted and now I had more to be tired about. But we soldiered on. I embraced my role as CEO of his therapy program. I did my best to balance all the moving parts and all the people I loved that were affected by them.

Fast forward time to the present. Joey has language and lots of it. We don't have long conversations, but I can understand his needs, wants, and even sometimes his wishes for life. He has acquired many new skills that each feel like a giant milestone and none of which are ever taken for granted. He still has meltdowns and there are challenging behaviors we haven't figured out yet. But it was worth it. All the extra work and all the extra time was worth it.

I know now that this was the best path for us. But I also know that I had to manage it carefully to ensure that we worked on what was most important to Joey. I also needed the support and understanding of our unique family so that what we worked on was realistic for us, gave us the biggest bang for our buck, and incorporated supporting the path Joey chose. It wasn't about what I wanted for Joey but rather what did Joey want for Joey. I had to keep us all focused on who he was and what was important to him.

Over the years I developed some tools and tricks to accomplish these goals. In my role as an administrator, I have worked with other ABA families. I wanted to get it right for all of us. I learned that being sensitive to each family's unique culture was critical. Being compassionate was the armor that guards us from judgement of others and criticism of ourselves. I learned some key factors that kept our programs culturally sensitive and compassionate. I learned how to support families who were trying to manage ABA programs and life all at the same time.

Tools and Tricks for the Therapist

- Parents/Caregivers know their child best. Always remember this and acknowledge that they are the experts.
- Acknowledge frequently that this is hard, that they are doing a great job, and that we are a team.

- Use sensitive language - Talk in plain English with terms parents and caregivers already know. Meetings with parents/caregivers should be referred to as collaboration meetings, progress monitoring, and/or behavior skills training meetings. It is not a parent training meeting (I already know how to be a parent).
- Be approachable - Actively listen before responding. Keep any judgments out of your response. Be watchful of your nonverbals.
- Write realistic goals. Change your approach when things aren't working. If a family is not following through, how can you change the goal so that they will be successful?
- Give options. Ignoring a behavior is just not always possible. Give options so parents/caregivers can be successful.
- Keep parents and caregivers informed. Talk about the progress but be honest about the challenges.
- Work on what matters - What is important to that individual? What is important to that family? What does a typical week look like for that family? Do they value family dinners, eating out, holidays or their faith? Find out what a typical week looks like and ask what they want it to look like.
- Work on the future - What is wanted for the future (school, job, activity)? What do we need to get there?
- What is next on the horizon? - Is there a dentist or doctor's appointment coming up? Is everyone prepared for it to be successful? How are everyday tasks such as toothbrushing and nail clipping going? Are there any birthday parties coming up? Should we practice for these?
- What are the memory making moments? What are the holidays and occasions that matter to that family? Most of the time when you ask a person what their favorite memories are there is a holiday involved. So don't forget about these. Prepare for them.
- Support family relationships by including the siblings, cousins, grandparents, and anyone else important to the family.
- Even the best thought out plan is not going to work if it isn't realistic for the family or staff. Keep what you are asking for families to follow through on realistic.

Tools and Tricks for the Parent, Caregiver, and Sibling

- Trust yourself and remember that no one knows your child better than you.
- Be kind to yourself. Your child is working hard but so are you.
- Make sure your ABA team is approachable. If they are not, try talking to them

see *Supporting Families* on page 42

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Advance Your Career with the Synchrony Tech Scholarship for Autistic Adults

By Courtney Carroll
Manager, Hire Autism
Organization for Autism Research

The demand for professional certifications has significantly increased in recent years, especially for IT and technical positions. This increased demand has led many job applicants towards continuous learning and professional development prior to and during employment.

A 2020 IT Skills and Salary Report found that eighty-seven percent of IT professionals have at least one certification, while nearly 40% are already pursuing their next certification. You may be wondering why certifications and other training programs are so desired and what the benefits of taking these courses are.

Many factors play into landing a job or growing your career. However, professional development and continued education in your field of interest are among the most significant factors. In a competitive job market, certifications can help autistic individuals gain the skill set they need to meet a job description's preferred and desired requirements.

Certifications improve one's resume by showing potential employers that you have the skills necessary to complete the job, you are invested in your career, and you are up to date on the latest trends (Jobscan).



In presenting to an employer that you have the skills they need, your chances of landing the job increase. A new Coursera study found that employers are, on average, 72% more likely to hire a candidate who has earned one.

Not only can completing a certificate increase one's opportunity to land a job, but it can also help job seekers already in the workforce receive a promotion or higher salary. Of the 9,505 participants in the 2020 IT Skills and Salary Report, nearly 20% reported that they either received a raise or a promotion after getting a certification.

Outside of the extrinsic and monetary benefits of taking a certificate program, there are direct benefits to an individual's overall success and happiness in their role. Pearson Vues 2021 Value of IT Certification Report surveyed 29,000 professionals who pursued IT certifications and found that candidates experienced many intrinsic benefits from certification. 91% reported increased confidence in their abilities, 84% reported greater determination to succeed, 76% reported feeling more respected by co-workers, 76% also reported greater job satisfaction and 74% reported greater autonomy at work.

With the mission to support autistic adults in finding and maintaining meaningful employment, Hire Autism (HA), a program of the Organization for Autism Research (OAR), offers the Synchrony Tech Scholarship. Unlike OAR's other scholarships, which support autistic students pursuing life-skills programs or two and 4-year degree programs, the Synchrony Tech Scholarship supports autistic adults interested in obtaining technology-related training and certifications to pursue or advance their careers.

Acceptable training and certification programs include but are not limited to, the following areas: cybersecurity, game/app development, web development, machine learning, data analytics, cloud computing, ethical hacking, and artificial intelligence.

Whether you are already in a tech career and looking to be promoted, trying to gain the experience you need to land a job in the tech industry, or trying to increase your tech knowledge for another field, this scholarship supports those individualized goals.

What does it take to pursue further training or a certification course, and how do you find the right one?

1. Identify your motivation for taking the course. This will be your "why." Some common reasons include:

see Scholarship on page 42

Teamwork: Building A Successful Neurodivergent-Neurotypical Marriage

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

As I sit down to write this, my husband and I just celebrated our 39th wedding anniversary. We met through a mutual friend - an ex-boyfriend of mine. Joseph and I had gone our separate ways a few months before I received a phone call from "Caper" (his chosen "call sign"). I was surprised by the out-of-the-blue call but agreed to meet him.

As if Fate had dictated it, I knew from the get-go that Caper was the guy I'd spend my life with; a very esoteric *Knowing*.

One of my strongest early memories is of Caper tolerating a *Guess my Stuffed Animal's Name* game. I recently asked him why he put up with it. "Because I liked you and it made you happy," he answered.

A Tough Start

Our early years of marriage were tough, with many highs and lows. Caper's employer moved him within Ontario twice in our first two years. My early childhood was spent moving frequently for my father's job, and it traumatized me as a girl, as well as after marrying. It left me in a chronic state of stress. I had meltdowns and was hospitalized several times in psychiatric units.

He came to the hospital daily to visit. I needed and valued those visits, but I grew



Bride Annie - August, 1984

defensive, believing he thought he knew me better than I knew myself and knew what I needed more than I - or my doctors - did.

According to Yolanda Renteria of the Gottman Institute, "Defensiveness is more common in neurodiverse couples because while one person's brain may view something as acceptable in the relationship...the other may not. It is also common for the neurodivergent partner to feel like they have to explain themselves constantly, which leads to hypervigilance, guilt, and shame. This

constant impasse in communication leads to a dynamic where both partners feel on edge whenever conflict arises" (Renteria, 2022).

Caper and I certainly experience this due to misunderstandings and misinterpretation of the other's perspective. It's difficult for us to understand how differently our brains process information and sensory input. At times, we each feel misunderstood. I attempt to resolve these conflicts by using "I" statements; by owning my own feelings and beliefs. He's able to use this same strategy, but it's a newish concept to him, while I learned it in therapy years ago.

The Importance of "I" Statements

"I" statements allow us to take responsibility for how we're feeling and communicate it in a healthy way when feeling sad, angry, or upset. "I" statements are a communication tool that help resolve conflict, reduce blaming, and give space for partners to respond rather than react (Surtees, 2020).

Struggling with Differences

Nearly all couples struggle with some aspects of their relationship. But there are numerous differences affecting emotions and behaviors in ASD brains. Among the many variances are:

- Difficulty managing impulsivity
- Difficulty reading non-verbal cues

- Rejection-sensitive dysphoria
- Sensory and emotional overload
- Executive functioning challenges
- Hyper-fixation on special interests
- Low frustration tolerance

Given these differences, what can you do to prevent your relationship from drifting apart and growing in bitterness? Again, Yolanda Renteria of the Gottman Institute suggests a solution.

"Change the Narrative"

For neurodivergent-neurotypical (ND-NT) relationships to thrive, it's essential to understand the differences between how such couples process information and how cognitive differences impact their ability to bond with one another. How can we "honor those differences and...set realistic expectations around them" (Renteria, 2022)?

Make a List

Start a list, with your partner's help, of the things you both struggle with. My list includes:

- Interrupting and being interrupted

see Successful Marriage on page 53

Managing Feeding and Toileting Challenges in Children with Autism

By Bianca Coleman, PhD, NCSP, BCBA-D
Behavior Therapy Associates

Challenges with toilet training (e.g., frequent accidents, withholding urine or feces) and eating (e.g., food selectivity, getting sufficient nutritional intake) may have a significant impact on the child's functioning in the home, school, community, and social events. These issues often impact the entire family. Individuals diagnosed with Autism Spectrum Disorder experience challenges related to feeding and toileting at a more significant rate than those without the diagnosis (Schreck, Williams, & Smith, 2004). When faced with these areas of concern individually, the task of increasing skill levels to age or developmental expectations for nutritional intake or "socially appropriate" ability levels can be an overwhelming task for a parent. When feeding and toileting issues are co-occurring, caregivers are often at a loss as to which area to address first, the method or progression of intervention, and how to best support their child.

When Is It a Problem?

Early challenges associated with feeding may be initially overlooked or attributed to "typical pickiness" or a "phase." Issues with initially refusing meals, limiting



intake of novel or previously consumed foods, or minor behavioral challenges may persist. These may evolve into a more substantial concern when growth and health are impacted, functioning and participation in daily activities are impaired, or social-emotional development and appropriate interactions are diminished (Mcmanus et al., 2003). While more commonly reported parent concerns regarding their child's eating often involve selectivity, either by type or texture, there

are a variety of other concerns that may exist such as:

- Phobias
- Behavioral issues
- Oral motor issues
 - Packing or holding food in the mouth
 - Delayed or absent chewing

- Tongue Lateralization
- Medical and behavioral complications
 - Delayed gastric emptying
 - Rumination
 - Complications from Gastroesophageal Reflux Disease
- Chronic emesis (vomiting)
- Weaning from tube feedings

Challenges with toileting are most often identified when a child displays frequent "accidents" or fails to meet age-appropriate expectations for toilet training. Reports of "being full" or a lack of appetite, frequent abdominal pain, or irritability may be associated with a gastrointestinal or urinary tract issue. Individuals diagnosed with Autism have been shown to be more frequently referred to constipation clinics than the general population (Pang and Croaker, 2011). Challenges related to toileting may include:

- Constipation
 - Having less than 3 bowel movements a week

see *Managing Challenges on page 52*



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Are you interested in improving your overall well-being alongside other parents of children with autism? Then this study might be for you!

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- ✓ You are the parent of a child (age 5-12) with autism and challenging behavior
- ✓ You speak English
- ✓ You have access to a device with audio and video capabilities
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Time Commitment: A maximum of 9 weeks. It will include an intake interview, 1-6 virtual group sessions, and 2 sessions of individual parent training.

Location: All study components will take place virtually.

If you are interested in participating or have any questions, please contact Abigail Moretti at morett94@rowan.edu

This study has been approved by Rowan University's IRB (Study #PRO-2023-5)



An Autistic's Vision for Neurodiversity-Affirming Therapy

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

As a neurodiversity community self-advocate, I have come across far too many stories of emotional distress and trauma in connection with neurodivergent individuals' lived behavioral therapy experiences. I understand where they're coming from and I empathize. As a late-identified autistic, I, like them, have often felt disabled by society's expectations around behavior which fail to sufficiently consider neurodivergence. The therapists mentioned in these stories held such expectations, clearly to the detriment of their clientele.

I have learned a great deal from neurodivergent individuals with all kinds of backgrounds as a result of my advocacy efforts. I have also learned from members of the clinical community as well as from my own clinical experiences, not many of which were effective with respect to skill-building and help with various personal challenges over the years. When I put it all together, it becomes apparent that greater understanding between the neurodiversity and clinical communities is sorely needed.

Greater understanding, so that a vulnerable segment of society experiences less



hardship and more acceptance and successful therapeutic outcomes. So that the distrust which too many neurodivergent individuals hold for the clinical community can be addressed. So that the ways in which therapy is practiced in clinical settings become more neurodiversity-affirming.

If I were in a position to bring the clinical and neurodiversity communities together for a meaningful dialogue, I would start by proposing the following guidelines, derived from all that I have learned from others in both communities and from personal experience:

- **Meet the client where they're at.** Do not start out based on where you want the client to be. Instead, design a therapeutic agenda based on each client's unique sensitivities (sensory and emotional), thinking patterns, communication style, strengths, talents, abilities, challenges, and vulnerabilities.
- **Communicate with the client in unambiguous, detailed, literal terms.** Neurodivergent individuals tend to thrive in the midst of structure and certainty. Communicating in this fashion will cultivate

this kind of therapeutic environment. If your neurodivergent clients are left to assume or infer what you mean, confusion or emotional unease may result.

- **Nurture the client's self-esteem.** Be mindful not just of what you say but how you say it. Give high praise when the client takes a step in the right direction and when a goal is attained. Avoid setting the client up for failure by keeping your expectations down to Earth. Show acceptance and strongly encourage self-acceptance.
- **Promote client self-advocacy, autonomy, and choice.** Encourage clients to communicate which specific skills and challenges they want addressed, what they are not comfortable working on, when they are ready to move on to something else, when they need to take a break, etc.
- **Monitor the client for signs of distress.** Be wary of both verbal and non-verbal cues in this regard. Minimize the possibility of distress, trauma, and/or meltdowns by determining and implementing necessary accommodations at the outset. Confirming what triggered these outcomes in the past (if they did in fact occur prior to therapy) and mitigating

see Affirming Therapy on page 44

Leveraging Smart Technology to Enhance Independence for Autistic Individuals

By Amanda Pfohl, MA, SYC
and Lauren Tucker, EdD
Southern Connecticut State University

Independent living for autistic individuals requires a complex set of tasks and increased responsibility for caregivers, who often support independence remotely. Considering how technology can complement this task is crucial to maximizing available resources and enhancing the lives of those individuals. Integrating technology can initially support communication and evolve to enhance other activities of daily living. Building communication skills is an important prerequisite step that supports using technologies to assist in daily routines. For example, if the person doesn't have the skill to turn off technology, the reminders will be negated and possibly result in frustration and resistance.

What is Smart Technology?

Some examples of smart technology include Amazon Alexa, Amazon Echo Dot, Google Home, and Google Assistant, while there are many more! What makes these devices "smart" is their ability to use artificial intelligence and internet services to automatically communicate wanted information to a user, with remote accessibility.



Starting with Communication

Many who have been diagnosed with an autism spectrum disorder require an intervention focusing on the aspects involved in producing or understanding speech and language (Marston & Samuels, 2019). To interact with Alexa, or other smart technologies, an individual must articulate a command in a way that is intelligible. The use of these devices may initially cause frustration for the individual, given the initial inability of the device(s) to decipher unique speech. However, one of the benefits of virtual assistants is the potential to help improve

speech (Marston & Samuels, 2019). To avoid unnecessary frustration, one of the first things that should be demonstrated is how to turn off Alexa. "Alexa, stop." "Alexa, pause." "Alexa, off." When a person's speech is misunderstood, one of these simple phrases will stop the device from continuing its response. If an individual utilizes an augmentative and alternative communication (AAC) device, these commands can be programmed and practiced (Williamson, 2019). Practicing communication interactions is the crucial first step for caregivers and teams to take when integrating smart technology within daily tasks.

Where to Go Next?

Have some fun! It is essential the user wants to engage with the smart technology, so they need to feel comfortable communicating with it! Xin and Leonard (2015) noted that using highly preferred activities can increase an individual's communication skills and should be considered during practice. Start by asking the device for a joke, a new fact about a preferred topic or where the nearest amusement park is! Interacting with smart technology in a fun, engaging and non-pressuring way is an easy way to get the individual familiar with the device while practicing their communication skills.

Transitioning to Reminders/Routines

Using smart technology can support independence, while also providing safeguards for our older community, including those with disabilities. Pradhan et al. (2020) noted that voice assistants embodied in smart speakers enable voice-based interaction that does not necessarily rely on expertise with mobile or desktop computing. These platforms allow the opportunity for caregivers and families to effectively program devices for daily reminders and routines remotely. The consistent and intuitive interface design also allows access for individuals themselves to program and utilize the features of the smart devices.

see Smart Technology on page 45

Supporting Families to Prepare Students to Be Participating Members of Their Community

By Dianne Zager, PhD
and Carly Werner, MEd, MS
Boca School for Autism

For over five decades, I've had the privilege of serving students with autism and developmental disabilities and their families. I've been employed as a teacher, administrator, professor, consultant, and advocate in public, private, nonprofit, and for-profit settings, working in preschools, primary, middle, secondary, and university programs. I've observed programs across the United States and even globally. During these years, I've spoken with thousands of parents, and have heard a common theme from parents across all walks of life, from affluent families in cities and suburbs to immigrant farm workers. All of these parents wish for the same thing. They want their children to receive an education that will help them to become productive adults who will be accepted and fulfilled within their community.

The purpose of education is to guide students toward this goal - to maximize their potential and independence, and to prepare all individuals to live, work, and recreate as participating members of their community. In the 1980's, in the beginning of my career, employment outcomes for adults with



ASD were dismal (Szatmari, 1989). Since then, over the past several decades, there's been a plethora of research in the area of transition; and, yet, currently, despite all the research and advances in the field of special education, the same low rate of unemployment and underemployment persists (Anderson, Butt, & Sarsony, 2021).

The Americans with Disabilities Act of 1990 provided a framework to address the

grave need for supports to fully include all persons in their communities. The New Freedom Initiative (2001) recognized that people with disabilities need a complete and appropriate education in order to join their communities as equal members. The Olmstead decision (Olmstead v. L.C., 527 U.S.581) mandated that services to people with disabilities be provided in the most integrated settings appropriate for their

needs. These legislative initiatives were put forth to promote inclusion of people with disabilities in all areas of society by increasing access to universally designed programs.

However, today parents still search for effective school programs that will accomplish the goals set forth in these twenty-year-old initiatives. To meet these goals, families need school partnerships so that their sons and daughters may grow into independent productive adults. As stated in these initiatives, the focus of curriculum needs to be redirected toward fostering necessary lifelong skills and knowledge that enable students to succeed in either postsecondary education or employment.

Educators and parents must of necessity become true partners. The commitment to include, listen, hear, respect, and engage parents is paramount in fostering student growth and enhancing interaction at school and in the home. In this article, Carly Werner, Director of [Boca School for Autism](#), a school focused on transition for middle and high school students with autism, and I suggest critical avenues in which schools can engage and support parents to maximize student potential.

Specifically, we highlight some practical ways in which schools and parents

see *Preparing Students on page 47*

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Post-Secondary from page 15

Unlike high school, the student may affirmatively ask for an accommodation. In the public school setting, services were legally mandated once included in an Individualized Education Program or otherwise. In college, accommodations are more like a safety net - once obtained, they are there if the student asks for them. To encourage self-advocacy, talk to your student about how they feel about the need to take the accommodations, and encourage them to use them if it will help them be more successful.

Some common accommodations include separate testing locations, extended time, and technological supports. Residential accommodations may also be available. Students who take on internships, externships, or attend programs off campus, of-

ten hosted by third parties, must separately seek accommodations for those environments. Similarly, outside testing agencies have their own separate applications for a student to secure accommodations.

With preparation and planning, communication and collaboration, love and support, college life can be a wonderful, exciting, and successful experience for your student.

Tara C. Fappiano is a Special Education and Disability Advocate who regularly works with families to prepare their students for success in college and beyond. She also acts as an advocate for her clients when challenges arise in post-secondary educational settings. She may be reached at tcf@tarafappiano.com, and you can learn more about her practice at www.tarafappiano.com.



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“Reflecting on the Journey” A Retreat for Parents of Autistic Family Members

By Barry M. Prizant, PhD, CCC-SLP
Elaine C. Meyer, PhD, RN,
and Barbara Domingue, MEd

This past year marked the 25th anniversary year of our annual weekend retreat for parents of young and adult autistic individuals. This innovative family support activity has become a highlight of the year for us, and for many of the approximately 60 parents of autistic family members who join us each year, serving close to 500 mothers, fathers, and caregivers over the life of the retreat. Over the years, the parent retreat has taught us so much about the challenges and triumphs of raising an autistic child or supporting an older autistic family member as experienced by families of varied ethnic, cultural, and socioeconomic backgrounds. It also has enlightened us as to how an event that occurs over a 30-hour period once a year can have such a powerful impact on parents and caregivers, and ultimately on extended families. More than anything else, the retreat has demonstrated the profoundly energizing impact of providing parents and caregivers with an opportunity to step out of the demands and craziness of everyday life events and connect with a community of others with the experience of sharing their lives with



Moms sharing their experiences and feelings at the annual Reflecting on the Journey retreat

an autistic person, and in some cases, individuals with or without autism diagnoses. The retreat provides a safe context for parents and caregivers to share their stories, joyful and humorous as well as frustrating and even agonizing, and know that they will be listened to by compassionate com-

patriots who share similar challenges and triumphs in their lives' journeys. There also are many opportunities to take stock of the year, have fun, laugh, and cry, while being well-fed and cared for, lifting the burden of being the care provider that for some is a 24/7 commitment and necessity.

The Initial Inspiration

Almost 30 years ago, two of the authors, Barry M. Prizant, PhD, CCC-SLP (BP) and Elaine C. Meyer, PhD, RN (EM), began to reflect on the privilege and restorative benefits of having the opportunity to “get away,” enjoy nature, and break the stress cycle of life’s everyday demands during their annual hiking vacation. In our careers, our work has involved supporting families who experience a multitude of practical as well as emotional challenges related to raising autistic children and supporting adults (BP) or providing support for children with medical emergencies and chronic medical conditions (EM). We began to consider that such “getaway” opportunities were rarely, if ever, available to parents whom we met with on a regular basis, and who experienced moderate and often chronic levels of stress in their daily lives. We knew that our ability to “get away” provided us with a number of benefits: the opportunity to distance ourselves from everyday routines and to reflect on challenges that were embedded within these routines; the opportunity to reframe - that is, to develop a slightly different perspective on life’s challenges; to nurture and strengthen our relationship; and ultimately, the opportunity

see [Parent Retreat on page 46](#)

Lessons I Learned From Job Coaching

By Andrew Arboe
Autistic Self-Advocate
and Public Speaker

Job coaches are professionals who not only support an individual with a disability in a community setting, but also teach skills to help them be ready for future employment. I have two perspectives, that of a person who had a coach and being the coach myself. Back in my secondary school days, I had some job coaches who taught me various skills that enabled me to be independent at the workplace. The coach was not only chatty, but effective in their teaching. These elements gave me a visual cue when I actually became a job coach years ago. It was one of my first major roles in my work in special education and I looked forward to building up new skills. I worked for Plainville Community Schools from 2018 to 2020 where I was able to work with about three autistic young adults. Each student gave me ideas on how to interact with people and methods to help them along the way. I had a wonderful supervisor who taught me various job coaching concepts, and they still serve me to this day. Today, I work for a private school, [FOCUS Center for Autism](#), where some job coaching is involved, and it has helped me realize how I missed it. In honor of re-discovering one of my past roles, I want to offer future job coaches lessons I learned over time.



Andrew Arboe

Listening to Your Students

This is a no brainer, but it is super important to know. When you are out there working with a student, you are creating a rapport between yourself and the student. If you do not develop rapport, it will be harder to teach skills. You must interact and learn more about your student to get something going. What you want to know is their likes and dislikes - not just of school but hobbies too. I still remember meeting two students

for the first time, and they were not sure how to react to me. I noticed this and asked about their hobbies. One student brought up anime and gaming and the moment I mentioned those same hobbies, the student lightened up. This interaction improved the rapport for that school year, and I was able to obtain their employment preferences; for example, their preferred job field and position. This helps the special education team come up with ideas and experiences that can empower students.

Knowing and Respecting the Gray Line

While it is good to interact with the student, it is important to know and respect the gray line. It is between yourself and your student. The gray line is an abstract concept where you have to remind yourself that your role is a professional one. It is good to chat with your student and interact with others at the jobsite, but remember that you are there for one purpose. You must display professional values and focus on creating a good environment for your student to succeed. Focus on the student above the customers and jobsite workers present. At times, it may be okay to help but it depends on the circumstances. Usually, most job coaches try to hold off from helping to let the student engage in the task. Sometimes when a store gets chaotic, you may have to step in to help with store flow.

Accepting Unexpected Tasks

While there are assigned routine tasks each day at job sites, sometimes you may have an unexpected new task. Do not dismiss it as it may introduce new experiences to your students. I recall in one of my past experiences, I had someone who started to face items in a store, meaning needing to make it noticeable and place it directly at the front of the shelf (facing is the term used to describe the arrangement of items

see [Job Coaching on page 49](#)

Autism Without Fear: An Autism School Seeks Behavioral Health...Through Humanism

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

Disclaimer: This past year I consulted for the League School of Greater Boston, the school that is the subject of this piece. I worked with their students on a self-advocacy curriculum, and I've also presented for the school on separate occasions. Seeing what they are attempting up close demanded an article.

The meeting of administrative leaders was almost to a close. For 90 minutes, these colleagues had been sharing the myriad of changes they'd seen over the past decade, when the [League School of Greater Boston](#) was starting to shift its approaches to "behavior," even as a concept. While always an eclectic mix of approaches, the school was committing more and more to SCERTS, and using ABA less like a blueprint, and more like a supplement. But change is hard, and so amidst the overall victories, it was also imperative to reflect on the toll that this transition was taking on them.

Educational Director, Patrick Fuller, a 30-year veteran of special education, had remained mostly silent through most of the meeting. And for this very reason, towards the end, Fuller was then somewhat am-



The League School of Greater Boston

bushed, and asked for his thoughts.

He recalled the period that began around 2015 - one that continues today - when on the well-known job site Indeed.com, former teachers began posting negative reviews about the school. Many in the room nodded, acknowledging that those still visible opinions would serve as permanent reminders of the aforementioned toll. It summoned memories of people they'd worked

with, who despite whatever animosity may have resonated over the school's ideological changes...these were once, real relationships they had with fellow humans, that had ended painfully.

Fuller's experience added some perspective.

"Some of the things I was taught (in how to educate autistic students) were just horrific. 'Drill and kill'," Fuller remembered,

appreciating the school's ongoing transition to a more humanistic system. *"It's not just in terms of ABA. It's in terms of everything we do...I'm really excited by this group, and seeing where we can go."*

The League School of Greater Boston is situated in Walpole, Massachusetts, close to the Rhode Island border off both I-95 and I-495. It contains many of the demographic similarities of other traditional autism schools, such as serving a wide range of autistic abilities in its enrollment (usually a little over 100 students). This varies from numerous non-speaking autistics to very verbal students whose challenges are mainly rooted in emotional regulation. The age range is full (3-22 years old) and the school has a long-established residential wing. Most admissions are paid for by the state and down the road, expansion will almost certainly become a necessity.

Traditional autism schools, historically, have had their philosophies rooted in the use of Applied Behavioral Analysis (ABA), the longstanding strategy for correcting behavior in autistic people. However, the League School always kept their options open. To some during ABA's

see Autism School on page 48

Living and Aging Independently on the Autism Spectrum: An Inside View

By Karl Wittig, P.E.
Advisory Board Chair
Aspies for Social Success (AFSS)

Having been diagnosed late in life at the age of 44, I lived for the better part of my life on the autism spectrum without myself or anyone else being aware of it. During the time in which I finally knew about this, I was already an older adult and, most recently, a senior citizen. Unlike so many autistics, however, I was able to have an occupation and career, live independently, and retire without the need for caregiving at any time as an adult. As such, I have become aware of the types of challenges and difficulties often faced by autistics when they must care for themselves. Because of our autistic differences, however, quite a few of these are unlike those faced by typical adults, even though there may be some similarities.

My own life experience shows that it is possible for some (hopefully many) on the autism spectrum to live independently with minimal if any need for caregiving. Although my situation is not very common for much of the autism community, I need to emphasize that, even though I was very fortunate in having gainful employment that enabled me to live independently without need for supports, many autistics of comparable or even greater intellectual ability and education-



Karl Wittig, PE

al accomplishment have not been nearly as lucky; they were often not able to live independently, thereby needing support and even caregiving for much if not all of their lives. Given the realities of the age that we live in and the increasing estimates in the number of autistics, it is essential that those who are capable of living and aging independently be able to do so with a minimum of caregiving. I will try to provide a few insights into what must be done to attain this.

Early Adulthood

As a younger adult, the transition to independent living was greatly eased by my having lived in a college dormitory as a student. Such an environment provides a gradual transition between living at home, where one's needs are provided for, and many daily living skills not required, to a situation where one is completely responsible for such. While such a gradual adjustment is certainly helpful for any young adult, it is nothing less than essential for autistics, who have well-known difficulties with transitions of any kind. Because of this experience, I was able to gradually acquire the basic skills needed for daily living, even though for me these were little more than minimal. At least, though, I could take care of my needs without the benefit of caregivers or other supports. It also helped that in a few areas (household finances, tax preparation, basic home maintenance and repairs), I was able to do for myself (and sometimes others) what many people often hire someone else to do, as these were within my specialized areas of ability - I am an electronics engineer who was always good at math and fixing things. One particular challenge for me, common to many autistics, was learning how to drive a car. I successfully accomplished this, but not without considerable difficulty. How I managed to do so is a story unto itself. Nevertheless, in a society with limited public transportation,

this is an essential skill if one is to live independently. Appropriate instruction needs to be made available to autistics of any age who need it.

Unlike many autistics, I was actually married and, more generally, in a long-term relationship for the two decades prior to my autism spectrum diagnosis. As it happens, this was not a conventional relationship, as there was a significant age difference (she was older and had spent years in a religious order) - a situation not uncommon among autistics. Many of my challenges, as they were, had heretofore been attributed to experiences growing up, or else regarded as eccentricities and personal peculiarities. After knowing me for a short time, however, she made a number of (correct, for once) observations about these issues, such as my near-total obliviousness to much of my social environment, and the fact that I was completely unresponsive to hints of any kind. Both of these turned out to be important clues for my subsequent diagnosis, but that was still many years in the future. In any event, I had someone who provided supports in my areas of deficit (even if she was not always happy about it), especially those involving interpersonal and social skills, which like most autistics I was always deficient in. More specifically, she would often point things out that I was unaware of and clue me in as to what I needed to do (or not do, as the

see Living and Aging on page 50

Helping Families with Disabilities Transition from Child to Adult Systems of Care

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

Having a child diagnosed with a lifelong disability is like planning a trip to one country, but unexpectedly arriving in a different country (read Emily Perl Kingsley's essay [Welcome to Holland](#)). Just imagine, you have nothing packed that would make the trip easier or more comfortable, and you do not speak the language. It is a land of new faces, communities, and systems.

Over time, the new land starts to become familiar. You find your own group of like-minded friends and advocates, and learn how to "drive." Over 16-plus years, you become an expert at understanding this country, and can even help others become acclimated.

Similar to learning how to navigate a new country, as a parent or caregiver of a child with disabilities, you have learned how to navigate systems of care. You have become fluent in the [Individualized Education Program \(IEP\)](#) process, you understand the purpose of [Intensive Behavior Health Services \(IBHS\)](#), you can read a [functional behavior assessment \(FBA\)](#) with full understanding, and you know all of the acronyms in the "alphabet soup"



vocabulary of child-serving systems. You also are aware that a child's "transition" should begin long before the age of 14 with a checklist of what to do, and how and when to do it. For example, it takes time to write a [special needs trust \(SNT\)](#) with a special needs attorney. The SNT needs its own tax identification number, so identifying a financial institution and applying to the state is the first thing that should be done before creating a trust to ensure your loved one's assets are protected and do not

work against their "needs-based" government benefits.

Then, one day, your child turns 18. Now what?

Below is what I learned while caring for my now 21-year-old daughter, Annie, who has autism and intellectual and developmental disabilities, among other differences.

- Get your child registered and onboarded with [supplemental security income \(SSI\)](#), which can take anywhere from

three to six months once all [documentation](#) has been submitted. *Note:* The Social Security Administration may conduct a lookback of up to three years on your loved one's accounts to determine [eligibility](#).

- Make sure [special needs trusts](#) and an [Achieving a Better Life Experience \(ABLE\) account](#) are established in order to protect your loved one's public benefits as well as provide a means for them to pay for things they need and want in their life.
- Consider [guardianship](#) if it is required to most appropriately continue care for your loved one. The [guardianship process](#) can be costly and confusing, and will likely require an additional special needs attorney.

Before you know it, your child will turn 21. What's next?

On your child's 21st birthday, some of the services they have received their entire lives will disappear - which is incredibly stressful! Just a few of these services include: [Intensive Home Behavioral Services](#), [home health aides and/or child respite services](#).

As parents of special needs children, our

see [Transition on page 55](#)

Parent Involvement as a Metric of Quality Care

By Erica Ballard, MA, BCBA,
Caitlin Summers, MA, LPC, ACS,
Ellen D'Amanto, PhD,
Joe Hess,
Howard Savin, PhD,
and Kristen Daneker, MS, BCBA
First Children Services

A family-centered approach has been considered best practice for many years in early intervention and pediatric rehabilitation (Bailey, Buysse, Edmondson, 1992; Baird & Peterson, 1997). For students with complex medical, physical, developmental, and behavioral challenges, a family-centered approach is critical. According to King, Teplicky, King and Rosenbaum (2004), three basic premises are components of this framework: (1) parents know their children best and want the best for their children (2) families are unique and different, and (3) optimal child functioning occurs within a supportive family and community context. These guiding principles provide the foundation for including parents in decision making and creating partnerships with our families at [First Children Services](#). Emphasis on the identification of needs as well as the strengths of our families is our focus. Opportunities for parents to connect occur in many ways at First Children. Parents are welcome to observe or participate in all therapy sessions at the school. Parent connections are



critical for support and home carryover, as home-school collaboration is one of the indicators of program quality for students with severe disabilities.

Parent involvement is essential to effective care because parents best understand if behavior interventions are effective in their child's natural environment, and where skill gaps may continue to persist. If an intervention is not suited to a client's unique circumstances, it will not be an effective intervention. Additionally, families that are a supportive and collaborative part of the treatment team will be more motivated

to ensure treatment fidelity and will provide the most constructive feedback about which parts of the intervention are working and which ones need to be revised.

Clinicians often come into the lives of clients and their families at vulnerable times. Typically, families are dealing with a major transition and seek services for the first time following a diagnosis or transitioning from services that no longer suited their needs. From initial contact to ongoing service delivery to titration of services, it is critical for families to feel secure in trusting the care of their loved ones to their

clinical team. Clinicians at all levels should present themselves as non-judgmental, reliable sources of support and education. Families should feel at ease around clinicians and feel confident they are there to be compassionate and helpful. This feeling of security and trust is critical to ensuring honest communication and collaboration across all settings. When clients are preparing to transition out of services because they no longer require the same level of care, their families are the bridge to independence. A strong foundation of collaboration and trust is what will ultimately provide a family with the ability to graduate from services and live a life with improved outcomes and independence.

First Children Services Family Highlight

The Transitions program at First Children offers small group instruction to support students with varying degrees of school refusal, social anxiety, and other mental health issues from attending school regularly. Several years ago, our team came together to look at the needs of one of our more complex students. The student presented with significant levels of school refusal, avoidance, disruptive behaviors, Autism, trauma, and mood dysregulation. The team realized that we would need to take a comprehensive integrated approach to the course of treatment. The staff worked

see [Parent Involvement on page 39](#)

Autistic Lived Experience: Life Magazine Labeled Me “A Bright Child Who Can't Learn”

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

In April 2023, it was my distinct privilege to be invited to [The Center School](#) in Somerset, NJ, the special needs school where it all began for me as a Kindergartener back in the mid '70s, to give an author talk about my book [A Long Walk Down a Winding Road](#). I felt as though I had triumphantly come full circle, having attended the school as a vulnerable, unidentified autistic and learning-disabled youngster, and returning as a proud, self-confident, openly autistic author, advocate, public speaker, husband, father, and successful information technology consultant. Who I would become speaks to the strong educational foundation The Center School helped instill in me during those critical early years, and I will forever be indebted.

The school had recently celebrated its 50th anniversary, and as a token of the staff's gratitude for me having traveled far to share my book, I was given an authentic copy of [the October 6, 1972 issue of Life Magazine](#) which featured an article on The Center School and its students when the school was a little more than a year old. Very heartened by this gesture, I could



hardly wait to take the trip back in time I knew was in store for me: ads for TV's and cars which today I can imagine seeing in a museum, articles about how the North Vietnamese people had learned to live with ongoing bombing, Richard Nixon's lead in the presidential election polls and the piece I was most eager to check out, what Life Magazine had to say about my early elementary school back in the day.

What I read I did not see coming, and the emotional impact was not subtle by any means. It didn't matter that the article was

more than 50 years old. What did matter was what it said about me and my fellow Center School classmates.

Entitled "[An Agony of Learning](#)," the article described The Center School's learning-disabled students, which would include me two years after publication, in particularly harsh terms. We were referred to as youngsters who could not learn properly and victims to be pinpointed. Something had gone wrong with our damaged nervous systems. We possessed "brutally handicapping learning flaws." One of us had been

thought of as retarded prior to arriving at The Center School. Another boy's picture was shown of him crying tears which "masked a futile effort to understand."

To say that "[An Agony of Learning](#)" helped perpetuate harmful stereotypes about learning-disabled individuals is an understatement granted these descriptions. Neurodivergent individuals like me (those of us with [neurotypes](#) that are in the minority - autism, ADHD and learning disabilities, for example) contend with these kinds of stereotypes to this day. Though more than 50 years old, the article remains relevant in this respect.

Not one of the aforementioned depictions is consistent with my own memories and lived experiences as a learning-disabled grade school student. Learning was sometimes challenging for me, other times not, depending upon the academic subject I was studying, but never agonizing in the true sense of the word. Nothing has ever been wrong with my nervous system; I was simply born with a divergent neurotype which brings unique challenges as well as strengths and talents. The notion that I was a victim as a child is laughable. Not all forms of hardship render an individual a victim, particularly if one learns how to compensate for them, as I did.

see Lived Experience on [page 51](#)

Bridging the Gap: Empowering Families Awaiting an Autism Diagnosis

By Andrea Lavigne, PhD, BCBA
and Nick James
Autism Care Partners

The prevalence of autism spectrum disorder (ASD) continues to rise. According to the CDC, 1 in 36 children are diagnosed with autism by the age 8¹ and as a result, the need for comprehensive family support systems has never been more pressing. Unfortunately, the barriers to clinical support and care for a family begin well before receiving a diagnosis. A recent study published in the *Journal of Pediatrics* revealed an average 27 month wait for families seeking a diagnostic evaluation.² This reality is particularly concerning when juxtaposed with the abundance of data that supports the positive impacts of early intervention for children diagnosed with autism. These positive impacts are not only beneficial to the individual on the spectrum, but to the broader family unit. Families caring for a child with ASD experience higher divorce rates, higher depressive symptoms, neurotypical sibling isolationism, and several other complicating factors at the family level.³

The statistics above highlight the significance of supporting both children and families of children on the autism spectrum as soon as concerns regarding development arise. Generally speaking, the sequence of events for a family is often as follows:



1. Receive a referral for a diagnostic evaluation (most commonly from their pediatrician)
2. Seek out a qualified diagnostician (national average of 27 months)
3. Await the results of an evaluation (typically several months from initial visit)
4. If a diagnosis of autism is confirmed, determine the services that best fit the needs of their child (such as Applied

Behavior Analysis, speech therapy, and occupational therapy).

While receiving a diagnosis of autism often opens doors to exceptional treatment options, there exists a critical gap related to the lack of clinical support for a family while they are in the "pre-diagnostic" waiting period. Depending on the age of the child, the state in which the family lives, and the funding source for care, treatment options may be relatively limited before a diagnosis is received. Today, families, clinicians, and health insurers tend to wait for

a formal diagnosis (autism or otherwise) before an action plan is put into place. The reality is that families are seeking a diagnosis due to a concern from themselves or their provider. That concern alone reveals the need for a plan to be put in place to support both the individual and family unit, irrespective of the outcome of a diagnostic evaluation.

There are a variety of clinical solutions that can be explored to improve this gap and need. For example, there are groups exploring the early pairing of social workers and other mental health professionals alongside curated toolkits in the home, that are meant to empower families to take action while having the support of a clinician to guide them while they await the outcome of a formal diagnosis. This type of pre-diagnostic family support program is designed to address the myriad of questions and concerns caregivers often face during this pivotal period. Conducted via telehealth, the program is led by licensed clinicians who develop individualized goals for each child.

While there is naturally a focus on the developing child, the clinician in this program engages the family in the care process. Parents and other family members are empowered through a curated therapeutic activities kit which they receive in their home, containing targeted activities to enhance a range of skills, such as communication,

see Empowering Families on [page 41](#)

Autism and Marriage: Making Your Relationship Work Under the Pressures of Caregiving

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

Having a child with autism can certainly put strain on a marriage. I should know. After over 20 years of marriage with two children on the autism spectrum, my marriage came to an end.

So why am I writing an article about making your relationship work? Because it's too important not to. My hope is that your marriage can defy the odds and not become a victim of the incredibly high rate of divorce among special needs families, which is often mentioned to be as high as 80%.

Could my marriage have been saved? Perhaps. Can your marriage be strengthened and nurtured to try to avoid divorce? Quite possibly, but only if both parents are fully dedicated to making the marriage work.

So, what can parents do to strengthen and nurture their relationship, especially when faced with the pressures of caring and providing for one or more children with complex needs? I will share my perspectives and advice, not just as a mom who was the primary caregiver of children on opposite ends of the autism spectrum who unexpectedly faced divorce and learned how to navigate the process, but also through my



training and experience as a Certified Life, Divorce, and Transition Coach.

The first challenge parents face is the acceptance of the diagnosis of their child's disability, and if they choose to embrace or deny the reality of the situation. Each parent may process a child's diagnosis and challenges differently, and at different timelines. As with any kind of loss or change, parents find themselves going

through a Grief Cycle, with emotions, reactions, and actions based on which phase they might find themselves in, with the progression usually being Denial, Anger, Bargaining, Depression and finally Acceptance. Being a parent of a child with a disability is usually not something people think about until they are faced with that reality. It takes time to process to get to the point of full acceptance of a child's

disability and that the vision they had for their child, their family life, and their future has taken a drastic turn. Some couples are brought closer together, through their commitment to support each other and the child, but sometimes the day-to-day and long-term challenges take a toll on a marriage. By recognizing and respecting when each parent may need a break or assistance, and by being able to communicate needs and feelings with the partner and with others, parents can support each other and strengthen their partnership, and in turn, better parent their child.

Oftentimes a couple cannot handle all the pressures of special needs parenting alone. Nor should they. Having a support network helps parents not feel so alone or overwhelmed and can inspire and motivate parents to try new approaches to support themselves and their child. Though they may be hard to find, there are many resources in the community to support parents and families, including mental health professionals, parent coaches, schools, disability organizations, online and in-person support groups, places of worship, as well as family members and friends. Having a helping hand or a bit of respite can help families tremendously by giving parents an opportunity to take a break from the

see Autism and Marriage on page 54

How to Overcome Dental Health Challenges for Children with Autism

By Jessica Sassi, PhD, BCBA-D, LABA
CEO
The New England Center for Children

Dental visits can be difficult, if not impossible, for children and teens with autism and developmental disabilities. These challenges can preclude important preventative care that impacts underlying health issues. In these situations, dental care also becomes a quality-of-life issue - not only being able to get children the dental care they need but doing so in a context in which they are comfortable.

There are oral health disparities among children with autism as the characteristics of the disorder may prevent individuals from successfully tolerating oral examinations and procedures. The dental office is an unfamiliar setting, with noises, smells, and contact that can be frightening or uncomfortable. Children with autism may struggle to sit still throughout the exam or cooperate with elements of the exam and treatment. Further, there may be few local providers that are accustomed to meeting the needs of individuals on the spectrum. Travel to such specialized sites may be challenging for those students and resource intensive for parent or provider.

How can schools and dental providers remove barriers to care for children with autism? This article will present a blueprint for dental service desensitization for



children with autism and show how special education schools can partner with dentists to build in-house clinics.

Dental Desensitization Program

According to joint research from the [Department of Pediatric Dentistry at Franciscan Children's](#) in Brighton, MA and [The New England Center for Children](#), desensitization programs tailored to the needs of children with severe autism help them overcome disruptive behavior.¹ Further re-

search from The New England Center for Children suggests that more frequent practice and exposure to the dental context can improve outcomes.²

According to research from the [University of Washington Center for Pediatric Dentistry](#), dental desensitization is key to successful dental care.³ Factors that predicted a successful dental examination included an ability to be involved in group activities, ability to communicate (verbally or non-verbally), and understanding key dental terms and procedures.

Special education schools can empower their teachers and students with a dental desensitization program tailored to the needs of the individual students. The typical program includes initial assessment, a dental skills curriculum, and an in-school mock dental suite.

Initial Assessment - The program begins with an initial evaluation to identify dental health and any behavioral issues related to the dental experience. Staff may also survey parents and providers for further information regarding previous dental visit outcomes. The goal of the assessment is to determine whether the behavioral issues are specific to the dental context and what elements of a dental exam can and cannot be successfully completed by the individual.

Dental Skill Curriculum - A life-skill curriculum of dental hygiene and dental office practice may include teaching oral hygiene fundamentals such as brushing, flossing, swishing of mouthwash, and eating a mouth-healthy diet. The curriculum should break down each individual task into smaller components, which can be introduced in a graduated fashion as the individuals' tolerance and cooperation improves. Some approaches contextualize the dental process as a story with students shown pictures or videos of the equipment and step-by-step directions on what will happen.

see Dental Health on page 43

Your Child Has Just Been Diagnosed with Autism Now What?

By Ann-Marie Sabrsula, MS
Director
The Arc Westchester Children's
School for Early Development

Every family has their own personal journey towards an autism diagnosis for their child. Whether it brings the confirmation of what may have been suspected or the news of something completely unexpected, the diagnosis of autism spectrum disorder can have a significant impact on a family. Like the disorder itself, the response to the diagnosis can also fall along a spectrum. Worry, sadness, fear, helplessness, anger, validation, and relief are just a few among the range of reactions parents may experience. The effects of having a child diagnosed with autism spectrum disorder have been found to be complex and wide-ranging (Karst & Van Hecke, 2012). As might be expected, this moment quickly becomes a pivotal point in the life of a family and navigating next steps will have lasting effects.

Take Time

A first step for a parent should be to take time to adjust to the diagnosis. The intention of the formal assessment, re-



sults, and diagnostic feedback is to provide children and their parents with as positive an interaction as possible but are experienced relative to each individual family. The diagnostic process as a whole can be an overwhelming experience. There is much to process and consider for you, your child, and your family before being ready to make an emotional shift. For many parents, concern and worry may have been experienced long before the ac-

tual diagnosis and sit in a well-established place among one's emotional landscape. Be patient with yourself and take the time that you need to best process information critically and make good, informed decisions going forward. With the realization that, with the diagnosis, you may now better understand your child, you can take a next step to learning more about their unique profile and how you can best support them.

Learn

Learn about autism spectrum disorder, speak to your pediatrician and other professionals in the field, explore information from reliable sources, know your rights, and learn about the range of services that are available to your child and family. Engaging your local early intervention system for a child under the age of three or your local school system for children three years of age and older would be the best next step towards accessing the services that they need. The importance of an early diagnosis of autism spectrum disorder and subsequent access to effective intervention is well established in the literature (Elder et al., 2017; Volkmar, 2014). By accessing both, you have already taken vital steps to help assure that your child gets what they need in order to make developmental gains.

Advocate

Be a voice for your child and your family. While navigating through what can be a complex system of service delivery and treatment, determine what will be helpful for your child and best suit their needs at this point in time. Children on the autism spectrum have both strengths and areas in

see Just Diagnosed on page 55

The Critical Role of Grandparents for Autism Families

By Marina Sarris
SPARK
Simons Foundation
Autism Research Initiative

Grandma is sometimes the first to suspect. Nick Juritza sat up and crawled a bit later than usual. "My mom noticed little things about my son," says Nick's mother, Kelli Juritza. "She said to me, 'You know, you might want to get him checked out.'"

Juritza is among several parents in the SPARK autism research study who say that their children's grandmothers were the first to point out developmental delays that turned out to be signs of autism.

Many grandparents play an important role in the families of children with autism. They may provide advice to first-time parents, emotional support, financial help, transportation to appointments, or babysitting, according to some parents and also researchers.^{1,2}

More than a decade ago, Connie M. Anderson, Ph.D., conducted the largest-ever survey of grandparents while she was a researcher at the Interactive Autism Network. Anderson's research suggests that grandparents, just like parents, find both struggles and joys in their relationships with children on the autism spectrum.

Anderson discusses her research and provides helpful advice in this recorded webinar: [Grandparents of Children on the](#)



Autism Spectrum: Their Own Role, Their Own Challenges.

What Researchers Know About Caregivers of Children with Autism

Parents, who are typically their child's primary caregivers, have attracted more attention from researchers than grandparents. Studies show that parents of children with autism experience more stress, have less leisure time, and earn less money than the parents of typically developing children.³⁻⁵

And for some parents, caregiving may extend past an autistic child's 18th or 21st birthday, if their child requires significant support or supervision in adulthood.

Grandparents may worry about two generations of their families, according to a study by Anderson and others.⁶ In that study, 1,870 people responded to a survey about their greatest challenges and joys as grandparents of a child with autism.

The grandparents said that they worried about their grandchildren, as well as about the parenting stress that their adult chil-

dren faced. "They are never just parents," one grandparent said, referring to parents of autistic children. "They are caretakers, teachers, therapists, and a million other things."⁶

Grandparents also shared many of the same challenges as their adult children, according to the study. They change their daily activities to accommodate the child's needs. They wonder how to predict and manage challenging behaviors, such as tantrums and wandering away in public places. "Even a simple trip out for ice cream can go wrong in a heartbeat," one said.

Grandparents would like to learn how to bond and communicate with their grandchild: "My greatest joy would be to hold a conversation with my grandson. He speaks some, but it's more like I'm assuming what he's trying to say," one grandparent responded.

A grandparent described her autistic grandson as "my greatest joy and my greatest despair."

Another grandparent reported difficulty with a grandchild on a daily basis. "We need help ASAP."

Grandparents Helping Grandparents

Some 15 years ago, Bonnie Gillman saw the need to create a community around grandparents. Her grandson had been diagnosed with autism, and she wanted to learn

see Grandparents on page 40

(Autistic) Girls on Film? An Analysis of Autistic Female Characters in Media and Fan Interpretations

By Emily “Ly” Stewart, BA(Hons), MSc
Media Psychology Graduate
and Journalist

Contrary to popular belief, autistic characters in TV and film are nothing new. The first instance of an autistic person being portrayed on-screen is popularly believed to be Amanda from the 1969 crime drama *Change of Habit*, starring Elvis Presley and Tyler Moore. Initially, the little girl is believed to be deaf, but is later diagnosed and stated outright to be autistic - a common misdiagnosis of the time and even today (Berke, 2021). While incredibly dated by modern standards, including long, uncomfortable scenes of Amanda’s “treatment,” the film has been praised for its accurate portrayal of what was known about autism at the time.

Despite the first on-screen autistic being a girl, however, recent discussions of autistic representation in TV and film - much like research into autism in general - is almost entirely dominated by male characters. Literature, both academic and otherwise, is saturated with discussions of *Rain Man*’s Raymond Babbitt or *The Big Bang Theory*’s Sheldon Cooper; male mathematical savants with poor social skills, whose traits portray them



as “autistic enough to laugh at, but not autistic enough to represent the autistic community” (Gaeke-Franz, 2022, p.9). And while progress towards more positive representation is being made, there is still very little in regard to autistic women and girls and their experience on the spectrum.

The number of autistic characters in media is small and, when you consider the fraction of those that are female, autistic women rarely have opportunities to see themselves on-screen. This drought of

representation has led many neurodiverse fans to take matters into their own hands; labelling characters as autistic themselves, regardless of official input. This practice is referred to online as “headcanonning” - creating an individual interpretation of a pre-existing piece of media, including its characters and overall story (Fanlore, 2022). The reasons for headcanonning a character as autistic can vary from explicit reasons, such as the characters behaviour, subtext, or simply their “vibes” (autistic-headcanons, 2022). Regardless of a fan’s

reasoning however, autistic headcanons can allow neurodiverse audiences to further identify with their favorite characters, as well as feel more represented by the media they consume.

But this begs the question: how do actually autistic female characters compare to the characters audiences have claimed as autistic?

In 2022, I conducted a content analysis of eight female characters from a variety of movies and TV shows; four being confirmed autistic, four being popularly believed to be autistic:

Confirmed

- Isabelle (*Mozart and the Whale*, 2005)
- Renee (*Loop*, 2020)
- Entrapta (*She-Ra and the Princesses of Power*, 2018-2020)
- Julia (*Sesame Street*, 2016-present)

Headcanonned

- Ponyo (*Ponyo*, 2008)
- Amelie (*Amelie*, 2001)

see [Girls on Film on page 54](#)

Harnessing Technology to Support Individuals with Autism and Their Families

By Karen Lindgren, PhD
Chief Clinical Officer
Bancroft

We are in a moment of limitless possibilities. Tech innovation is the new zeitgeist, and its development and growth are moving bewilderingly fast. With it comes possibilities to provide the best care and the best outcomes for those living with autism and their families. For providers largely focused on the human and not the machine, it can be a confusing time, knowing there is so much that can be harnessed within the technology landscape, but with little understanding of how to capture the benefits. That’s why the power of partnership with tech allies could provide better care and outcomes, leading the way for other industries to follow suit. We are on the precipice of big changes, and providers, who are in the unique position to understand the challenges experienced by those living with autism and their families, can find dynamic collaborators in technology companies who are in a position to help with innovative solutions.

Providers aren’t technology experts. That’s why we need the best minds from different places to come together to solve the challenges that those with autism, and their families, face. The partnership between providers, technology companies,



businesses, and universities, with their extensive research capabilities, can have a profound impact on the accessibility and user experience of technological interventions. Consider a scenario where a communication app developed through this partnership is designed to accommodate different language preferences and sensory sensitivities, ensuring a more inclusive experience for all users. Alternatively, consider one that is used to create a personalized space where information on a child with autism can be shared with families,

physicians, and educational settings in real time, reducing communications challenges and enhancing the ability to deliver tailored interventions.

Some of these technologies are already available and are poised to offer creative answers to those with the skills to unlock them. It takes both providers, who understand the challenges and barriers to better care, and the technology community’s ability to envision creative solutions based on their unique vantage point in a rapidly changing industry.

Virtual Reality: A Window to a New World

Research is being done on the benefits of virtual reality (VR) on everything from Narcan administration to save lives after an opioid overdose, to anxiety reduction, to improving athletic performance. By partnering with VR companies, human service providers can harness the same thinking to usher in new ways to transform autism care, enabling individuals to explore new environments, develop social skills, and manage sensory sensitivities in a controlled and immersive way. For children with autism, VR environments could serve as safe spaces to practice real-world scenarios such as navigating a crowded street or engaging in social interactions, building confidence, reducing anxiety, and enhancing communication skills.

VR technology could also allow therapists and educators to create personalized interventions that cater to the specific needs of each individual. For instance, therapists could simulate social situations and guide the child through appropriate responses, thereby fostering improved social interactions. As technology advances, VR may also facilitate remote therapy sessions, making help more accessible to families regardless of their location, as well as assisting in the training of both therapists and families, creating better outcomes and seamless interventions.

see [Technology on page 53](#)

Navigating the Sandwich Generation: My Personal Journey As a Neurodivergent Entrepreneur, Mother, and Daughter

By Michelle Markman
Neurodivergent Relationship-Based Coach
ND Coach, Inc.

I am a sandwich generation mother and daughter; I can attest to our unique challenges. I have the added challenge of a disability, or as I like to refer to it, a unique neurotype. Despite growing up thinking I was a neurotypical person who was just unlikeable or “weird,” I have always been extroverted and affectionate. I love people, and meeting and connecting with new individuals brings me joy. However, over the years, I’ve realized that many people do not resonate with or reject me for reasons I did not initially comprehend. Accepting my diagnosis was originally a struggle. Although my brother was diagnosed with AuDHD (Autism and ADHD) at a young age, I considered myself different from him - the good girl who behaved. Yet, as time passed, I began questioning if I was autistic.

Low Support Needs,
Not No Support Needs

Shortly after marrying my husband, I faced a challenging period while adjusting to my new role as a wife. I revisited my diagnostic paperwork from college, prompt-



Michelle Markman

ing me to delve into online research. Like many neurodivergent adults diagnosed later in life, I contacted fellow neurodivergent individuals online. I encountered difficulties with certain autism groups, not realizing every Facebook group has a private owner. Feeling like I did not fit in with either neurotypicals or autistics, I

wondered where I truly belonged. I wasn't entirely sure.

Coaching With a Twist

During this time, I sought assistance from a coach. Although it proved transformative and enabled significant personal growth, I sometimes found the Socratic questioning overwhelming and stressful. Having relied on external answers, unlocking them within was challenging for specific topics, necessitating additional help.

I combine coaching and mentoring to aid my clients who are genuinely stuck on a topic. I offer personal anecdotes and words of affirmation to help them surmount barriers and achieve sought-after transformations. This unique approach stems from my identity as a neurodivergent-affirming and neurodivergent-identifying coach.

Being a First-Time Parent

Becoming a parent during a pandemic presented challenges. I grappled with conflicted feelings about seeking help or support. While everyone wants time with the baby, the genuine need is for assistance with other tasks - cooking, cleaning, and chores - allowing for quality bonding. Occasionally, having someone else care for the baby so you can shower or rest is a tremendous gift.

One regret from my child's infancy is not involving my family more. Despite my parents' significant help, I didn't include my brother, his wife, or my cousins much, which I regret as they've moved away. I wonder if involving them more would have kept them closer.

Assisting Aging Parents

Presently, I am navigating challenges as my parents age. One parent is battling cancer, and the other has an autoimmune disorder. Both are in their mid-seventies and still firm but certainly struggling more as the years pass. I have relied on them for my childcare, but with the recent diagnoses, I must find childcare - a stressful endeavor. I am trying to find a caregiver who understands my unique child's needs and won't punish them for sensory challenges if they act out. I don't want someone who will punish them for their sensory challenges or if overstimulation is difficult.

Motherhood's Isolation

Building a supportive network is paramount for mothers. Every mother needs a village, not just neurodistinct mothers but particularly for those with extra support

see Personal Journey on page 50

From Parent to Advocate: My Mission to Help Other Families

By Christina Silva-Soto, MS Ed, QIDP
Parent Advocate

When my son Oliver was about nine months old, I noticed some milestone delays. I also realized that he had a tic. He would get very excited - wailing - when he saw something that caught his attention. It was also around that time that I knew I had to quickly become his advocate.

Naturally, I wanted to find answers for Oliver as soon as possible. At fifteen months, I took Oliver to our pediatrician. I presented all my concerns for Oliver to the doctor, and we immediately launched into an early intervention plan.

Each stage that led to his autism diagnosis seemed to bring greater challenges, but I knew I had to prepare myself to secure the services and resources that Oliver needed. He spoke no words and barely made sounds. When it was recommended that he have speech therapy for two days a week, I advocated for five days per week. I researched support groups of other families who were facing similar situations with their children, and that's where I found my home.

An in-person support meeting at Parent to Parent proved to be life-changing for us. Other families shared their journeys and resources. Through those meetings, I discovered that I wanted to help families just like mine by relaying our experiences. We all had so much to navigate, and we all needed



Christina Silva-Soto, MS Ed, QIDP

support. We were there to help each other.

I walked away with so many suggestions and recommendations, and I also helped families, even as I continued to navigate our submission requests for Oliver's services. We had many challenges from finding a developmental pediatrician to setting up his evaluations. I wanted to share the information I had and provide assistance to others whenever possible.

Eventually, Oliver began to attend socialization classes at Rainbows Reach on Staten Island. The owner of the organization suggested that I launch a support group for families and caregivers of

young people with disabilities and offered me space at Rainbows Reach to hold our monthly meetings. In those sessions, I supported families with their questions and paperwork. Our network of families grew through conversations on social media, and soon, we increased our meetings to every other week.

Around that time, I also needed information about the Committee on Preschool Education (CPSE) and Early Intervention services for Oliver. Advocacy had become so important to me, and while I knew a lot about services for young people with disabilities, I had questions. I discovered an organization that supports families of young people with disabilities from birth to age 26 throughout all five boroughs of New York, [INCLUDEnyc](#). I would come to rely on INCLUDEnyc over the years with other inquiries about Oliver's education.

Advocacy for all families became my mission. After operating a business for over 20 years, I knew it was time to pivot in my career to support families just like mine. I had a Master's Degree in education, and my husband suggested that I make a career change to help other families on a full-time basis. I discovered the Statewide Learning Management System (SLMS) offered by New York State. SLMS furnished crucial information and training with respect to the Office for People with Developmental Disabilities (OPWDD). That led me to uncover different facets of the OPWDD, and the training sessions helped me to become

an educated advocate and eventually a certified self-direction broker.

That was the turning point that led me to my current role as Director of Member/Family Engagement at Tri-County Care where I connect parents to the critical information and resources they need for their loved ones with disabilities and to help them navigate the OPWDD Home and Community-Based Services (HCBS) Waiver eligibility process.

Guidance for Parents in Need of Support Services for Autistic Children

My experience with organizations like Parent to Parent and INCLUDEnyc are examples of my best advice for parents who need support with services for children who have autism: it's important to always seek help when you need it. As I continue my work in supporting other families and advocating for Oliver, I encourage parents and caregivers to follow some guidance I've learned along the way:

- **Don't be afraid to ask for help.** Parents need to know that resources are available. You are not alone.
- **It's never too soon to find help.** Seek out Early Intervention for your child through your pediatrician or a developmental pediatrician as soon as possible.

see Parent Advocate on page 55

Supporting Immigrant Parents (Now U.S. Citizens) In Navigating Services for Autistic Children

By Trudy Ann Pines, EdD
Assistant Principal
AHRC NY City Middle/High School

There has been an increase in the prevalence of childhood disability worldwide. One in six children, ages 3-17, has recently been diagnosed with a developmental disability.¹ Parenting children with a disability poses challenges for all parents, although immigrant parents experience more difficulties in caring for their children with disabilities related to adaptation, finance, accessing services, and stigma.² Some of the challenges immigrant parents face in raising children with a disability include adapting to the new country's culture, norms, customs, and the language barrier, which is the most common barrier in schools, and the lack of information on resources available to immigrant parents and their child with a disability.³

More than half of the students identified with a disability in AHRC New York City's schools are from culturally diverse backgrounds, with some new immigrants and other new families who have been in this country for many years. Immigrant families who have been in the U.S. for many years were born and raised in Latin and Central American countries such as



Ecuador, Dominican Republic, Mexico, and Puerto Rico. Limited English language proficiency is a significant factor that may inhibit immigrant parents from taking part in their children's education and access to services. Additionally, some school staff are not as open to diverse cultures as they might be, therefore complicating matters further. Immigrant parents with limited English language proficiency may not feel confident communicating

with the school staff about their concerns related to their children's cognitive and social-emotional deficits due to the nature of the disability. Furthermore, immigrant parents may not understand their children's special education needs and parents' rights to ensure their children receive appropriate education. Therefore, schools must prioritize engaging their families best throughout their transition from school to adulthood.

Family Engagement Process

When engaging with immigrant parents of a child with a disability, they have reported not receiving the information and resources available to help their children's academic, social, and emotional needs to succeed in school.⁴ In my experience as an educator, I have a primary role in the families' engagement process. I recall helping an immigrant family whose older child, diagnosed with autism spectrum disorder, was struggling to adjust to the classroom routine upon returning to school from the 2020 COVID-19 shutdown. The parents could not understand why their child was having such behavioral challenges, and they expressed feeling embarrassed to seek help on behalf of their child. After several meetings and conversations with the parents, I realized that parents' beliefs about the nature of their child's disability may have impeded access to the information and resources available.⁵ A parent reported in conversation, "In our culture, we do not discuss our home issues with professionals; we believe we must solve our home issues to the best of our ability, but our child's behavior at home and in the school community has been so difficult to manage, and we concluded that we truly need help,

see *Immigrant Parents on page 51*

Supporting Families with Autistic Children - What More Can Be Done?

By Narpinder Kaur Malhi, MD
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The Group for the Advancement
of Psychiatry Family Committee

According to a March 2023 [press release](#) from the CDC, about 1 in 36 (2.8%) children have been identified with Autism Spectrum Disorder based on data gathered from 11 communities around the United States. This is a 22% increase from 2018, which found the prevalence of ASD to be 1 in 44 (2.3%).

What is Autism Spectrum Disorder (ASD)?

ASD is characterized by challenges in social communication and interaction and restricted or repetitive behaviors. Individuals with ASD have variable ways of learning, paying [attention](#), or regulating emotions. It is also reported across all racial, ethnic, and socio-economic groups.

In recent years, with increased screening and identification, [progress has been made](#) in understanding this complex disorder. [Treatment interventions](#) are provided through various educational approaches, developmental therapies, and behavioral interventions. [Medications](#) have also been shown to produce positive outcomes in treating behavioral and [psychiatric](#) symptoms in individuals with ASD.



Family Challenges Around ASD

Alex, a 12-year-old African American boy, was brought to the outpatient clinic for treatment of his disruptive behavior. Alice and John have no biological children, and Alex was adopted shortly after birth. John works full-time while Alice stays at home.

Alex was diagnosed with ASD at the age of 7 when he faced significant challenges with his emotions and behaviors. The adoptive family members were mixed race, with the father and Alex being black and

the mother being white. The family entered treatment with the belief that his behaviors were linked to his diagnosis of ASD.

Alex had a history of challenges with regulation of his emotions, struggles with maintaining focus, limited impulse control, and being easily agitated. His parents mentioned that they do not have a holistic approach to addressing his issues. Despite his father believing that he needed more structure and discipline, his mother believed that he lacked [emotional regulation](#) skills. Alex perceived his father as strict

and disciplinary and he worried about his mother, so he did not express his feelings to either of them.

While raising a child with autism can be rewarding, given their many unique passions, talents, and strengths, it also brings a set of challenges for the families. Family members may experience a mix of emotions, including love, joy, frustration, and [stress](#) as they navigate the complexities of autism. Unfortunately, families suffer.

[Higher levels of mood disorders](#) are seen in families with [autistic](#) children which is attributed to their experience of stress associated with diagnosis, genetic factors, and intergenerational family dynamics. Parents of children with ASD experience more marital strain and are [twice as likely to divorce](#) compared to parents without a child with ASD.

Families can experience stress at each stage of their child's life. Their journey starts with difficulties in accessing needed services when they first notice their child's developmental delays and then have to scramble to find accurate diagnoses and treatments.

[Parenting](#) children with autism also involves stress associated with their children's challenging behaviors, communication difficulties, isolation, and atypical [attachment](#) behavior. Stress can be further exacerbated when parents are unable to secure appropriate resources during school-age

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Latine Caregivers from page 1

delays in learning about evidence-based practices (Lopez et al.). Once early autism intervention services are secured, caregivers report limited direct coaching models within this system of care (Hampton et al., 2023), which perpetuates the cycle of disparity. Within their communities, caregivers report high levels of stigma associated with autism, for example some Latine families report feelings of embarrassment, rejection, and family burden, which contribute to caregivers' reluctance to raise developmental concerns with providers (Zuckerman et al., 2014). Some Latine families believe their child will grow out of their symptoms which can cause further delay in pursuing diagnosis and interventions (Rivera-Figueroa et al. 2022). Finally, Latine families also feel discomfort and mistrust with professionals due to cultural and language differences in expressing their anxieties.

Resilience represents a shift in understanding factors that may impact a family's experience from a deficit orientation towards a more holistic and contextualized lens, focusing on strengths and healthy adaptation. In the literature, family resilience is defined as the "characteristics, dimensions, and properties which help families to be resistant to disruption in the face of change and adaptive in the face of crisis situations" (McCubbin & McCubbin, 1988, p. 247). Broadly, Latine caregivers share several assets or promotive factors - including characteristics of individuals (e.g., optimism, bilingualism) and families (e.g., family cohesion, intergenerational households, family support and stability) that increase the likelihood of positive outcomes (Cabrera et al., 2022). Though limited, research with Latine caregivers of autistic children have found that Latine families often report lower levels of parenting stress, coping, and negative family impact across time (Hickey et al., 2021). Specifically, Latine parents may be more likely to seek out social support, in line with *familismo*, a concept referring to the commitment of Latine families to maintaining strong kinship ties, which may serve as a buffer (García-Coll et al., 1996). Further, it is well documented that collectivistic cultures, which are associated with Latine families, place more value and opportunity for caregiving help outside of nuclear families, which in turn could lead to less stress, different coping, and less negative impact on parenting feelings and the parent's social life. It is important to caution that this can be a source of stress if external family members lack knowledge of autism or deny that the child is autistic.

Cultural Adaptation and Responsiveness

Importantly, parent-mediated interventions include low numbers of Latine caregivers as participants (Nevill et al., 2018), and many specifically exclude bilingual families (McDaniel et al., 2020) or families with limited English proficiency. Given the limited cultural and contextual fit of interventions and the unique needs of the Latine population, significant adaptations are needed in terms of delivery, therapeutic process, inclusion of cultural knowledge, attitudes, and behaviors to make evidence-based practices more culturally appropriate. Although this work is promising, research in this area is limited to teaching direct strategies to caregivers and most



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cultural adaptations continue to rely on surface-structure adaptations, or changes to the materials, messages, and format of intervention delivery, as opposed to changes to the core components of the intervention that are thought to produce change outlined in the EVF framework (Dubay et al., 2018). However, exciting work in this area has recently emerged, particularly for parent-mediated interventions including cultural adaptations of psychoeducation in autism (Parents Taking Action; Magaña et al., 2017), and acceptance and commitment therapy (ACT; Cañon et al., 2023). Most cultural adaptations use the ecological validity framework to guide the process (EVF; Bernal et al., 1995).

The EVF has been used to adapt interventions to consider eight cultural dimensions that may impact how an intervention is conceptualized and deployed. The eight EVF dimensions: preferred language, attributes of persons involved and their relationship (i.e., therapist, parent, and child), incorporating metaphors (i.e., symbols of the cultural group), considering content (i.e., cultural values and traditions) and concepts (i.e., theoretical orientation and intervention conceptualization), considering culture in determining goals, considering culture in designing methods/procedures of intervention, and considering the context of families during interventions (i.e., economic, social, and community factors) are carefully considered to conduct cultural adaptations. We offer some recommendations and considerations when working with Latine caregivers of autistic children based on the current literature.

Recommendations When Working with Latine Caregivers of Autistic Children

Education and Coaching - Given the limited knowledge of autism reported in the Latine community and the limited interventions on caregiver direct coaching, it is important to integrate education and coaching early on. In addition, exposing Latine families to new knowledge that is constructed and guided by autistic voices can help in their understanding and conceptualization of autism from multiple perspectives (e.g., social model of disability). Thus, providing an opportunity to reflect on their child's diagnosis in an empowering way that respects and supports their child's unique needs. Further, this framework could impact engagement in pre- and post-diagnostic services (Hickey et al., 2021).



Ana D. Dueñas, PhD, BCBA-D

Cultural Match of Interventions - Interventions are needed that match home language, have strong contextual fit, are motivating (e.g., meaningful, interesting), and relevant (i.e., information can apply to daily life) (DuBay, 2022). These considerations can establish relevance and encourage caregivers to feel invested and engaged.

Supporting Community Acceptance - Given the high stigma reported among the Latine community about autism. It is important to continue to support caregivers by helping to educate community members at large about autism. To become confident advocates, Latine caregivers could benefit from becoming well-versed in who their child is as an autistic individual in a way that empowers them to share with family members and their community.

Considering Intersectionality of Race and Disability - It is important to consider the sociopolitical climate of Latine families that intersects with having a child with a disability (e.g., immigration status, biases), and the social constructs that may influence the autistic person (Casio et al., 2021). Latine families may be dealing with additional trauma and may benefit from having space to talk about experiences specific to their experience.

Positive Reframing - Emerging perspectives, like the neurodiversity paradigm, may help families in their positive reframing of autism and have been shown to improve adjustment in families (Bekhet et al., 2012).

*We acknowledge that both "Latine" and "Latinx" seek to remove gender from the Spanish word Latino. We use Latine as it is native to the Spanish language and can be seen in many gender-neutral Spanish words like "estudiante."

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unique behaviors.

The Primary Source of Stress

Autistic children are usually referred to numerous intervention services including school support, occupational therapy, applied behavior analysis, physical therapy, and speech therapy. All parents reported a main source of their stress were barriers to autism services, such as battles with insurance companies to cover autism services, finding service providers within a reasonable distance of their home that did not have months long waitlists, and scheduling multiple therapies into their busy week.

Feeling Alone

All the parents talked at length how they felt very alone. Since the possibility of a meltdown occurring when out in public - and being judged by others - is always present, many parents described shopping exclusively at one store, shopping during hours with fewer shoppers, or having their spouse complete errands.

Guilty Feelings Leading to Stress

Those parents with multiple children discussed at length the unrelenting feeling of guilt about the unequitable division of attention and care given to their autistic children versus the other siblings. This led to a robust discussion surrounding family vacations and how they are more exhaustive than relaxing for parents. Due to the amount of time it takes to prepare their autistic child for a vacation paired with no respite care while on vacation, most parents reported planning few - if any - family vacations. The parents reported feeling guilty and expressed sadness seeing their neurotypical children missing out on new adventures, new places and experiencing a much-needed stress relief.

One Dream

For parents, the weekly therapies feel like a road of unending appointments, consuming time that could be spent on their other children. As the parents wished there were a better way to coordinate the numerous therapies, one parent dreamily asked, "Wouldn't it be nice if the therapies were under one roof?" And just like that, a dream took hold; could there be one agency that



Heidi Hillman PhD, BCBA-D

offered a suite of therapies? Additionally, could one of the therapies be mental health counseling for parents?

What Would Help Parents

The biggest ask by parents: Be patient with us, especially when we are grumpy. We are doing the best we can under the circumstances. Realize that every day comes with challenges and few reinforcing encounters; we don't feel valued. One parent said, "I feel guilty for saying this, but just once I wish the therapists were as happy to see me as they are seeing my autistic child."

Beneficial Supports

All parents reported parent support groups provided a supportive space for them to cope with their stress by reflecting on their stressors and connecting with other parents. One parent specifically mentioned being surrounded by parents who "get it and are non-judgmental" was helpful. Parents said they preferred support groups led by parents rather than professionals. One parent said he would love to see more support groups led by autistic adults, since most are led by non-autistic individuals.

One parent noted that agencies often set up parent trainings, support groups and workshops without offering supportive services like childcare, "and then they wonder why parents don't show." Another parent mentioned those families who have the most support usually attend the agency-sponsored programs, whereas the

families who would really benefit are not able to attend due to lack of childcare or schedule conflicts. When planning support groups or workshops, parents mentioned scheduling them during the school day or Friday afternoons, rather than evenings.

One support all parents concurred with: A mentoring class that equipped them to be better advocates for their child during IEP meetings. All the parents said they felt the IEP process was stressful and fraught with frustration. One parent said, "I would gladly pay for a professional to guide me through the IEP process, making sure my concerns are heard and my child's needs are met." All the parents wholeheartedly agreed they would pay for that service.

Information is Power

All parents discussed the importance of being informed on autism, making them more confident in knowing what was best for their child. From the moment that an autism diagnosis is given, the parents explained, "Lack of access to reliable information is a significant barrier to adjustment for families." Another parent said, "It is how parents cope, more information helps parents cope emotionally." The parents reported feeling frustrated and overwhelmed differentiating the legitimate interventions from the faddish, unproven approaches. One parent said, "Information is power. It is how I can help my child be more successful in life."

Respite is the Most Important Support

If you could list one support as the most important, what would it be? When I asked this question, all parents responded in unison... adult time. One parent summarized it well, "For all the stressed-out parents with kids on the spectrum, I can't emphasize enough how luxurious it is to have even a small amount of time away." One parent said if agencies scheduled a two-hour "parent night out" or "parent afternoon out," it would be popular. All the parents agreed, "Most people assume parents of autistic children have family willing to watch their kids, which is not the case. For some, therapy sessions are their only personal time."

Conclusion

The interview highlights the importance of support for parents. It became apparent that every day comes with challenges and

unknowns which can be emotionally draining and stressful. Not all parents receive support from family and friends, which leads to the importance of formal supports offered by agencies. Some may argue that services for autistic children indirectly help parents. True, however supporting parental needs is usually not the job of the child's therapist. Offering services solely for parents may be a dream. But what if there was one agency that housed multiple therapies? What if it housed mental health counselors for parents? What about adding social workers to help parents navigate services and information? What if there was an education advocate who walked parents through the IEP process? And parent support groups and parent-night outs were offered monthly? Slowly the dream of supports can become a reality.

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Skilled Workforce from page 8

5. The caregiver continues practicing the skill with feedback from the clinician until they have learned the skill to mastery.
6. The clinician provides ongoing performance feedback on the implementation of the skill within the context of ongoing treatment.

Evidence-based training models such as BST provides clinicians with a foundation to enhance the skills of caregivers as behavior change agents. However, the training model does not end there; we must continue the collaborative relationship between clinician and caregiver by providing ongoing feedback.

Performance Feedback

An important skill in the training process with caregivers is the ability to deliver performance feedback related to treatment adherence. Daniels and Daniels (2006) describe performance feedback as the sharing of information related to a person's performance that supports a change in their behaviors and plays a key role in one's ability to learn. The how and when to deliver feedback has been evaluated extensively over the year (see Balcazar et al., 1985; Alvero, Bucklin, & Austin, 2001; Sleiman et al., 2020). Some common characteristics of effective feedback consistent within the literature include specification of presented information, immediacy of feedback delivery, and individualization of feedback. While it is still unclear which combination of characteristics produce the greatest effects, all authors were consistent in noting the use of performance feedback as a potent and cost-effective tool for clinicians wanting to change behaviors (Daniels & Daniels, 2004; Sleiman et al., 2020). However, no matter the combination used, the effectiveness of feedback can be easily hindered if we don't take the time to understand how the delivery of feedback can affect the caregiver/clinician relationship.

Social Validity

Effective training and feedback models must extend beyond the technical procedures to create a supportive and responsive relationship with caregivers (Taylor et al., 2019). The need for therapeutic relationships with those we serve is well rooted in our history. Wolf (1978) presented this point in his seminal article: *Social Validity: The Case for Subjective Measurement or How Applied Behavior Analysis is Finding Its Heart*. Social validity provides a framework for establishing a supportive and therapeutic relationship by asking what caregivers think about proposed goals and procedures, and about the outcomes achieved (Wolf, 1978). What people think about what we do matters. Without caregiver acceptance, no amount of training or feedback will produce the best outcomes for those we serve. Recently the field has shifted focus; again, from technological procedures such as *what* questions we ask to *how* we ask those questions in the context of delivering services, including caregiver training. From the goals to the procedures to the outcomes, we must support caregiver training by providing compassion and care every step of the way.



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Compassion and Care

Developing and maintaining caregiver relationships requires clinicians to develop skills in the area of compassionate care and interpersonal relationships. Taylor, LeBlanc, and Nosik (2019) describe compassion as "bringing action to the empathic response" (p. 655). Actions on the part of the clinician may be actively listening to concerns, reflecting on the caregiver's perspective, or allowing themselves to feel what the parent may be feeling. In the context of feedback, clinicians can leave time after the delivery of feedback to hear parent concerns or consider adjusting the treatment plan after reflecting on the caregiver's perception of the plan's feasibility.

Let's look at an example. A clinician trained caregivers on a treatment plan to decrease the sleep onset of a four-year-old. The initial training produced 100% adherence to the treatment plan. During the one-month check-in, the clinician noticed that caregivers were no longer completing the 5-minute checks until the child fell asleep. Following this observation, the clinician simply asked the caregiver, "I noticed that you are no longer completing the 5-minute checks. Could you tell me a little bit about why?" The caregivers thanked the clinician for asking and shared that they were no longer able to because only one caregiver was available during the bedtime routine for all three children in the house. With this feedback, the clinician provided an alternative method to complete the checks via a baby monitor and the treatment plan was a success. In this case, the way in which the clinician provided feedback strengthened the therapeutic relationship and ultimately the outcomes for the child and family.

An equally important area is the development of interpersonal skills. Similar to compassion, interpersonal skills are specifically related to one's ability to listen and speak, both vocally and non-vocally (Sellers, LeBlanc, & Valentino, 2016). As noted earlier, clinicians should take the time to learn the family's culture and beliefs, including their communication preferences. For example, some family members may not make eye contact when receiving feedback or shy away from suggesting treatment plan changes even though the plan may not fit within their family's system. Wright (2019) provides a discussion on the practice of cultural humility, describing the process as a lifelong journey of learning. We, as culturally humble clinicians, must continue to learn and always consider the



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cultural identifiers of others in the context of the work we do.

One example that always comes to mind is cultural differences around where people sleep. There are many different variations in sleeping arrangements within a family unit. We must educate ourselves on the preferences of the families we serve. Extending on the question posed by Wolf in 1978, we must ask caregivers not about *our* goals as clinicians, but rather about *their* goals as an important member of the team. If a caregiver comes to us with a concern about bedtime routines and that family happens to co-sleep as unit, it is not up to us to decide that co-sleeping must end. It is up to us to discuss how we can best support caregivers in producing meaningful change within the preferences of their family unit.

Conclusion: Putting it All Together

Our goal as behavior analysts is to achieve best outcomes by providing high quality, evidence-based services in collaboration with the greater team. To achieve this goal, we must support that team, in particular families and caregivers. One way to provide such support is through caregiver training. Thus, skilled clinicians will be well versed in training methodology, such as BST and performance feedback. However, to provide training and feedback alone will not foster the therapeutic relationship necessary to achieve best outcomes. Clinicians also must be skilled in working collaboratively with caregivers by providing support through training with compassion and care. The integration of technological and interpersonal skills is more than just adding steps to the training checklist. It requires clinicians to create a feedback loop with caregivers through the therapeutic relationship. We must ask for caregiver input each step of the way, hear what caregivers are saying, and incorporate this information into treatment plans. It is through this process that we as clinicians will provide the support needed to achieve best outcomes.

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their programming. It becomes more of a win-win situation when you start small and practice ways to reach these goals of improved self-care.

Given the limited number of hours in the day, you may be wondering how this self-care business is supposed to work. We know that kids often thrive on structure, and that they are adaptable. If you begin to slowly add time in the day for your own breaks, they will learn that these breaks and times are important. This practice also models appropriate self-regulation and the importance of recognizing when to take a step back to identify what you may need.

It's easy to identify what gets in the way of making your own mental and physical health a priority. Parents have endless amounts of tasks that need to be checked off the list. Fatigue, lack of resources and time, and self-blame are just a few of the reasons most noted to usurp self-care efforts (Serrata, 2012; Gorsky, 2014; Merluzzi, et al. 2011). Disruptions in sleep can have a significant impact in functioning, both for you and your child. Limited resources in terms of available quality care providers, as well as funds for those supports, are often a challenge for families. Right now there is a nationwide shortage of qualified providers of care, and this shortage has meant that a lot of families are providing more and more of the care to their family members at their own expense. In some cases, caring for a child, or a young person who has just exhausted their school-based entitlement (to free and appropriate education), can be a full-time job with an ever-changing job description that seems impossible to master. This can lead to feelings of guilt around taking any time for self-care. It may seem selfish to spend time on yourself, and this mindset can limit your interest and desire to seek out self-care opportunities.

I facilitate a monthly Sibshop program, and I was so pleased to learn that a few of the parents were dropping their children off to group and then heading out to a local restaurant for some much-needed time



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away from the demands of the day. They often report that they look forward to this time for their kids to have support, but also for them to be able to refill some of their reserves by spending time with other parents and lending support and care to one another. This is a great example of how to maximize time and resources to benefit self-care. Perhaps this is a strategy that might work for you.

Other areas of focus that may support increased self-care opportunities are family training, resource sharing, and system resources that can assist the whole family. With training, families are better equipped to manage the daily needs of their children by increasing the consistency of programming across settings. Training for family members can also improve the likelihood that interventions would be successfully generalized into the home setting, thus reducing the overall demand for time and resources from the parent. It is important to also recognize the limits of what care some family members are able to provide, whether because of age, external responsibilities, or other reasons. It is equally important to show some grace when a resource deemed less "appropriate" must be utilized. For instance, sometimes a tablet is the best option to occupy a child's time,

depending on what tasks must be completed at that time; food via the drive-through may sometimes be a caregiver's only option for dinner. When parents can let go of some of the guilt, shame, and judgment surrounding decisions like these and generally how they parent, they can also free up resources for other areas of focus.

Resource sharing is another way to work toward a model of self-care. This approach can include partnering with another family to identify times when the families can help each other. For some of my families, this looks like a few hours on a Saturday where the kids are dropped off to someone else for a little bit, and then this is reciprocated for the other family when needed. While their way of providing help might not be the way you would do it, if your child is healthy and safe, a few hours away from you with someone else equipped to care for them won't hurt and will likely benefit you and your entire family greatly.

System resources are another way to approach an increased focus on self-care. Many apps offer meditations for various lengths of time, providing small respites from your day-to-day routine as a caregiver. Even simple things like listening to music, watching funny pet videos, or just playing your favorite game on your phone or tablet can provide a much-needed brain break.

When it comes to self-care, there is no one-size-fits-all approach, and it's important to note that it will take time to establish a new routine to shift your focus of care to a better balance. Start small and build as you feel comfortable, and you'll soon feel more refreshed and ready to take on those bigger challenges with a healthier mindset. Breaking down self-care into smaller manageable tasks and options helps us not get stuck in thinking that conditions have to be perfect in order to take a moment for ourselves. You can build these daily moments into your day, every day, through family training, resource sharing, and system processes. When our routine only serves the individuals with special needs in our lives, we all run the risk of burnout, fatigue, and sometimes even detrimental outcomes for our loved ones, including ourselves. Assur-

ing that time and attention are paid to the unique needs of each family member sets everyone up for success.

In conclusion, it is not lost on me that most of us don't pay attention when the airline personnel remind us to put on our own mask before helping others. I do not suggest that incorporating self-care strategies into your already busy routine is easy to do. But what I can tell you is that the small investments made over time to develop these practices can yield results that may pay huge dividends later within yourself and your family. You are worth these efforts, and all the time and attention needed to get started with the first step.

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Parent Involvement from page 29

with the family to integrate the support of a BCBA, behavior tech and licensed clinical social worker to support the course of treatment. The goal from the beginning was identifying how the team could best support him and foster his success within the program. The family was more than receptive to this as they only wanted the best outcome for their son.

Over the next several months a team of educators, mental health professionals, BCBA's and behavior technicians were involved in coordinated planning and intervention. This required regular, frequent meetings to provide clinical updates, home visits, observations, and counseling sessions. While the results were not instantaneous, we saw progress happen. The student achieved the goals he set for himself. He mastered the goals the multidisciplinary team set for him as well! He was able to identify healthy coping strategies, identify when he needed a break, and sought counseling supports. Over time he became one of our higher performing students, even

supporting new students who entered the program. And in the end, he thrived and was able to successfully return to the public school with minimal accommodations.

None of this would have been accomplished without consistent, regular, and compassionate team planning, for both the organization and the family. Our comprehensive and collaborative process helped the student and the family succeed. Achieving this level of success starts from the beginning. There is not a "one size fits all" approach and to appropriately support our students is a group effort.

In closing, it is our philosophy at First Children that FAMILY is critical to the effective treatment of kids with challenging needs. This takes two forms - involving parents and family members in all aspects of the care and treatment of their children; and extending support and service to parents and family members who struggle with the unique challenges of having kids with special needs. When a family entrusts First Children with the care of their children, they get a long-term partner willing to go above and beyond for the whole family.

The future of services for children and families is constantly evolving. While there are arguably more resources provided to children and families today than at any time before, there are also challenges. For one, it is critical that policy makers, payers and providers focus resources on the real needs of kids and families, not some pre-designed model of care in which one size fits all. In this it is crucial that resources are allocated to serve the unique needs of family members of children and support them in being integral members of the treatment team. Similarly, it is immensely important that organizations like First Children remain financially limber to be able to pivot their services to address the changing and increasingly complex needs of children and their families. To do this, they need to be smart financial stewards and be open to opportunities to work with others who can help support the mission with operational, clinical, and financial expertise and resources.

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Emotional Support from page 10

these expectations helps decrease miscommunications in the moment when someone needs emotional support. If someone's intrinsic needs are different than their partner's, it is impossible to intuitively know that they should do something, let alone what to do, in these situations. In my clinical practice, I recommend couples use the code phrase "support or strategy." This takes away any difficulties with cognitive empathy or assumptions about what the other person needs and allows for direct, clear communication about whether the person wants emotional support or needs a practical strategy in that moment.

Providing emotional support for a partner does not mean that you need to be a therapist or say all the "right" things. Rather, it means making an effort to meet an expressed need that has been identified, in the way that has been clearly outlined between partners. Next, I offer some strategies to begin strengthening the ways in which partners approach integrating meeting emotional support more effectively in their relationships.

Strategies to Implement Emotional Support

Allow for Task Shifting - Task shifting, or switching from one activity to another, ensures that both partners have the opportunity to be present in the conversation. Before beginning a conversation where support is needed, clearly state there is an important topic to be discussed or give a partner a "heads up" earlier in the day that a conversation is needed. This allows for both partners to be fully focused on the discussion and not distracted by the previ-



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ous task they were engaging in.

Manage Expectations - Go into the conversation with realistic expectations. Both partners brains are wired differently and needs for emotional support vary. Emotional support from a partner may be different than the support one might give their friend, sister, or relative, but that does not inherently mean it is not valuable or supportive. An individual on the spectrum can say "do you need support or strategy?" if the need is unclear. A neurotypical partner can say "I need support not strategy" if they feel their partner is seeing the support need as different from what they want in the moment.

Acknowledge and Validate - For many neurodiverse clients who have struggled

with providing emotional support in the past, their fight, flight, or freeze response kicks in when faced with more emotional conversations. This is typically rooted in the fear of doing it incorrectly again and continuing this negative pattern with their partner. However, when there is a concrete plan for what to do in a situation, it is easier to move forward and decreases the chance of freezing up. This is an opportunity to *acknowledge* that a partner is sharing something difficult and to *validate* that fact. An individual on the spectrum does not have to agree with their partner's perspective of a situation, and may in fact have a vastly different viewpoint. The goal of providing emotional support is not to agree but rather to identify that something is "a difficult situation" for a partner. By listening and validating, it shows someone is working to meet their partner's needs and making an effort to provide emotional support.

Communicate Desire to Support - After acknowledging and validating, a partner does not need to offer sage advice or say exactly the right thing. Asking a partner "How can I help?" or "How can I support you?" shows the desire to provide support to a partner. This allows a spouse to communicate whether they need their partner to listen to them vent, need help with a tangible task that will make the situation better, or something else. Since all brains are wired differently, the only way to determine this is by asking clearly and directly.

Conclusion

As with all relationship strengthening tools, providing emotional support takes time and repetition to become part of a couple's pattern. This process requires

couples to understand neurodiversity within their specific relationship, operationalize what emotional support means to each of them, and use practical strategies to change the way they are supporting each other. Through practice, this approach can begin to reshape how emotional support is offered and received within a neurodiverse relationship and make for stronger, more fulfilling connections.

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Grandparents from page 32

how to best help him and his parents, who lived nearby.

"There were no books at the time or internet sites devoted to grandparents. My background was in nonprofit work, and my husband was a physician, so I had good access to the medical community. But I needed grandparent input to know how to best help my family, and how to prepare my home to make it comfortable for my grandchild," Gillman recalls.

So in 2006 she founded the Grandparent Autism Network (GAN) in Orange County, California, where she lives. She held the first meeting, which included dinner, at her home. A hundred grandparents showed up, forcing her to remove furniture to accommodate all of them.

Although grandparents are experienced at raising children, many realized that they had much to learn about autism. Gillman had professionals and representatives of autism organizations speak at GAN meetings, which were held monthly in different cities to reach as many grandparents as possible in Orange County. Today, the GAN website attracts visitors worldwide, Gillman says.

Grandparents had many of the same questions their adult children had when the grandchild was diagnosed. How do you communicate with a child with speech delays? What do you do when a grandchild is

very sensitive to noises, crowds, or bright lights? How do you respond to a tantrum or keep a grandchild from wandering away?

Grandparents often help each other with advice and tips. "When you talk to other grandparents, they can tell you what worked in their family for holidays, what worked in their family for travel, and what worked for outings, to make sure your grandchild is safe," Gillman explains. "They just have life experience to share with other grandparents."

A Grandparent's Advice

Gillman offered these tips on ways that grandparents can help:

- Be a good listener. Encourage and compliment your grandchild's parents as much as possible.
- Discuss but do not question the therapies or diets that were chosen for your grandchild.
- Help give respite time to parents. If you are uncomfortable caring for your grandchild with autism, plan activities to do with your other grandchildren outside of their home.
- Bring in meals, offer to do carpools.
- Set aside a safe, quiet place in your home

with some of your grandchild's favorite things for their visits.

- If your grandchildren live far away, send them a calendar to mark the days until your visit together.
- Create a visual schedule using drawings or photos of what you will do together during the visit.

Grandparents as Autism Advocates

Anderson's research shows the concerns of grandparents, along with their strength and resilience. For example, some grandparents have become autism advocates. They educate others about autism and send letters to the school district about services, according to the study.⁶

Grandparents also ask local and federal government officials for more funding and support for the autism community, Gillman says.

Some grandparents may not be as able to help, or be as supportive, as their adult children would wish. But many families praise grandparents' role in the lives of their autistic grandchildren.

Juritz says that her parents and parents-in-law have been supportive of her son, Nick, who is 13. His grandfather is his best friend, she says. "We're so fortunate that we have had our parents who are with us all the time."

Resources

- See SPARK articles and recorded webinars about parenting and caregiver stress.
- View SPARK's recorded webinar on "Grandparents of Children on the Autism Spectrum: Their Own Role, Their Own Challenges."

This article has been republished with permission from SPARK. You may view the original article, published on April 21, 2023, at https://sparkforautism.org/discover_article/grandchild-has-autism/.

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Telehealth from page 13

(Sutherland et al., 2018)

- A 2020 study of telehealth by Lindgren and colleagues found that parent-mediated telehealth BHT improved communication and social skills and decreased behavior problems in young children.
- A 2019 study by Wallisch and colleagues looked at parent perceptions of telehealth and reported that parents appreciated the way telehealth was compatible with daily life and found coaching by telehealth very helpful.
- A 2022 study found that a BHT program that provides social skill training for teens with autism was just as effective through telehealth as in-person (Estabillo et al., 2022).

Which Providers Are Available in Person Versus via Telehealth?

Another important question: “Which providers are available in person versus via telehealth?” Once families are no longer tied to providers in their drivable geographic area, their choices are likely to ex-



Doreen Samelson, EdD, MSCP

pand. Telehealth may allow parents greater opportunity to select caregivers who are a good fit for their family’s needs. This is particularly important for parents in areas where there is limited access to autism care. For some parents, especially in rural areas, telehealth may be their only realistic option. Having an increased ability to select well-qualified providers that parents are comfortable working with can be an important contributor to the success of their child’s treatment.

For older children, parents should consider their preferences, talking to their tweens and teens to find out what they prefer. Allowing youth to choose how they receive treatment can improve their buy-in for participating.

I also encourage parents considering telehealth to talk with other parents in their situation to learn from their experiences, and to discuss the decision with their existing care team.

A final word: This doesn’t need to be an all-or-nothing decision. Parents can utilize a hybrid approach that mixes in-person treatment with telehealth and can change their approach as their family’s needs and circumstances change.

Doreen Samelson, EdD, MSCP is the Chief Clinical Officer of Catalight, a non-profit that provides access to innovative individualized care services, clinical research, and advocacy - so people with developmental disabilities can choose their path. Samelson is a licensed clinical psychologist and leads the organization’s behavioral health research team with a focus on promoting the overall well-being of families.

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Autistic Burnout from page 11

support and resources to help them when they are experiencing burnout. Being a parent makes it tricky to just “rest” when little humans are needing you to feed them, clothe them, play with them, regulate them, love them... most of us feel like we can’t actually take a break.

That is why we need to learn ways of recovering from burnout within the context of being 24/7 caregivers to littles. This might mean that we offer more screen time while we are experiencing burnout. It may mean that we rely more on our community and family, if available. It also may mean that we need to make tough decisions about how we can cope and how our choices affect those around us.

It is important to learn how to recognize autistic burnout when it is occurring. Some signs to look out for are: Exhaustion, decreased functioning, sensory sensitivities, social withdrawal, communication diffi-



Danielle Aubin, LCSW

culties, increased anxiety, increased meltdowns, loss of interest, cognitive fatigue, physical symptoms, and emotional numb-

ness to name a few.

The signs of autistic burnout vary for each individual, but it is important to learn the signs that you are in autistic burnout. The number one thing most burned out autistics need is some form of rest. Our system has been overloaded and burned out and we need to recuperate. For me, this has looked like unlimited iPad time for my kids so that I can physically lay down. It means playing with my kids from a supine position. It means saying no to more playdates and park days. Although I know those things are important for my children’s development, I know that having a recovered parent is more important.

When you have learned how to notice that you are burned out, it is important to support your recovery from burnout. Although rest is the #1 remedy, there are other ways to help yourself recover. It’s important to set clear boundaries to support your recovery and communicate your needs to others. Limiting stimuli and spending time

in a relaxing, low-demand environment can be helpful as well. It is also important to reflect on the issues that caused the burnout in the first place and address them via changes in your environment or by organizing your time differently.

When you are burned out, it is important to find what nourishes you mentally, physically, emotionally, spiritually, etc. What energizes you and fills your cup? Even if you aren’t burned out, it is important to prevent burnout by discovering how to meet your needs. Is it listening to music or walking in nature? This requires some self-inquiry and experimentation. I believe it would be hard to be autistic in this world without getting burned out at some point. It’s important to be gentle with yourself and seek help/support when needed.

To contact Danielle Aubin, LCSW, AuD-HD Psychotherapist at My Autistic Therapist, visit www.myautistictherapist.com or email danielle@danielleaubin.com.

Empowering Families from page 30

cognitive skills, fine and gross motor skills, emotional skills, social skills, and play skills. Families are equipped with tools to collect data to track their child’s progress and new goals are introduced as their child masters skills.

By offering this comprehensive, family-centric approach, the aim is to provide sustainable strategies that will benefit families - not just while they await a diagnostic evaluation but long after as well. Many families have found it extremely beneficial to receive support and learn strategies on how to address their concerns while waiting for a diagnostic evaluation.

While we as a field continue to grapple with the imbalance between the need and availability of qualified autism diagnosticians, continued efforts are needed to bring

supports to families who may otherwise have little options other than to wait.

Andrea Lavigne, PhD, BCBA, is Chief of Regional Service Delivery and Nick James is Chief Development Officer at Autism Care Partners.

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Residential School from page 18

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Supporting Families from page 22

about what you need and state your needs specifically. If that doesn't work do not hesitate to ask for a different therapist.

- What are the most important memories you have? If there is a holiday, event, or place that is a part of those best loved memories ask your team to program for those successes for your child.
- Ask yourself what worries you the most. Ask what you want in 1 year, 5 years, 10+ years and then review the goals and decide if what you are working on will get you there. You are the CEO of this program. The goals should fit your lifestyle and the uniqueness of your child.
- Set up regular meetings to discuss the goals and progress of your child. Don't wait for others to set it up. You aren't overstepping, you are being a good caregiver.



Bobbi Rogers and her son Joey sharing a special moment on his graduation day

- Follow through with what you can and be honest with your team when you can't.
- If something isn't working speak up about it.
- Go throughout your day and jot down

what your struggles are. Sometimes you are so used to day-to-day life that you don't even realize that everyone breaks out in a sweat when it is time for day-to-day activities like nail clipping and tooth brushing.

- Try to keep school, home, family, and friends all on the same page.
- Remember who you are. What is the uniqueness of your family unit? Do you love sports, games, books, tv? Do you go to movies, restaurants, or camping? These may not feel like big-ticket items such as communication, but they matter. Don't be afraid to prioritize working on these things too.

It is possible to implement an intensive approach, such as ABA, to teach new skills while remaining compassionate and realistic. Intensive is not the opposite of compassionate. When we are sensitive in our approach, intensive is synonymous with seeing the potential and working

towards it. As caregivers we often worry whether we are doing enough. But you have everything you need to be successful. You have love. Love will help you get up when you are tired. Love will help you do more when you have already done so much. Love will help our kids see how much they matter. Love will help us all remember, as caregivers, that we are doing the best we can.

Bobbi Rogers is the parent of three children. Her son Joey is autistic and is the inspiration for everything she does. Bobbi is the founder of NY Families FIRST and the Senior Director of Community and Industry Relations at Proud Moments ABA. She has presented on such topics as Caregiver/Parent Collaboration, Autism Advocacy and ABA nationally and has started multiple programs across NY that support Autistic individuals and their families. She sits on the Board of the New York State Association for Behavior Analysis and is chair of the Parent, Family, and Advocate Committee.

Scholarship from page 23

- Interest in changing careers
- Seeking a promotion
- Acquiring a skill that is currently missing on your resume
- Gaining more confidence in a skill your current role requires

2. Explore training or certificate courses in your field of interest and vet the programs.**3. Do your research and find the answers to the following questions:**

- What are the requirements?
- How long will it take? Certificate courses can vary in length but, on average, take users between three and seven months to complete (Coursera).
- What is the cost?

- Is this program in person or remote? Many certificate courses can be done from the comfort of your home.

- Is it industry-recognized/offered by an accredited university or organization?

- How does the program link to your career path?

4. Narrow down the programs you are most interested in.

- Attending an information session or speaking with a representative of the program can help gain answers to questions and provide clarity.

5. Apply for your program and the Synchrony Tech Scholarship!

- The application process for certificate programs will vary by organization. For some, there is a more formal acceptance process; for others, users can register anytime.

It is important to note that the Synchrony Tech Scholarship does not allow for retroactive payments. Therefore, if your desired program is one that you can register for at any time, we encourage you to submit your scholarship application and wait to hear back from OAR before beginning your certificate journey. Applicants can expect to hear back from OAR about the status of their application within 60-90 days of submission.

OAR is actively accepting applications for this scholarship on a rolling basis through December 31, 2023. The awards for this scholarship range from \$500 - \$5,000 and depend on program cost. All interested applicants can learn more about the scholarship and apply online by [visiting this link](#).

When scholarship recipient Lucinda Hemingway was asked how this scholarship would impact her career, she shared, "The OAR Synchrony Tech Scholarship has granted me the opportunity to learn the formal training of frontend development coding. This program is making

me feel a renewed strength I felt I did not have permission to have before. I am really thankful for this opportunity from OAR, and I think this will increase my chances of getting a job that fits me better."

Courtney Carroll is Manager, Hire Autism at the Organization for Autism Research. Have questions or want to learn more about Hire Autism? Contact us via email at mail@hireautism.org.

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Innovations from page 19

Simply Home partners with residents with disabilities to create person-center solutions that integrate with your home to allow greater independence and confidence. The company will outfit a home for a resident with limited mobility to make it easier to operate lights and locks. They can equip homes with a bed, stove, and motion sensors in addition to panic pendants that alert a caretaker in case of an emergency.

Google Home / Amazon Alexa can integrate with a calendar to audibly alert a resident about reminders for daily tasks or can keep track of shopping lists. Parents can remotely add alerts and check integrated lighting and alarms systems.

Autism is for Adults

Many people don't realize that autism is not solely a childhood challenge. Creating public visibility into autism in childhood has resulted in improvements with early diagnosis. Now we are in a critical need to raise awareness that most individuals with autism are adults and need continued support for the challenges that they face.

**Stacey Ledbetter**

According to the CDC in 2020, there were approximately 5.5 million autistic adults in the U.S., representing 80% of the total autism population.⁹ Autism needs a publicity make-over to highlight that there are immediate needs for funding, innovation, and collaboration to meet the unique needs of autistic adults who want and deserve to

have the opportunity to live purposeful and independent lives.

Stacey Ledbetter is the mother of an autistic young adult and founder of NFlyte. Motivated to find tools to empower her daughter to live her most independent life, she founded NFlyte which is an all-in-one practical life skills platform for autistic adults with support needs. She serves on a committee at SOS Care/Village Vision in Charleston, SC whose mission is to create affordable housing for I/DD adults.

For more information about Nflyte, visit nflyte.com or email the author at stacey.ledbetter@nflyte.com.

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Dental Health from page 31

Development of a dental skill curriculum may benefit from partnership with a dentist. In the case of the New England Center for Children, they partnered with Smigel Supersmile[®] Dental for curriculum advice and procurement of a dental chair and instruments for an in-school mock dental suite.

In-School Mock Dental Suite - An in-house mock dental suite with chair and dental tools can acclimate and desensitize children with autism to the dental experience. Bright lights, new smells, and moving chairs can be unnerving to children with autism.

The dental process can be broken into multiple steps that are then introduced in a graduated fashion, moving through the process as each step is successful. The protocol can include walking into the room, sitting in the chair, bib application, bite blocker application, visual inspection of teeth, mock scaling, cleaning with toothbrush, flossing, mock fluoride application and dental clinic probes. For children with autism, achieving success and comfort with each step often requires dozens of sessions over three to six months.

Children who are comfortable with the dental exam process receive twice-a-year oral care from qualified pediatric dentists in a school's area. Such care would include cleanings, cavity fillings, orthodontics, and oral surgery.

In-House Dental Clinic: From Desensitization to Actual Dental Care

The ideal scenario offering the most comfort to children (and thus the greatest chance for dental success) is a true in-house dental clinic at the school. The benefit of having the dental clinic on-site is that students can practice their dental desensitization in the actual dental clinic, which should increase the likelihood of any gains made during desensitization translating to

**Jessica Sassi, PhD, BCBA-D, LABA**

the actual dental exam. The expectation is that students will be more comfortable and prepared for their check-ups and able to tolerate the experience with far less disruption to their daily routine and most importantly, the anxiety that comes with a trip to the dentist.

How does a special education school go about creating an in-house dental clinic? There are three stages to consider: 1) Partnership with a local dentist group; 2) Design and construction; 3) Operations.

Stage One: Partnership with Local Dentist Group - In partnership with a dental clinic, a school can take dental desensitization and care to the next level. The in-school clinic will have dental services provided by the partner dentist, offering the full breadth of dental services and state-of-the-art technology for enhanced care without the student having to leave the school.

In the case of The New England Center for Children, the school partnered with New England Dental Group. Dental groups may welcome the opportunity to partner with a special education school. Dentists

are able to deeply impact the lives of children and by extension their families. It demonstrates a deep commitment to giving back and making a tangible impact in the community.

In order to execute an initiative as complex as a fully-functional, on-site dental clinic, a school should align with a dental group that meets certain criteria: ability to provide expertise in the area of dental suite construction, willingness to provide clinicians to perform exams and check-ups and to thoroughly train them to work with an autistic population, ability to provide more in-depth services, such as sedation, and a strong reputation in the community.

Stage Two: Design and Construction

- An important step in determining the feasibility of operating a clinic in one's school is to bring in experts in the specialty field of dental office construction. They will examine the proposed space and determine electrical, plumbing, and equipment needs. From this will be produced a detailed renderings of a one-or-two-chair clinic and estimated costs for construction and equipment.

Once the costs and schematics are approved, the construction dates can be set. As part of this process, your school's nursing staff should work closely with the dental clinicians to ensure that they are fully trained and comfortable working with your students.

Stage Three: Operations - Your partner dental group will provide the hygienists and doctors to work in the clinic. A likely schedule would be two days per week, which may grow with demand. Visits would be general exams and cleanings; should more in-depth procedures be required, students could receive care at the dentist's "home" clinic. The school's desensitization program can be performed in the actual clinic in which students real exams and cleanings will be held.

From our experience at The New England Center for Children, feedback from

parents has been overwhelmingly positive. A heavy burden is placed on staff and parents around scheduling off-site dental exams, obtaining consents, verifying insurance, and on teaching staff who are responsible for transporting their students to and from the dentist. The in-house clinic and professional dentist staff alleviate these and other time-consuming administrative processes which benefits everyone.

An in-house dental clinic will likely require donor support in addition to a partnership with a dental group. A dental desensitization program and clinic can set your school apart and will garner positive response from staff, parents, and donors. Good dental health equals good general health. Anyone who has worked with special needs students knows that having dental services on-site is a game-changer for kids, teachers, and parents.

Jessica Sassi, PhD, BCBA-D, LABA, is CEO of The New England Center for Children, a nonprofit research and education center dedicated to transforming the lives of children with autism worldwide since 1975.

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Affirming Therapy from page 25

the possibility of the emergence of such triggers would also help.

- **Knowledge of the client's neurotype is essential.** Without an understanding of autism, ADHD, learning disabilities and other [neurotypes](#) that fall under the neurodiversity umbrella, those clients who exhibit them will be underserved or possibly harmed. Therapists need to be learning about these neurotypes from those of us who live and breathe them every day. A Google search on “neurodivergent writers” will reveal plenty of reading material worth checking out.

- **Avoid referring to autism and other neurodivergent neurotypes as “disorders.”** Many neurodivergent individuals view themselves as simply being different, rather than disordered. “Disorder” implies that we are abnormal, that we are broken and need to be fixed, that we are puzzles to be solved and that the only legitimate way forward for us is to become more neurotypical. What we need instead is acceptance and, ideally, to feel a sense of belonging.

The use of identity-first language is helpful in this case. Take, for example, “autistic person” and “person with autism.” Both may appear to mean the same thing, though [they are not one and the same](#). The latter is indicative of person-first language, which to many would imply that autism is a disorder or a con-



Sam Farmer

dition that should be treated or cured. Not so with the former, which is indicative of identity-first language.

- **Absolutely no aversive interventions or punishment of any kind.** These are highly likely to cause emotional distress or trauma and send a message to the client that they are not accepted for who they are. Therapy must focus on helping neurodivergent clients overcome challenges and develop skills *on the client's terms*, not on resorting to punitive measures when the client says or does something to which the therapist objects.
- **Ask the client to share their lived ex-**

periences. A neurodiversity-affirming therapeutic process must incorporate the neurodivergent client's lived experiences. Otherwise, therapy inevitably proceeds blind, sharply increasing the likelihood of adverse outcomes.

- **Input from somebody other than the client is worth considering only if the individual is a true ally.** For example, when a parent or someone close needs to speak on behalf of the client, as may be the case with younger neurodivergent individuals. A true ally will speak to the client's actual lived experiences, not over such experiences, ideally as if to be “walking in the client's shoes.”
- **Hold realistic expectations.** If a therapist's expectations are too inflated, the client is destined to fail, in which case self-esteem may be compromised. Expectations should be based on an assessment of the client's strengths, challenges, and sensitivities. Patience is paramount in that progress is often made in small, incremental steps. Expectations also need to be flexible in that sometimes, the client may need to take a step or two back before moving forward toward a goal.
- **Provide an environment in which it is safe for neurodivergent clients to unmask and bring forth their true, genuine selves.** Many neurodivergent individuals have unfortunately been programmed to mask, often because of a desire to fit in or in response to trau-

ma. As such, unmasking may take time, or it simply may not be possible. It is up to the therapist to create a safe environment in which clients are free to unmask without consequence, if they so choose. For example, the client should be allowed, if not encouraged, to [stim](#) in whatever way they need to in order to self-regulate, and to exhibit any quirky, idiosyncratic behaviors.

- **Lead with humanity.** Doing so entails showing compassion toward clients in a way that prioritizes the clients' wants and needs. Show that you care and that you are there to help and facilitate rather than fix or cure. Exercise kindness and empathy.

Reform is needed now because one more instance of emotional distress or trauma resulting from therapy that disregards neurodivergence is one too many. This vision for neurodiversity-affirming therapy, or one that resembles it, would ideally help to rewrite the prevailing narrative.

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

Positive Psychology from page 12

strengths, not their challenges. When we identify their strengths, it increases their positive self-regard, their self-esteem, and their engagement with the program.” According to Angela Lee Duckworth, Tracy A. Steen, and Martin E.P. Seligman, “Positive psychology is the scientific study of positive experiences and positive individual traits, and the institutions that facilitate their development. Troubled persons want more satisfaction, contentment, and joy, not just less sadness and worry. They want to build their strengths, not just correct their weaknesses. And, they want lives imbued with meaning and purpose... Furthermore, the fostering of positive emotion and the building of character may help - both directly and indirectly - to alleviate suffering and to undo its root causes.”² The staff and counselors weave in the principles of positive psychology through exercises, practices, and engagement to increase positive self-regard, self-esteem, nurture one's strengths, and deepen one's gratitude, meaning and purpose. As described in [The Community of Practice for Supporting Families of Persons with Intellectual and Developmental Disabilities](#), “Within positive psychology, disability is seen from a lens of hope and opportunity rather than as pathology (Wehmyer, 2013).”³ Through practices, interactions and exercises, the shift towards strength and positivity promotes self-esteem, growth, and engagement.

From the outset, START/CSIDD and the Resource Center teams follow a strengths-based philosophy steeped in positive psychology and PERMA (Positive Experiences; Engagement; Relationship; Meaning;

and Achievement). These practices are inherent in all interactions and treatment provided. Additional assessments include a happiness assessment, a [University of Massachusetts Recent Stressors Questionnaire](#), and a medication evaluation. A treatment plan is created to build on their strengths, happiness, resilience; and modeling these qualities for family members and caregivers is essential to provide as much stability and support as possible. At the Resource Center, a safe, positive, and low stimulation environment is maintained. Participants are provided with opportunities to identify and build on their strengths through solution-focused skill building as well as therapeutic supports and positive experiences. Therapeutic group activities promote positive, strengths-based approaches and skills. Exercises to foster gratitude are conducted to build a shift in perspective and a grounding in noticing what is good, beneficial, and helps give meaning to their life. Identified strengths are posted on the walls of the participant's room and their names are written on their bedroom door which helps build their rapport with staff and increase their self-esteem and engagement.

As Martin E.P. Seligman, Ph.D., writes in his book [Authentic Happiness: Using the New Positive Psychology to Realize Your Potential for Lasting Fulfillment](#), “Experiences that induce positive emotion cause negative emotion to dissipate rapidly. The strengths and virtues... function to buffer against misfortune and against the psychological disorders, and they may be the key to building resilience. The best therapists do not merely heal damage; they help people identify and build their strengths and their virtues.”⁴

Therapeutic practices utilized at the Re-

source Center include:

- Identifying a “Word of the Day” to emphasize a strength and call attention to it when someone embodies its qualities throughout that day;
- A Positive Affirmation Board in participant's bedroom to describe three strengths from their plan;
- A Strengths Spotting envelope is created on their first day with strengths added daily as they exhibit them; and
- A Positivity Tree in a communal area to identify strengths.

At the end of their stay, each participant receives a certificate which identifies their top three strengths. These practices help the participant and their caregivers “...focus on using wellness practices to improve the mental health stability... help increase social engagement with others, identify new or enhance existing interests and wellness activities to be used across settings to decrease stress and increase happiness.”⁵ The intent of these therapeutic practices is to help the participant develop and deepen strengths that they can tap into when they leave the Center and return home.

Family members and caregivers who receive support from S:US' START/CSIDD program have shared similar coping techniques and positive support. Some common themes that came up among family members interviewed are the need for social support, whether it comes from staff or people in their social circle and the empathy that comes with it; regular exercise; time outside in nature whether it be in their

garden, taking walks or hikes in nearby parks; and time with their loved one with a disability especially when they are engaged in an activity which increases their sense of agency and brings a sense of harmony and ease into their family. An overwhelming majority expressed gratitude for the visits that their loved ones have had at the Resource Center and the support they receive from their Clinical Coordinator during their home visits. Debbie, who has a son with a disability and lives with her, is enrolled in START/CSIDD and has also stayed at the Resource Center. She appreciates the kindness inherent in the treatment and the consistent routine that he experiences during his overnights stays. She expressed, “I appreciate the suggestions and strategies that my Clinical Coordinator has shared with me to help foster ease with my son. Staff have been amazing with him, they are so kind, compassionate, and respectful. COVID-19 was really stressful because without the routine of an in-person program, my son developed a lot of challenging behaviors. I needed support and assistance because it was really difficult. The Resource Center and staff are so comforting, warm, and loving; my son wishes he could go every weekend. He packs his bag and leaves it by the door hoping he can go. I'm so grateful and thankful that we found this program!”

Another mother, Heidi, has a 21-year-old son with a disability who lives with her and his two siblings. Her son is enrolled in the START/CSIDD program to obtain support and build on his strengths. He has had both planned and unplanned stays at the Resource Center. Heidi shared, “My

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Smart Technology from page 25

Reminders can be quickly programmed into smart devices and even repeated. For example, you can say “Alexa set a daily reminder at 7 am to take medicine.” While utilizing smart technology, there is the potential to increase an individual’s independence. You remove the need for another person (whether a family member, caregiver, nurse’s aid, etc.) to need to be physically around to remind the person to take their meds. Instead, the individual can take their medication without additional support. Does the individual take PM medication as well? No problem, “Alexa set a daily reminder at 5 pm to take medicine.” Not a daily medication? “Alexa set a reminder every Wednesday at 2 pm to take medicine.” Setting reoccurring reminders is a practical and efficient way to support independence.

Reminders for upcoming events and important dates can also be helpful. For example, after a telehealth appointment, an individual can say: “Remind me on October 4th to go to the doctor’s office.” Furthermore, a caregiver may even set a reminder to go off at 2 pm saying, “Sarah is picking me up at 4 pm for doctor’s appointment.” Using smart technology for reminders can be extremely beneficial to all individuals, especially those with memory deficits. Pradhan et al. (2020) conducted a study that found individuals were reluctant to use reminders as they were concerned

**Amanda Pfohl, MA, SYC**

they would forget to set them. However, it was also noted that there was positive feedback regarding others (families, caregivers, and doctors) setting reminders to support memory.

What’s the First Step?

Taking the first step to integrate smart technology into the daily routine can be overwhelming, however, breaking the process down can be crucial to success. First,

**Lauren Tucker, EdD**

find a device that is affordable and compatible with current technology and install it. Accessing mainstream training materials and tech support can help familiarize everyone with the functions. Next, when beginning to integrate the tool within an individual’s day, start with low-risk, highly reinforcing commands. Incorporating this practice ensures future uses of the smart device won’t result in immediate frustration and resistance. So, let’s start with, “Alexa, improve independence with com-

munication and routines today!”

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years. They may experience feelings of anguish and disappointment when they witness their child being rejected by peers in their teenage years. Finally, families can experience **burnout** when they are later faced with increased demands of caring for autistic adults.

The desire to reconcile differing views on how to parent and treat a child can further strain the relationship between parents. In addition, an autistic child’s siblings may experience feelings of **jealousy, embarrassment** followed by the stress of **caretaking** responsibilities as adults.

Differences often ensue between extended family members and parents over both the causes and the remedies for the challenges of autistic children. All these factors can strain the family environment and may lead to more behavioral outbursts in children with autism, limiting their developmental progress.

Family Therapies for ASD

Family plays a vital role in the effective treatment of children and youth with ASD. While **family therapy** does not cure ASD, it can offer a comprehensive approach to address the unique needs of individuals with autism while strengthening adaptive family dynamics. It can help break the negative cycle of interaction to create a unified approach to parenting.

Mental health professionals and families can work together to find the right intervention that suits the needs of families to foster growth and harmony in relationships. A variety of approaches require substantial involvement of families in the treatment process.

Applied Behavior Analysis (ABA) is an effective modality that works to teach new skills, including improving

social and communication skills. It also works to eliminate challenging behaviors while focusing on increasing desired behaviors through prompting and reinforcement. A **family-focused ABA approach** promotes parental involvement and empowers parents.

The **Developmental, Individual Differences, Relationship-Based model** also called “floor time” encourages parents and therapists to follow the interests of the individual to expand opportunities for communication.

One study in the UK showed positive outcomes for **Systemic Autism-related Family Enabling (SAFE)** which is a systemic family **therapy** approach designed to address autism-related needs. Treatment includes problem-solving to address poor socio-communication, mental health difficulties, and challenging behavior.

How Can Mental Health Professionals Help?

Things that mental health professionals can do to support families caring for children with autism include:

Share knowledge and tools to better understand autism, its impact on life, and adjusting to a diagnosis of autism - which can be **traumatic** for some families.

Explore the boundaries, roles, and hierarchies within a family to create a more supportive and structured environment that fosters **collaboration** among family members caring for a child with autism.

Enhance communication and feedback among family members to mitigate feelings of despair while addressing the behavioral concerns commonly seen in children with autism.

Utilize active listening and find mutually acceptable solutions to support family members’ concerns.

Focus on positive parenting skills such

as positive reinforcement, token systems, structured routines, etc.

Support families in building social networks such as joining parent support groups through **autism speaks** to make connections and share experiences.

Talk to parents about self-care to manage their own stress such as practicing **meditation**, deep breathing, daily exercise routine, making time for family and friends, and acknowledging their accomplishments in the face of child-rearing difficulties.

As Alex and his parents entered the family therapy sessions, the therapist initially addressed contrasting parenting styles by fostering communication between both parents and giving them the opportunity to articulate their parenting perspectives. As a result of enmeshed boundaries, the therapist explored how one parent and a child form a close alliance instead of parents remaining a cohesive unit. Parents were consistently provided psychoeducation about the implications of ASD diagnosis on family functioning and dynamics.

Over time, the family developed the ability to resolve the issues independently, leading to an enhancement in family cohesion and adaptability. Family therapy played a role in redirecting attention from ASD as the central guiding factor in family dynamics facilitating an overarching balanced approach to address the difficulties.

Family therapy can generate positive relationships that can help develop cohesive, orderly, and supportive environments. By restructuring family dynamics, and providing **education**, support, and play-based interventions, it can address the unique challenges faced by families living with autism.

In choosing the right intervention, therapists can collaborate with families to enhance communication, foster understanding, and promote the well-being of their loved ones with autism. Every family living with autism has unique challenges.

Finding the right therapeutic approach can make a significant difference in the journey toward a harmonious and supportive family life.

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to emotionally “refuel” to be better prepared to deal with the inevitable stressors that we would be returning to that are part of the routines of everyday living. From these experiences sprung the commitment to create similar opportunities for parents and caregivers for whom such a “get-away” could not only be helpful but could fulfill an essential unmet critical need. We knew intuitively that offering such a retreat experience that was run primarily by professionals would come up short - the retreat needed to be developed and facilitated through a partnership with parents and parent-professionals who were highly sensitive and trained in meeting the needs of other parents, as well as partnering with autistic adults in facilitating retreat events. We (BP and EM) discussed the idea with a long-time friend, parent-professional, and colleague, Barbara Domingue, MEd, and a partnership was created with [Community Autism Resources](#), a parent-established and run Massachusetts state-funded family support agency. Out of this commitment, the “[Reflecting on the Journey](#)” retreat was born.

Why a Retreat Weekend?

The need for a retreat was supported by our practical experience with parents as well as research on stressors impacting parents of autistic family members and the types of supports that parents perceived as most helpful. Common stressors may be directly related to the autistic person’s condition, such as challenges posed by the autistic family members’ difficulties in social communication and emotional regulation and co-occurring medical conditions, as well as the impact of the autistic individual’s disability on familial relationships, including siblings and extended family members. Others concomitant stressors include a sense of isolation, the need and difficulty in explaining autism to others, embarrassment in public due to reactions and misunderstandings of others, and fatigue due to sleep deprivation. Too often, parents and caregivers may experience feelings of “not doing enough,” uncertainty about the future, and are challenged by disorganized and bureaucratic medical and educational systems.

Helpful supports for parents include a good night of sleep, non-judgmental social and emotional support opportunities to talk with and establish relationships with other parents to share experiences, opportunities to relax, have fun, and not be “on call” all the time. Moreover, the retreat setting provides a safe context where others who share similar experiences naturally understand emotional reactions and the unusual situations that parents often find themselves in. We did not realize at the beginning how much the retreat would provide an “emotional opening” for parents, which ultimately required a high degree of sensitivity and attention to provide caring support for those parents whose emotions surfaced within the safe and compassionate environment, often to the surprise of the parents themselves, especially fathers. And for many parents, the retreat provides an opportunity to meet and learn from autistic adults whom we invite, and who receive an honorarium for participating. In recent years, we have had autistic parents of autistic children join as parent participants.



Barry M. Prizant, PhD, CCC-SLP

The Retreat Design and Format

The retreat was designed to provide a relaxing and supportive environment for parents or caregivers to reflect on, explore, and share the rewards and challenges of raising an autistic child. Initially, we did not have high expectations of the impact of the retreat experience. We thought if we could provide a brief “breather” for parents, that would be enough within a day-and-a-half format. The retreat needed to offer opportunities for rest and relaxation, discussion, social support networking, making new friends, and learning from and participating in fun activities with other parents. However, due to the fact that a great stressor on parents is a feeling of having so little control over events in their lives, we always emphasize in the welcome session that all participants should feel free to do what they felt they needed to do – attend sessions, take a walk or a hike with their partner, sleep in, read a good book - in short, whatever they felt would nurture and serve them best. We do urge parents to attend the opening welcome and orientation session where everyone is introduced and the philosophy and schedule of the retreat are reviewed. We also emphasize the importance of attending the closing circle, when we reflect on the retreat experience and, for some parents, reflect on the past year and prepare for the coming year.

We knew that the setting would be important, and we chose a retreat center in a beautiful, tranquil wooded country setting affiliated with the University of Rhode Island that has remained our home for most of the years. A weekend at a downtown Holiday Inn simply wouldn’t cut it!! We also knew that the format needed to be different from a conference or typical support group meetings run by professionals or family support agencies squeezed into one’s weekly schedule. The experience needed to be one of immersion and the atmosphere needed to be relaxed, casual, and accepting, in stark contrast to the parents’ everyday packed schedules, which often involve the stresses of caring for an autistic child or adult, and too often being judged by strangers in public situations or even by trusted friends and relatives. To support this “immersion” experience, we ask parents to commit to an overnight stay and attend from the opening welcome on Saturday morning through the closing circle and Sunday lunch in order to create an experience that had a natural flow and sequence from beginning to end and a full commitment to the experience.



Elaine C. Meyer, PhD, RN

The “Nuts and Bolts” of the Retreat

The retreat draws 50-60 parents each year and the agenda follows a specified format that has evolved over the years, including the full group opening welcome session and closing circle and three discussion/activity periods (Saturday am, Saturday pm, Sunday am), each offering 3-4 concurrent 90-minute sessions of loosely structured, small discussion or activity sessions (each with one or two facilitators). Topics of the discussion/activity sessions have developed into three strands with many topics that we alternate from year to year:

1. Issues related to the specific experiences and challenges of understanding and supporting the development of autistic individuals (e.g., communication and emotional regulation, nutrition and diets, identifying and building strengths and talents, Q&A with autistic adults);
2. Issues related to personal experiences and family coping/adapting (e.g., dealing with agencies and schools, public encounters, family routines, issues affecting siblings and extended family relationships); and
3. Issues and activities related to the importance of self-care and self-nurturance (e.g., yoga, meditation, massage therapy, aromatherapy, scrap-booking and outdoor team-building and trust activities).

Since the first few retreats, one of the clearest trends that has evolved is an ever-increasing involvement of “veteran” parents who have attended previous retreats suggesting topics and facilitating discussion sessions based on their experiences, expertise, and talents. As noted, a great addition to the retreat over the past 10 years has been the participation of autistic adults as guests and as session facilitators.

An essential nurturing aspect of the retreat is food and fun. The retreat includes five nutritious, delicious, and plentiful meals served buffet style at family-style tables of 6-8 persons, and fun activities including free time for recreation (hiking, hay rides, canoeing), social table activities (puzzles, pool, crafts), a wine/cheese/cocktail hour, and Saturday night entertainment, which has ranged from bands and DJ’s to movies to bonfires and games “like an adult summer camp!” as many parents have commented.

Parents who have attended range from



Barbara Domingue, MEd

Initially, funds were provided through Massachusetts state seed grants and for many years since, funds have been raised primarily from proceeds from an annual autism conference as well as private foundation grants. 80% of costs are subsidized for most parents with a sliding fee scale, and parents with significant financial limitations may attend cost-free. Parents have attended from around the US, primarily from the Northeast states, from Canada, and from South America. To be clear, this is a retreat for parents and caregivers. When we survey parents each year about their interest in having arrangements for their autistic family member(s) to attend, approximately 80% consistently indicate “no” as they feel it would be a very different experience that would not serve the same purpose. Some parents who attend regular support meetings locally or virtually have indicated that the retreat weekend is a unique and very different experience from the episodic support meetings scheduled in the flow of everyday routines or community events such as autism fundraising walks or weekend social events for families. In recent years, we have added a training component in which teams of a parent and professional, who have committed to replicate the retreat in their geographic region, attend a full day training provided by the authors on the Friday abutting the retreat weekend. Team members then stay as participants for the full retreat weekend, providing the opportunity to first acquire the skills to plan and carry out a retreat and then have the lived experience of an actual retreat. This has resulted in the retreat being replicated in Canada and in the US.

The Impact

Evaluation questionnaires and reflections voiced in the closing circle over the past 25 years suggest that the retreat has become far more than a weekend “breather” from the inevitable stress and challenges of caring for an autistic family member, often due to factors not specific to the autistic family member’s disability (e.g., disorganized educational and healthcare systems, judgmental attitudes in public, insensitive or poorly trained professionals). Parents report sustained long-lasting effects, and for some parents, remarkable benefits. Parents who have attended more than one retreat indicate that it provides them with an opportunity to regularly reflect on the challenges and successes of the

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can work together to plan and reinforce learning, beginning with assessment and information gathering. The most valuable information about students' characteristics, interests, preferences, and behavioral triggers can be found in the reports of parents. Prior to beginning to build a program for any student, parents should be sought out and enlisted as partners in the process. Intake questionnaires, such as the Ziggurat Underlying Character Checklist (UCC) (Aspy & Grossman, 2007; Myles, et al, 2007), including an Inventory of Individual Skills and Strengths (ISSI), provide invaluable information. The information gathered through the use of questionnaires can be utilized to determine the students' skills so that instruction can be customized to build upon students' strengths.

Teachers also will find that information and insights they learn from discussions with parents is helpful in the process of building self-determination competency. Self-determination is a critical ability for adult independent living, yet it is not routinely found in IEPs or curriculum (Shogren, Raley, Burke, & Wehmeyer, 2019). Parental input will enable teachers to identify areas of strength and weakness on which to focus, and to target self-determination skills that will be used at home and in the community. Home life for the entire family will benefit from students' improved self-determination competence. This is clearly an instructional domain that benefits from parent-teacher collaboration, one in which teachers and parents need each other.

One suggestion for raising the quality of self-determination instruction is for teachers and clinicians to utilize the Self-Determination Inventory System (SDIS) (Shogren, et al. 2019). The SDIS is a useful tool for:

1. Identifying areas of strength and areas in need of instruction,
2. Monitoring students' progress in the development of self-determination skills over time, and
3. Managing and maintaining progress records.



Dianne Zager, PhD

When used as an information gathering tool with parents and students, this instrument yields meaningful information that can serve as a foundation for academic, social, communication, and transition program development.

A key factor to successful engagement of families involves the recognition and appreciation of familial and cultural values. Students with ASD can be found across ethnicities and cultures (West & Chen, 2012). This is especially challenging when students are from cultures that are foreign to the teacher. Teacher preparation courses offer an ideal platform to increase educator's knowledge about varied cultures, diverse ways of thinking, and alternative approaches to foster pluralistic perspectives. Understanding, respecting, and valuing differences will enable educators to see the similarities inherent in parents across cultures and will help educators tailor their instruction to be inclusive and sensitive of the student's culture.

Parents and teachers should come together to identify goals, plan programs, and examine progress. Research has shown that frequent home-school communication positively impacts community living. Schools can open the door for meaningful family participation, and can move beyond traditional family involvement practices, which have proven insufficient (Eisler, Godber, & Christensen, 2002). Teachers



Carly Werner, MEd, MS

might invite parents to form a joint committee of parents and faculty for the purpose of informally sharing information and supporting one another. In this committee, no one should be considered an expert. We're learning together and exploring ideas as a team.

In conclusion, frequent positive school-parent collaboration is an essential component of successful transition programming. In this article, we've explored the areas of information gathering, self-determination, cultural appreciation, and committee engagement, in which schools and families can join forces to prepare students for adulthood. Jointly completing a questionnaire as a means to arrive at common ground in identifying goals was suggested as an initial step in the collaboration process. When educators listen to parents as they discuss their son's or daughter's strengths, preferences and interests, the design of educational plans can be relevant to both school and at home settings. Also, by focusing on building self-determination competence, schools and families can empower young adults to be meaningful participants in their community. Additionally, engaging parents in active reciprocal committees can foster appreciation of each party's roles in relation to student development. By applying these strategies, schools and parents may be able to dramatically improve school outcomes.

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previous year, strengthen their marriages and family relationships, and establish new relationships with other parents that often continue after the retreat. Additional reported benefits include deepening their understanding of the autistic experience, acquiring information about helpful resources to address everyday challenges, developing new self-help and coping strategies, and returning home with a renewed sense of energy and purpose. Parents who attend for the first time, especially those not yet connected to communities of support, report the remarkable sense of "I have found my tribe!" Feedback from parents include the following themes:

- Some parents note the retreat is the first time they were away overnight, including periods of up to 10 years since their child's diagnosis. They learned they

can be away overnight and everyone "will be OK." In some cases, parents are seeking respite support from relatives or agencies for the first time.

- Many parents note that the retreat marks "our New Year" with an opportunity to move forward with new energy and new ideas.
- Parents who have experienced significant marital issues have noted that the retreat "has saved our marriage" as they are able to see that other families have similar stressors and challenges. Thus, they feel less isolated, are more motivated to seek support, and better understand how the experience of autism can affect marriages and family life.
- Returning parents report they "count the days" until the next retreat so that they can see old friends and refuel for the coming year.

- Parents who have never shared time with autistic adults report that their experience at the retreat provided a wonderful learning opportunity and great insight in understanding their family member's experience.

- Almost all parents come away with new ideas and strategies, openly express their love for their autistic family member(s), and have the chance to reflect not only on the challenges, but how having an autistic family member has also had a positive impact on their personal growth and the life of the family.

When we discuss the retreat with professionals and parents around the country, we have learned that "Reflecting on the Journey" is a truly a unique and cost-effective model of support that has a broad-ranging impact on parents during and beyond the weekend. It truly is impossible to capture

the emotional depth of the retreat experience in words, for both the retreat participants and the authors of this article, but we hope that this brief description of the retreat motivates parents and professionals to attend our training and retreat, and to create and seek out innovative family support activities.

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Listen to a podcast interview about the retreat by visiting uniquelyhuman.com/2021/12/17/retreat-weekend-for-parents-of-autistic-family-members. For more information about the annual parent retreat, please visit <http://community-autism-resources.com/annual-parent-retreat/>.

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heyday, the League School's openness seemed vague, uncommitted, even "intellectually sloppy." But as they have shifted more towards Social Communication Emotional Regulation Transactional Supports (SCERTS), ABA's figurative monopoly on overall autism treatment has, coincidentally, been steadily decreasing as the practice continues to undergo a very painful reckoning. Not only has ABA been linked to intensive trauma (especially through the practice's "Discrete Trials" component), but newer educational techniques have emerged that are rooted in more humane implementation. SCERTS is one such newcomer. And while the job is by no means finished, the League School has been painfully changing itself in incremental steps. Lindsay Thelin Wagner was once an Occupational Therapist (OT) at the school, and is now their Director of Neurodiversity and Community Inclusion. They have brought in autistics to teach autistics. And they now liken themselves to a full-on SCERTS school, one of few in the country.

But the League School's transition, in addition to being painful, has also not been so simple. For starters, they do not fully discard ABA, citing SCERTS's multi-disciplinary design (of which certain aspects of ABA can theoretically be a component). And the humanism that defines the principles of SCERTS is by no means a new concept with which the school is unfamiliar.

Carla Dyer has been teaching at the League School since 2000.

"I really didn't do much ABA. But other rooms did Discrete Trials, the same task over and over...The SCERTS model was sort of what I've sort of been doing all along."

Many teachers, not just Dyer, emphasized that because of the focus on emotional health, SCERTS techniques have been historically implemented even when teachers didn't have a name for them. Dyer, referring to her manner of refuting ABA's compliance-based ideas, cited one example...

"I had a student recently who just wanted to shut down. I try to teach them, 'You can just tell me that you need a break, or hold up a card that means you need a break.' I'm trying to give them a voice that says 'I'm not ready to learn right now.'"

Lana Falvey, a speech and language pathologist (SLP), and Tracey Mello, an OT, have been teaching together (minus a good-sized maternity leave for Falvey) since 2011. They too remember how diverse the school was in its use of behavioral strategies.

"There was a lot more butting of heads around here, like ten years ago when our behavior department was disagreeing pretty consistently with speech and OT." Falvey remembers.

Mello concurs: *"There's been a big effect from the SCERTS model."*

Surprisingly, the behavioral practices employed by autism schools are often not centralized. The overarching philosophies can differ classroom by classroom, and this is where cultural divisions can originate and grow in such schools. Unfortunately, Behaviorists (usually rooted in ABA) arguing with speech and OT professionals are a common staple of life inside most autism schools.

In response, one would think that the solution lies in managing the expectations of new staff during the onboarding process. If so, then what challenges exist for the training directors charged with this process?



Larry Sauer, CEO, The League School of Greater Boston

Deborah Torres is the school's Manager of Training and Quality Assurance, and Leslie Haney is the Teacher Trainer and Mentor. They cited that since it is so easy to get 40 hours per week of ABA covered by insurance (try getting even 5 hours per week of SCERTS, or other developmental-based alternatives), that the job market has exploded over the last decade with opportunities for new ABA technicians.

But somewhat ethically-challenged recruiters on LinkedIn almost never share knowledge of the practice's rapidly-growing infamy. And this results in a future moment of sadness mixed with disappointment for the well-meaning young people who enter the field, as these are almost always earnest folks who did not enlist because they "wanted to hurt autistic children."

Haney: *"I think it's hard to find teachers that have special education and behavioral backgrounds who have zero ABA experience but still have experience with our (autistic) population."*

Before switching to a training focus, Torres herself had a strong ABA background, but is immensely excited by the changes she sees. She talked about the joys of seeing an ABA-experienced new hire somewhat converted by the SCERTS training that is now a mandatory part of their onboarding procedures.

"For the new hires? (Our onboarding curriculum is) something that we've changed significantly." Torres smiled. "And that SCERTS training?...they love. Seeing the passion..."

To be fair, the truly torturous aspects of ABA are rarely seen anymore. Certainly no one slaps children as its founder, Ivar Lovaas, was known to do (Lovaas, by the way, is also the author of "Gay Conversion Therapy"). The painful eradication of self-regulatory stimming is becoming less frequent, eye contact is less mandated - frankly, knowledge about what all self-regulating behavior does to a person (i.e., it helps them) is being increasingly respected.

But discrete trials still exist. In a discrete trial, for instance, a clinician might spend that 40 hours with a (we'll assume) non-speaking autistic who flaps their hands as a self-regulating behavior they use to feel good in a confusing world. Well, now imagine the clinician grabbing those hands and shoving them into your lap for 40 hours a week, over years maybe? And you have no idea why they're doing this to you...

In principle, ABA has historically been about making a person with autism look and behave less autistic. ABA's implemen-

tation has been centered in compliance, not concerning itself with the "why" a student might act differently than a neurotypical. Behaviorists in general have historically avoided even asking the "why." And ABA's greatest allies have historically been parents, who did not know of the long-term damage that ABA might be causing. ABA changed the "offending behavior" faster than others, and you couldn't beat the cost.

But more and more parents are becoming educated about the psychological, emotional, and traumatic costs. And instead, they are increasingly requesting strategies that preserve their children's sense of self. More and more are enrolling their children in the League School for the very reason, and not despite the fact, that the League School is using ABA less.

Again, though; it's complicated.

Michaela Fanelli is one of three Assistant Directors of Education under Fuller. She's also a BCBA (Board Certified Behavioral Analyst - the certification of the professional authorized to implement ABA). But before that she was a regular classroom teacher.

"I had this one student who, to this day, has my heart. He identifies as neurodivergent. He was very gifted academically, but he had a lot of challenges with the social piece, and that brought on a lot of challenging behavior."

She didn't even know what a BCBA was but wanted to help. *"And so this woman (at the school) just gave me this data sheet and said, 'Good luck.' She didn't really give me anything. I didn't know what I was doing. But all I knew was that I needed to help this child."*

She Googled what a BCBA was, read up on ABA, consulted others, and read about behavior plans *"that basically said, 'Give the kid a sticker, and send them on their way.'"*

"It doesn't do anything. The sticker was meaningless. But I still created this plan for this one particular child. He loved it, and just had so many more successes each day...He's in public school today, and he's doing great." Fanelli then got her BCBA certification.

Fanelli acknowledges that in her case, the student clearly wanted the work that she was doing with him. He wanted a social life, and Fanelli was his only hope at that school. Fanelli stresses she wouldn't work with anyone otherwise. Though not all BC-BAs share her priorities, she stresses that

these days, most do. Fanelli, like so many, was unaware of the controversies when she entered the field, and now acknowledges the mistakes of the past. But when she examined her situation, she remains convinced that those harmful techniques/priorities had nothing to do with what she was personally doing with kids. She wants the practice renamed, "Progressive ABA."

"When I was first in (BCBA) school, they gave us strategies for getting the student to make eye contact...And I promise you, I have never taught an individual to do eye contact...if a student is engaging in self-stimulatory behaviors. I mean, who the hell cares?"

Cheryl White is the League School's COO. *"I don't know if we're moving away from ABA. Because I think it's a piece. I think it's more about refining what we do. It's not about 'We don't do this, we do this.' I've liked the idea of an adjustable toolbox for years, and not everybody's is the same...I think our advantage is going to be having everything available to us."*

Dr. Barry Prizant is the author of the iconic book, *"Uniquely Human: A Different Way of Seeing Autism,"* and is also one of the SCERTS authors. He could relate to how tough a transition this might be for a school like the League School. He acknowledges that traditional ABA (that practices discrete trials) has done incredible harm - he's no fan of ABA - but he acknowledges that strategically you can't just "speak to truth" if you're attempting such a seismic shift.

"What doesn't work," he prefaced, "is going in and saying to people who are emotionally and fiscally invested in ABA... 'Oh, by the way you've been torturing kids all along. ABA's nothing but torture.' So then how can we say 'we need to move forward and away from ABA' without people feeling, number one, threatened. Number two, that they've made big mistakes, and most critically number three, that they hurt kids and families."

Still, Prizant is suspicious of whether this new generation of ABA practitioners is onto something or is merely trying to find a way to lose - or exit the argument - with dignity. Referring to professionals who associate themselves with a "newer, gentler ABA," he explained.

"(They say) 'Oh, we follow the kids' lead.' 'We monitor the kid's regulation.' 'We don't do things that cause great anxiety.' Then? I think there is then the possibility to say, 'Here are some things that you are doing that SCERTS has been doing for a long time. A lot of what they call the new ABA is their attempt, through a behaviorist lens, to be more child and person-centered. But, either you're doing it on a lip-service level, in other words you don't really get it, or we could show you how to do it a lot better, and it's called SCERTS.'"

And in how to make these changes less hard, or less loaded with insinuation for such folks, Prizant concludes, *"I've been wondering how we can cast ABA as 'it's in the past. It's old school. This is the future. The whole field is moving in this direction.' (It's about) helping people feel as if they're simply on a new destination, with new strategies that are more respectful, and that...we're not turning back."*

Evan Casey, 19, has been a student at the

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Autism School from page 48

League School since 2016. He is a residential student and is soon to graduate.

“When I first came here, I was treated well, (but)...I definitely felt I had all of my behavior being corrected, and that my view on the world was wrong. Over the years as staff changed, perspectives changed. People started to view things differently.”

Casey does not know about ABA or SCERTS but he knows what he feels in the moment. These days he feels he is currently being treated by staff as someone younger than he really is, and “it’s annoying.” But he also confidently reported that attitudes towards his autism are better these days “by a wide margin,” and he credits his progress herein: *“There were some staff - they don’t work here currently - that were quite rude to students, in general, and were not particularly helpful. And overall there aren’t any people like that here (anymore).”*

Likely, but without knowing it, when talking about the teachers that aren’t there anymore, Casey could be referring to some of the authors of those Indeed.com reviews, one of whom referred to SCERTS as “pseudo-science.”

Larry Sauer came to work at the League School in 2018 and became their CEO in 2020. He is a 35+-year veteran of special education with training in clinical psychology.

“When I first came here there was a fair amount of conflict between the BCBA’s that were here, who in general were very strict ABA and saw ABA as the only answer... And the people that were trained in the SCERTS model. And they really were butting heads.”

But Sauer says that he is no “door kicker downer.”

“I’d rather work with people toward a shared goal.”

So Sauer headed forth with not only on a strategic change in philosophy, but also in implementation. This included a new system of communication at the school



Michael John Carley

that revolved around that centralization. Discussion was key. Administrators were asked to meet more often to talk through the changes. He wants it known that none of the “ABA zealot” BCBA’s were fired, and instead left of their own accord. But Sauer also wanted everyone to ideologically “get on the bus,” as he is known for saying.

But as Indeed.com testifies, many left anyway.

Some of what the exiting faculty cited in their comments (as justification for their authoring bad reviews) was the perceived “dangerous” nature of educating nonverbal or significantly-challenged autistic kids without traditional ABA and stronger restraints. But those that stayed feel this argument missed a point.

Chrissy Bunnell, another Assistant Director of Education, disputes the idea that SCERTS is dangerous. All of the changes mean having to work harder, yes, and a move to SCERTS necessitates the need to watch behavior more closely. Under more compliant-based ABA, according to Bunnell, staff had to respond more to moderate to extreme dysregulation, “because they were missing the signs of mild dysregulation.”

There is also the suspicion that the harder work, and not any ideological shift, drove people away. Not only is this reflect-

ed in asking “why” a behavior might exist before simply correcting it, but the harder work is also reflected outside any ABA vs. SCERTS conversations. For instance, instead of taking live-in students through the fast-food drive-through, residential staff now park the vehicle, and accompany the students in the restaurant who will then order for themselves. Herein, staff are acting more as teachers and less as babysitters.

Since Sauer took over, the administrators have been meeting every couple of weeks to talk about the culture change. Not only are behavioral strategies talked about, but pushes for neurodiverse teacher hiring campaigns have been strategized. They discuss language too, crediting one student for the school disuse of the word “maladaptive.” Lastly, another new focus for the school lies in the concept of Trauma-Informed Care, and according to Sauer, this might be an ingredient that contributes to eventual success.

“My opinion is that most, if not nearly all of our students have had some trauma in their life. Whether it’s physical abuse or being bullied in school because they were different...they have all experienced some trauma. And how the staff interact with them, and treat them, can either be retraumatizing, or it can be helpful. And I think developing a positive relationship is beneficial to them. Because maybe they’ve never had a positive relationship?”

And could the Trauma-Informed Care be extended to the rest of us, especially staff at schools like the League School, given how stressful this all is on them?

The background of the League School’s new Clinical Director, Stephanie Steen, lies not in autism, ABA, or SCERTS, but in Trauma-Informed Care. She recently spent fifteen years working with incarcerated men with major mental health concerns.

“I start with, ‘just be a good human,’ says Steen. Quoting what is also a tenet of SCERTS, she elaborated, “Trauma-Informed Care is really about the ‘why.’ ‘Why do we see behaviors?’ ‘Why do we see outbursts?’

‘Why do we see success?’... ‘What do we do to prevent retraumatizing this child’...

It’s not easy work, as the League School also gets sent many referrals from a Massachusetts DCF (Department of Children and Family Services) contract. But as SCERTS and Trauma-Informed Care both teach, every mysterious behavior is a story someone’s trying to tell us. The positive change in students’ mental health has been obvious at the League School. But humanism is hard work, and the students are not the most influential factors in determining culture change whatsoever. Steen understands this.

“I really think our focus is educating (and caring for) staff.”

To succeed, finding the right teachers will be the most important task. Sauer: *“People have to be here for the right reason. They have to like kids...I want a team of people whose hearts are in it as much as their heads.”*

Sauer no doubt means teachers like Dyer, who stated, *“I think good teachers are always looking at ‘how do we get (students) to want to respond to us?’”*

Back at the administrator’s meeting, one that Sauer had to leave early, his staff - good-naturedly - joke as they rise from their chairs, *“Is everybody on the bus now?”*

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. For more information on Michael John, or to subscribe to his free newsletter, you can go to www.michaeljohncarley.com.

Job Coaching from page 27

on the shelf). I remember not expecting it and was not sure whether or not to encourage it. It was something this one student started on their own. It did not click with me until I heard positive feedback from the jobsite staff. I realized that these unexpected tasks could add to job coaching and encourage students to take the initiative with tasks without prompting. Since then, I have always kept on the lookout. I was able to encourage another student to open the store door first thing in the morning because they wanted to do it and the

staff was fine with it. Whenever you are out job coaching, keep an eye out for these random tasks.

Working with Multiple Students

Sometimes, depending on your workplace, you may have to work with multiple students. There was one year where I worked with two students at the same time. Both had differing needs, meaning it was a challenge at first to work on them. Once I got to know them as a result of creating rapport, I was able to include some universal concepts, including doing a five-minute

break in a certain timeframe to let my students have some breathing room. During some work tasks, I was able to schedule the breaks so that each took a turn, so both students would be productive. Basically, I made a balance of working for their needs and I was able to make it a successful year for them. Of course, job coaching may have you work with a group of students with multiple staff members. For that, you should separate the roles to have one-to-one staff be with their students, and remaining staff members help with the moment to ensure workflow.

All in all, job coaching can use quite a

bit of energy, but it can be rewarding because of the interactions with students and creating those moments where they can celebrate their achievements. I learned a lot during my initial job coaching years, and coming back to my roots reminded me of how important a job coach can be. It is entirely up to you to make a direct impact on the populations you work with.

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Skilled Workforce from page 38

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Living and Aging from page 28

case may have been) in many situations. In some ways, this was similar to a person who covers for a partner with a deficiency in literacy or other comparable challenge, except that in my case there was no identified condition. Also, my deficits in basic life skills were mitigated by the fact that she helped with many of these things.

Sadly, she passed away less than a year prior to my autism diagnosis; it is a shame that she never learned just why I wasn't always the easiest person to live with, as she had sometimes observed.

Later Adulthood

After she passed away, I found myself having to take care of all my daily living activities. Although by that time I was capable of doing so, it was nevertheless not easy, as my skills here still left something to be desired. I actually asked some friends to look around my apartment and determine whether I had everything that I needed. Over the years, I had learned to shop for such essentials as food and clothing – the latter has always been especially challenging for me, and the fact that I barely cook was mitigated by severe selective eating issues (again, not uncommon for autistics, although mine are especially bad) which resulted in my having a “children’s menu” diet (i.e., no culinary skills to speak of were needed here). I could do basic housekeeping tasks but took my laundry in to a local establishment (necessitated by being busy working full-time at an intellectually demanding job).

Once again, it is not unusual for people to have difficulties with some aspects of daily living after the loss of a spouse, especially if they have been dependent on them for many years, but this typically happens with senior citizens; I was only 43 years old at the time. Once again, I was fortunate to have attained even this level of competence – many autistics are not able to do so and may need supports and caregiving for much if not all of their lives.

Within a year, however, I was finally diagnosed with Asperger Syndrome (this was in late 2000). Because I was gainfully employed and had (barely) adequate basic living skills, there was never any question about my needing support or caregiving services, nor did I have to ask for any accommodations at work (I never even disclosed this condition to my employer). The diagnosis was of value mainly for finally understanding so much of my life and the nature of the challenges that I had faced. Still, the importance of such cannot be overemphasized.

Where I was able to find some support, however, was within the autism community itself. I started regularly attending Aspie

group meetings (which I have been doing ever since), read every article (print and online) and book that I could find, and attended any talk, workshop, or conference that I could get to. All of this helped me to better understand the condition I had been living with for so many years, the deficits and challenges that it presented, and what I could do to help me mitigate or get around them. As before, I was able to do for myself what many autistics need others to do for them.

Becoming a Senior Citizen

Living past a certain age presents challenges for most adults, especially in a society where they must largely fend for themselves. For autistics, yet again, these can be even more formidable than for a typical person.

In our society, pensions, both public (e.g., Social Security) and employer-based (becoming much less common) are often available to retired individuals who have a specified work history, as are health and medical benefits (e.g., Medicare). The latter are also available to those who have a qualifying disability. In any event, adequate resources are needed if one is to age independently without need for caregiving. Consequently, planning for such must begin at the earliest possible time. Given the realities of the present day, it is essential to ensure that some form of income will be available later in life if one is to avoid, for as long as possible, the need for senior care which, in our society, is often quite dismal. As before, these issues are of concern to just about anyone, but for autistics they are of even more paramount importance. In particular, some form of health benefits must be available, since we as a population are susceptible to a variety of unusual health issues.

In my own case, I was lucky to have had a job that had provided me with a good income as well as retirement benefits (largely through employer savings plans). As such, I could rest assured that my basic needs could be met. Also, I purchased my own health insurance (through a state marketplace) until I qualified for Medicare. What has always been challenging for me, however, is the complexity of navigating our ever more complicated health care system. This can be daunting for anyone, but the byzantine and irrational practices of the health insurance system can be especially perplexing for autistics who generally have a need for predictability and order. Even the search for adequate health care providers, particularly appropriate medical specialists, has become very convoluted indeed. Autistics can use whatever help we can get in these areas.

When considering my living situation (I recently moved to a new apartment), I evaluated prospective neighborhoods in

New York City, where I have always lived, in which all essential needs are available within walking distance. Although I had driven a car for years when working, this would have been more difficult during retirement; I would have needed to park and maintain a vehicle, which in New York City is not easy. Furthermore, if I became unable to drive for any reason (not an unusual problem for seniors), I would become dependent on others for transportation – a situation I wanted to avoid at all costs. Consequently, I looked for a living situation in which all essential shopping, eating, and services were readily available at as short a distance as possible, and accessible either by foot or public transit.

Living as a Senior Citizen

Among my other considerations in finding a new apartment was the avoidance of “senior downsizing.” Like many autistics, I tend to keep a number of unusual collections. Unlike many seniors who can part with numerous items that had been kept mainly because of associated memories (difficult as this may be) or simply reluctance to dispose of good or useful items that were no longer needed, autistics are very attached to anything that pertains to their special interests, and the prospect of eliminating such is simply not acceptable. Consequently, I needed as much space as I could get. This meant finding a larger apartment (than the one I had lived in for 45 years!) in a less-expensive area, where I could keep my collections of old, vintage, and antique electronic, scientific, and mechanical equipment (and even have room for a workshop), along with all my books (mainly nonfiction) and videos (largely documentaries and academic lectures). As a retired senior citizen, these become especially important because they provide activities to keep me occupied. Also, like many autistics, I do not have conventional interests, particularly those typically ascribed to seniors.

As to socialization and finding community, this presents a substantial challenge. Looking at senior centers in my vicinity, I found that, while they certainly provide community and social activities for older adults, most of these are of no interest to me, and I would likely not fit into such an environment. In contrast, many things that are of most interest to me are generally solitary in nature. It is generally difficult for autistics to balance the need for community with their specialized interests and unusual preferences. In the meantime, my involvement with the Aspie and autism spectrum communities has provided me with some degree of such.

An important concern for older adults nowadays is the proliferation of scams

and con artists. While these have existed since time immemorial (perhaps all human history), the ubiquitousness of computers, smartphones, and the internet have created an explosion in an ever-expanding variety of these. Senior citizens are especially vulnerable to such, and thereby most often targeted, because they are more likely to live alone (hence lonely and even desperate) and less familiar with many scams that did not even exist until recently. This situation is even more serious for autistics, who, because of deficits in social cognition and theory of mind, are less able to recognize when someone is trying to deceive them. The best way to avoid becoming a victim of such is to become as familiar as possible with every form of scam, con game, and other trickery that is currently out there, and to be informed of new ones. I have found that [AARP has a variety of articles and resources](#) which are geared towards senior citizens but highly informative for everyone. Such victimization, horrific as it is for anyone, can be especially catastrophic for autistics who are totally dependent on limited resources for survival.

As an engineer with a broad background in technology, I am in a good position to recognize such scams, but even then I occasionally encounter one that I come frighteningly close to falling for. In my youth, I was very susceptible to individuals who liked to play a variety of tricks on me, and would often do so, not to mention those who would use or otherwise take advantage of me. Ironically, because of these experiences, I subsequently became very wary of anybody who tried to deceive me. All of this has helped me avoid such situations with a considerable degree of success. It is absolutely essential for all autistics, particularly seniors, to become as educated as possible in these matters.

What Can Be Done?

Because, by definition, anyone who was past a certain age by the time autism spectrum diagnoses finally became available will at best have been diagnosed later in life (as was the case with me), it becomes essential to at least try to identify as many of these individuals as possible, so that their needs can be correctly identified and addressed to the greatest extent possible. In the meantime, whatever education, training, and supports are needed by younger and newly identified autistics must be provided as much as possible, so that they can eventually live independently to the greatest extent that they can, and not require caregiving as they become older.

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Personal Journey from page 34

needs. Connect with others in your neighborhood and community, and attend online or in-person support groups, business networking events, and parenting groups. These can provide a safe place to give and receive support, and to celebrate successes.

Being an Autistic Mom and Entrepreneur

Thriving as an autistic mom and entre-

preneur demands discipline, resilience, and consistency. It necessitates pushing and sometimes trampling comfort zones, and embracing the unexpected to share your unique story, inspiring others. While no single voice can reshape perceptions of autism, a collective community effort can advocate for diversity and inclusion.

Changing Perceptions

In sharing my story, I aspire to reshape

how people perceive autism and neurodiversity. I am a successful entrepreneur, manager, and dedicated parent and daughter, and I am autistic.

Balancing isn't a straightforward concept. While dads and men may have more inherent support systems, mothers constantly waver between missing out on their children's lives and business opportunities. Even with a fantastic support network, juggling remains challenging.

Every mom who's wondered if they're

a good mother is a good mom. Release the “mom” guilt and honor yourself as a mother and an individual. You deserve passions, hobbies, community, and self-care.

Michelle Markman is a Neurodivergent Relationship-Based Coach and is CEO of ND Coach, Inc. For more information, visit www.michellemarkman.com, email michelle@michellemarkman.com or call (949)791-7883.

Immigrant Parents from page 35

but we do not know how to seek help.”

Parents are encouraged to be exposed to essential roles they can play for their child, take action, and ensure behavioral supports are in place.⁶ At the same time, I have to be sensitive to the family’s situation and be realistic about the family’s role in their child’s behavioral treatment by building a collaborative relationship and respecting the family’s cultural beliefs and priorities.

Parent Counseling and Training

Parent counseling and training in schools is not only essential to help immigrant families of children with special needs, but it also is considered the most effective intervention for these students.⁷ Discussion and empirical evidence related to the importance of family involvement in intervention for children with autism spectrum disorder dates back to the early 1970s.⁸ According to research, parents have potentially more significant impacts on their children’s outcomes.⁹ Parent counseling and training consists of educators helping parents understand their child’s educational needs, providing parents with information about their child’s development, parent support groups, social services, financial assistance resources, and other sources of information and support outside the school system. Immigrant families benefit from parent counseling and training as they will gain a better understanding of their child’s disability, will be better informed to be equal team members, and will be active participants in the implementation of their child’s IEP.¹⁰ One strategy I have found effective in providing parent counseling and training for immigrant families is to match the families with educators or trainers who speak the same language. I was able to offer transition services workshops in their native language to inform and facilitate access to services their child was entitled to receive. For example, the parents were informed in their native language of

**Trudy Ann Pines, EdD**

the benefits of obtaining New York State OPWDD (Office for People with Developmental Disabilities) eligibility, waiver, and care management services. Parents were encouraged and guided to participate in webinars in their native language to learn how to become eligible for services and receive care management support.

Parents expressed satisfaction in receiving such vital information as it would help support their child’s social and behavioral needs. Parents were further assisted by submitting referrals on their behalf to agencies for required evaluations to determine eligibility for services. Knowledge of the law, their child’s rights, parental rights, and the services their child was entitled to was crucial in deciding the best behavioral support for their child. The parents were given the Spanish version of [A Parent’s Guide to Special Education Services for School-Age Children](#), which is a map that lays out information on special education instruction, supports, and services that children with disabilities need to succeed during their school transition years. Information on agencies that provide behavioral services was provided through transition workshops via Zoom in their primary language. Thus,

incorporating technology in transition workshops was a practical solution to overcome the family’s language barrier.

Keeping immigrant families of children with disabilities informed is one way of supporting and empowering them to engage in their children’s educational journey from school to adulthood. However, engaging immigrant parents of children with disabilities continues to require ongoing new and innovative solutions to provide sufficient time to spend with them; offer two-way communication so their children’s specific needs are being met and services are being informed efficiently, and offer high-quality language interpretation and translation in their first language. Such innovative solutions include in-person conversations, written handouts, emails, video-streaming events, and partnerships with local community groups.¹¹ Most importantly, following up with immigrant families increases family engagement in schools, contributing to positive student outcomes. Immigrant parents of children with disabilities have their rights, and it is crucial to help them create opportunities to develop relationships and family leadership in the school community.

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Lived Experience from page 30

Worst of all, the article’s front cover reference does the most damage because of where it appears, in plain sight, circulated worldwide and looked at by who knows how many millions of people: “Bright children who can’t learn - and how to help them.” Not at all true of learning-disabled students, yet this was the messaging Life Magazine presented to its then extensive readership about us.

Words matter, particularly those that appear in the spotlight. They are often taken literally when a periodical as prominent as Life Magazine was in 1972 prints them, regardless of whether or not they are valid. Many will jump to conclusions and generalize when the stage is set for them to do so. The damage is done.

Had I been allowed to choose the front cover wording for the October 6, 1972 issue of Life Magazine, I would have gone with something more civil like “a new, innovative school is helping learning-disabled children,” “learning-disabled children exceeding expectations at a new, innovative school” or the like. “Bright children who can’t learn” is anything but civil. It taps into the “they are broken and need to be fixed” deficit-centric narrative around learning

**Sam Farmer**

disabilities and autism which was prevalent in the 1970’s and which persists to this day.

Civility tends not to sell as well as negativity does, and that is what front cover language is expected to do for a magazine, but at what cost? The stigmatization of disability ended up winning out for all the wrong reasons.

Having been diagnosed as learning-disabled in 1972, Life Magazine essentially

rendered me “a bright child who can’t learn,” though I was able to prove the front cover propaganda wrong. It wasn’t as if I couldn’t learn. It was that I learned *differently*. When the proper supports are in place and special education teachers know what they’re doing, their learning-disabled students learn plenty. I am but one case in point.

At The Center School, we learned how to work around difficulties by leveraging our abilities and we did so in a structured, accommodating learning environment. What I would accomplish after my departure stemmed from my success there. I performed well enough during my middle elementary school years to no longer require special education classes come 5th Grade. Throughout my middle and high school years, I consistently made the honor roll, after which I was accepted to my 1st choice college.

Nonetheless, “An Agony of Learning” and its hurtful portrayal of learning-disabled children did not do us any favors. How we were depicted had to have influenced public opinion at least to some extent, and public opinion affects us on many fronts, among these, our sense of self. Autistic individuals, including those of us identified early on as learning-disabled and later in life as autistic, tend to be very sensitive to how others describe us, and we

tend to take things at face value. I am most grateful that I have been able to develop strong enough self-esteem such that adverse external influences are for the most part kept at bay, though not all neurodivergent individuals are as fortunate.

It goes to show that the mass media should never be allowed to define how we view ourselves. This is for each of us, and nobody else, to decide. Toxic stereotypes and misinformation are regrettable realities which, with enough effort, can be risen above.

As for The Center School, so much can be said for this wondrous institution. Countless vulnerable young people who have attended this school have thrived against all kinds of odds. Defying what Life Magazine had to say about us all those years ago, our accomplishments speak for themselves.

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

Managing Challenges from page 24

- Stools that are unusually dry or hard
- Inconsistent stooling (abnormal size and consistency can be an indicator)
- Diarrhea
- Having at least 3 watery bowel movements per day
- Enuresis / encopresis (urinating / defecating in places other than the toilet)
- Frequent accidents during the day
- Refusal to use the toilet
- Regression
- Stool withholding

Contributing Factors

Factors that may specifically affect feeding-related tasks include but are not limited to:

- Anatomical structures
- Oral motor functioning and development
- Motor functioning
- Genetics
- Medical issues
 - Gastrointestinal functioning
 - Bowel issues
 - Cardiac, pulmonary
 - Sleep / sleep apnea
 - Food allergies
- Environment including schedules, setting, choice, and biological state
- Dietary impact
- Behavioral challenges which may be related to a medical issue or functional skills deficit

Contributing factors to challenges with toileting may include:

- Medical challenges

- Crohn's, Colitis, GERD, food allergies, Celiac Disease
- Motor or communication delays
- Fear of pain / aversion
- Environmental changes
- History
 - Inconsistency across time, settings
- Overarching behavioral concerns
 - Transition difficulty
 - Noncompliance

Feeding and toileting difficulties often have significant overlap with regard to physiological or biological contributing factors to one another (Field, Garland, & Williams, 2003). These issues frequently co-occur and may affect the intake of food, hunger, the ability to pass stool, or contribute to behavioral or gastrointestinal disorders.

What Comes Next?

Careful evaluation of the previously mentioned contributing factors is both necessary and beneficial to assess the impact before intervention. This may involve a medical or specialist screening in the areas of fine or gross motor, oral motor, gastrointestinal specialist, behavioral, or psychological for example. A thorough assessment of prerequisite skills should also be assessed before intervention. If you have started working with your child at home and have plateaued, or experienced a significant regression of skills, a reevaluation of the various skills associated with your goal for your child should be conducted.

Whether you are just starting the intervention process, or you have hit a roadblock, data collection is essential. This information may be used as a guide for where to begin, for evaluating progress with goals, for deciding when to increase the expectations, to take a step back, to change your course of action, or to let you know when additional assistance is required.

When working with a specialist provider, information regarding your child's bowel or bladder habits (e.g., accidents, meal schedule, food/calorie intake, behavioral data) is beneficial in helping guide your appointments, provide concrete and objective information to the provider, and determine the next steps.

Key Points for Intervention

One of the key features of Autism is a preference or insistence on sameness as well as rigidity with routines. This may result in a fearful approach to new things, expectations, or even new foods (Patrick & Nicklas, 2005). Taking small steps, repeating opportunities for practicing the skill, and gradually increasing the expectations based on previous success are a few of the hallmark features of successful intervention in these areas. Intervention and assessment in these areas should begin as soon as possible. Research has shown that smaller issues, such as your child's "pickiness," especially in children with Autism are far less likely to resolve on their own (Williams, Gibbons, & Schreck, 2005; Mascola, Bryson, & Agras, 2010). Data has also shown that children on the autism spectrum often experience delays in solidifying daytime toileting skills (Faulkner et al., 2017), further emphasizing the need for more immediate attention.

Supporting your child in the area of feeding and toileting often involves a significant commitment of time and attention and a high degree of consistency. As a parent or caregiver, it is important to consider if this allocation of focus and resources is feasible for your family. This decision will impact your next steps of intervention and the decision to include other professionals in your intervention plan. Support for the caregiver may also be needed in these cases.

Managing goals and expectations related to your goals for your child should also be carefully considered and frequently re-evaluated. Just as interventions should not be a "one size fits all," neither should our expectations for an individual. What is reasonable, healthy, and appropriate for your child may not be the case for another. Setting attainable goals that focus on the overall health and well-being of your child and the functioning and nature of your family should be prioritized.

Important Considerations

Consideration of the various levels of care and support options related to your child's areas of difficulty is essential. While specialized support is available for in-home intervention and consultation, it is important to consider the need for utilizing outpatient or inpatient providers, such as a dedicated clinic, to provide additional oversight, training, guidance, and caregiver support if the need arises. If you are experiencing a lack of or plateaued progress, significant increases in maladaptive

behavior, and difficulty with intervention implementation and consistency, you may need to consider modifying the approach to supporting your child.

Immediate medical consultation should be obtained if you suspect potential medical complications arising from frequent bladder infections or chronic or severe impaction or constipation. For concerns related specifically to feeding, careful attention should be paid to weight loss or gain to ensure nutritional needs for growth and development are being met.

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Adulthood from page 21

exclusively a chronological phenomenon. As such, there are a myriad of ways that we can support autistic clients in this "adultification" process, unrelated to what their actual living arrangement is at present.

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please visit www.wjcs.com.

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have to understand how we influence other people. That's just the beginning of advocacy. Advocacy has to lead to influence and then impact."

"Everyone is part of our community," Cokley said, adding that disability exists in one-third of U.S. households. "It's about thinking who is the weirdest, most obscure, most eccentric group that we could partner with, that has a piece of this fight and how

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do we bring them in.? "There is the opportunity to work much more broadly, much more boldly and build the kind of coalitions that other communities have had for decades. But we really have to get out of our own way."

To view a recording of the summit, courtesy of The CUNY Graduate Center, [click here](#). Use the passcode: ^b.5t@sE

Goldfarb Symposium from page 14

immigrants, LGBTQ and others whose voices have not been heard."

Panelists urged the audience to think about: who is in the room, who is at the table, who is making a change and who is voicing their life experience.

Disability organizations must forge partnerships to broaden their reach.

"When we talk about what we want to see for people with intellectual and developmental disabilities going forward, we shouldn't be talking about just disability," Marco Damiani, CEO of AHRC NYC, said following the discussion. "We should identify legislators who know very little about disability or women's issues. Our workforce is mostly women of color. We can't just go to people who are supportive. We

Technology from page 33**The Power of Apps:
Interactive Learning and Communication**

Mobile applications have revolutionized the way we communicate, learn, and interact, and they hold immense potential in supporting families with loved ones who have autism. Apps designed with individuals with autism in mind could offer a range of features, from educational games that promote cognitive development to communication tools that facilitate expression.

Language and communication barriers often pose significant challenges for those with autism. Specialized communication apps, often utilizing picture symbols or text-to-speech functionalities, can empower individuals to convey their thoughts, emotions, and needs effectively. These apps could bridge the gap between individuals with limited verbal communication skills and their caregivers, educators, physicians, and peers in really powerful ways.

Beyond communication, apps could as-

**Karen Lindgren, PhD**

sist in skill-building across various kinds of life experiences, including academics, daily routines, and life skills while providing families with one single source for information sharing, care collaboration and communication, all tailored to match an individual's unique strengths, challenges and needs.

**Artificial Intelligence:
Personalized Support and Data Analysis**

Artificial intelligence (AI) is in its infancy but growing up fast with much of its potential still unknown. What we do know is that AI is being used in industries from healthcare to hospitality with new uses being discovered daily. For those with autism, AI-powered systems could be created to adapt and evolve based on an individual's progress and responses, ensuring that interventions remain relevant and effective over time. These systems have the potential to provide continuous and dynamic support, making learning and skill development more efficient and engaging.

Data-driven insights derived from AI analysis can help providers make informed decisions about treatment plans, tracking progress, and making necessary adjustments. By identifying patterns and trends, AI can contribute to a more holistic understanding of an individual's strengths and challenges, enabling caregivers and therapists to create highly-targeted interventions.

**Enriching the Ecosystem:
Everyone Needs to Play a Part**

By uniting clinical expertise with technological innovation, we not only enrich the lives of those on the autism spectrum but also pave the way for a more inclusive and compassionate society. Technology can transform the way families support their loved ones, offering personalized interventions, enhancing communication, and fostering successful outcomes. However, it is the synergy between these technological tools and effective communication between providers and families that truly unlocks the potential of technology to make a meaningful and lasting impact on the lives of individuals with autism. Through this integration, we pave the way for a better and more accessible future. As a clinician, I am inspired by the potential, confident that our collective efforts will change lives.

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Successful Marriage from page 23

- Making assumptions / jumping to conclusions
- Sensory overload
- Shutdowns and meltdowns

Make a mutual, proactive decision about how to address these problems. Renteria suggests one partner might work on learning to listen more attentively while the other works on understanding why this may be difficult for his/her partner.

**Clear, Non-Defensive
Communication**

Make it a priority to *communicate directly and clearly* when it comes to matters that can become conflicts. Remember to use "I" statements.

Sensory Issues

If you're the partner with ASD, learn to recognize and understand your own sensitivities, e.g., to light, sound, touch, smell, taste, and sense, and let your partner know about them. Your NT partner will benefit from understanding how these sensitivities impact your nervous system and how your ability to cope is impaired.

Sensory input can cause either over- or under-stimulation. Examples of sensory sensitivities include:

- Crowds
- Loud noises/excessive talking
- Strong scents/tastes
- Textures
- Eye contact
- Bright lights
- Too much going on simultaneously

**Annie Kent, MA**

- Take a Time-Out

There will be occasions when you or your partner will benefit from taking a break. You might use time-outs when your neurotypical partner perceives direct feedback as criticism, or when the ND partner feels rejected because their partner asks for space.

Be proactive about these eventualities. Discuss when and why you might need some space. During your time-out, review the conflict, reflect on why you had to walk away, and consider what you could do differently the next time a dispute arises.

**What Caper Knows That
Makes Our Marriage Successful**

- **My intentions are always good.**
- **I get tongue-tied** trying to express my thoughts and feelings when put on the spot. However, please don't think you have to speak for me.
- **Learn my communication style** and

help me amplify my voice. Don't shut me down.

- **Emotionally charged words stay with me** for hours, days, weeks - even years - affecting my self-esteem.
- **Don't spring things on me** at the last minute. Let's discuss them first so we can make mutual decisions.
- **If you want me to do something**, ask me directly. Ask me to repeat your message to ensure I heard and understood you. I'll do the same with you.
- **I'm like The Princess with the irritating Pea.** There are foods I refuse to smell or eat because they overwhelm my senses.

- **I have control issues.** Controlling my surroundings is one way I can feel safe and comfortable.

- **I can be hyper-critical** and blunt. That reflects my need for perfection. I feel anxious when things don't look "right" or objects have been moved, making it so hard for me to find them. I may, unintentionally, say something others consider rude or inappropriate, because sharing information is "my thing," and I don't understand neurotypical social conventions.

- **Home is where my heart is.** My home is the place I'm most emotionally connected to. It's my favorite place, and you'll have a hard time getting me to leave it. It's our home *and* my childhood home: a fortress of memories where loved ones will forever reside.

- **I carry lots of baggage** - literally and metaphorically. I surround myself with "stuff" that brings me joy. When I leave home, I need to carry along the things that soothe and/or stimulate my senses: clothes, books, combs, photos, toys, shampoos, creams, and lotions.

To many people it's just stuff. But that *stuff* allows me to function in the NT world, and I'd be miserable without it. So, as my life partner said, "Here's to 39 more."

Annie Kent, MA Psychology, spent two decades working in public sector disability, mental health, and addictions advocacy and education. Diagnosed with three closely related categories of neurodiversity, a lack of awareness and understanding led to Autistic burn-out and retirement from the field. She remains an active advocate, learning and engaging remotely with several Autism and ADHD organizations and forums, including CADDRA. For more information, visit her website www.aspiefemmepress.ca or email Annie at anjolie1031@gmail.com.

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Autism and Marriage from page 31

constant demands of caregiving and to be able to spend quality time together as a couple, or even to have a bit of down time.

Many parents, especially mothers, tend to put their children first, above themselves, their spouses, and everyone and everything. They may be of the mindset that their child needs their constant attention, or that no one else is capable of taking care of their child or taking care of the child the way that they take care of them. This can result in burnout and depression, which can in turn affect the wellbeing of everyone in the household. It may seem counter-intuitive to some people, but the better care we take of ourselves, the better we can then care for our loved ones - not just our spouses, but our children as well.

Some parents may feel guilty about making time for self-care or time away from their kids. Some couples may not have had time or made time to go on a “date” or out-



Mary Ann Hughes, MBA

ings without their kids. I remember a couple I met at a resource fair saying they haven't

been out to dinner since their daughter, now a teenager, was born. This approach is not healthy for anyone, as it may lead to resentment, regret, or a parent finding relationships or outlets that cause detriment to one or both parents' health or the marriage. Having a trusted caregiver watch the kids while a parent goes out for quality time with their spouse or friends can help keep the spark in the marriage and friendships. This can also benefit the child to get used to other care providers and changes in routine, and to have Mom and Dad return refreshed and energized to be the best parent they can be.

It can be scary leaving your autistic child alone with someone for the first time, not knowing if the sitter will be able to handle your child's behaviors or needs, or how the child will react to the new person and to your absence. So start small, having the caregiver spend time with the child while you are still in the home so they can get to know and become comfortable with each other, and so you can also become comfort-

able with the sitter and their ability to care for and address your precious child's needs. And when you are ready to actually go out, you can start with short outings, and work up to longer periods of time. For example, you might start with a trip to the grocery store, work up to go out to a restaurant and a movie, and eventually a romantic weekend get-away! Doesn't that sound nice?!

Make time for yourself, your spouse, and your marriage to increase the chances of success for your marriage and for the well-being of everyone in your household. You are all worth it.

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Girls on Film from page 33

- Tina Belcher (*Bob's Burgers*, 2011-present)
- Dr Temperance “Bones” Brennan (*Bones*, 2005-2017)

The characters' behaviour, and how they are portrayed in general, was analyzed using diagnostic criteria from the DSM-5, as well as concepts from the Female Autism Phenotype (FAP) Theory - a recently developed model that aims to explain why autism manifests differently in women and girls. These include higher levels of masking (Hull et al, 2020); more “socially acceptable” special interests (Grove et al, 2018); and less notable social issues, usually as a result of the previous factors (Hiller et al, 2014). As the analysis continued, trends were identified amongst the sample, such as the presence of the savant stereotype, issues of morality, and romantic and sexual storylines.

From this, four key themes were identified: gendered autistic behaviour; sociability and relationships; empathy; and female autism as eccentricity. Each of which gave valuable insight into the differences between actually autistic and headcanoned autistic characters, as well as how autistic women are portrayed on a broader scale.

Looking at the findings, it would initially be safe to conclude that autistic females are portrayed in a primarily positive light. Each of the characters were shown to be highly empathetic, socially apt and display a variety of interests, careers, and personalities, aligning with FAP Theory. Upon first glance, this suggests that autistic females are not only portrayed positively, but are also accurate to real-life women on the spectrum. However, the characters present somewhat of a double-edged sword when looked at a little deeper.

In short, characters headcanoned to be autistic by fans reflected more of the autistic experience than characters intentionally written to be autistic.

For example, while all of the characters were portrayed to be social, only the headcanoned characters, such as *Bones* and *Amelie*, were shown to have difficulty with making friends and generally connecting with people. Confirmed autistic characters, *Entrapta* and *Isabelle*, discuss having social difficulties, but their troubles are not shown



Emily “Ly” Stewart, BA(Hons), MSc

directly to the audience. While the FAP Theory does address autistic females being better socially, it also acknowledges the trouble they have maintaining and starting friendships (Hiller et al, 2014). By not explicitly displaying these characters' social issues, creators limit the extent to which neurodiverse audiences can identify with them.

Similarly, the headcanoned autistic female characters were shown to openly display more autistic behaviours. Three out of the four confirmed autistic characters did not mention a special interest and, while the majority of the sample were shown to stim, the headcanoned characters displayed a wider variety of explicit self-stimulating behaviour, such as *Tina's* iconic groaning and *Ponyo's* bouncing.

The only exceptions to this were *Renee* and *Julia*, which raises its own unique point of discussion. There is something to be said about how the only characters to display explicit autistic behaviours were created for awareness. This, paired with how they are both shown to have higher care needs, perpetuates the idea that autism in females is mostly invisible and should only receive support if it manifests in an obvious fashion. On the other hand, there was a distinct lack of representation of females with higher care needs across both groups, which also reinforces the idea that autistic women are inherently “higher functioning.”

It was also difficult to determine whether the way female autistic characters were

portrayed reflected how women are expected to behave by wider society. While a majority of the characters being in romantic relationships does subvert stereotypes of those on the spectrum being asexual, it could be argued that this is more to do with the characters being women. Romance is a frequently cited area of difficulty for those with autism (Slocombe, 2022) and, while characters like *Isabelle* and *Amelie* have exes or turbulent romantic pasts, a majority are in relationships by the end of their respective stories - even children like *Ponyo*. Mass media often prioritizes a woman's marital or relationship status over other aspects of life (Signorielli, 1982). Thus, these relationships could be read as an expectation, not a subversion. As such, while media should not imply that those with autism are more likely to be alone, female autistic characters should be allowed to experience difficulty without expectations of their gender overriding their place on the spectrum.

Many conclusions could be drawn from my findings, but I believe the most important is how contemporary media's small selection of autistic female characters is failing to represent real-life women and girls on the spectrum. While crumbs of accurate, authentic representation are there, it ironically comes from characters who aren't technically on the spectrum, who grow to be beloved members of the community. TV and film seem to be afraid of allowing their female characters to outwardly display autistic traits, almost as if they are choosing between depicting them as a woman or someone on the spectrum, as if they are mutually exclusive.

It is near impossible for the representation of a particular group to be perfect. What may be classed as good representation to one person may be completely different to another. However, when the numbers are so small, when it is so hard to find yourself in the media you enjoy, the expectations for the characters that are supposed to be like you become much higher. Perhaps those in the media industry should start taking more notice of who their audiences are diagnosing.

Ly Stewart is a British BA(Hons) Broadcast Journalism and MSc Media Psychology graduate with 25+ bylines to their name. Ly's mix of creative and analytical backgrounds have given them a passion

for research, especially in regard to autism, media, and internet culture. Ly can be reached at emilyroosestewart7@gmail.com.

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Just Diagnosed from page 32

need of support with a tendency to progress across and within developmental domains at different rates. Each child will present with their own distinctive profile. As a result, the course of treatment you choose for your child should be uniquely tailored and individualized. The goal of early intervention for children on the autism spectrum should be to increase skills in those developmental areas most significantly impacted such as communication and socialization while lessening the impact of challenging behaviors (Will et al., 2018). As your child's best advocate, you should determine what this multi-modal approach will look like for your family. From the intervention setting to the educational/therapeutic modality to the individual providers, the goals, and priorities you have defined for your child should be reflected throughout.

Create a Network of Support

While taking care of your child, it is also important that you take care of yourself.

Research has shown that, when compared to those of neurotypical children, parents of children with autism spectrum disorder experience higher levels of parenting stress (Duarte et al., 2005; Hoffman et al., 2009). Identifying the resources, people, and activities that work best for you will be vital to relieving this stress (Elder et al., 2017). Seeking informal social support through friends, family, and your community can help to process the impact of the initial diagnosis and how you move through all that will come next. Consider talking about your experience with other families who share a similar parenting journey in the form of a support group or on-line community. These more formal forms of support can offer encouragement, validation, comfort, and a social connection now that your child is newly diagnosed or at any point in time. Your child's providers are there for you as well as your child. Related service providers and clinicians are available to offer you and your family the supports, resources, and coping strategies that will not only help your child to progress, but for you to feel empowered and better able to navigate

this critical period. The parent-professional relationship in early intervention is an important partnership for all involved. Should you need additional support, seek the help of a qualified professional who is familiar with parenting a child with autism.

Working through the stressors and emotions related to this unique journey in support of your own emotional health and growth will allow you and your child to flourish and thrive.

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Transition from page 29

plates are already overflowing but the key to success is planning ahead.

- **Community programming:** On the last day of your child's schooling, there is no guaranteed continuation of community programming. If you want your loved one to continue receiving services once they age out of the education system, make sure to research and enroll (if possible) in these services well before your child turns 21. Note: You can never plan too early; I started researching many years before Annie turned 21.
- **Day programs:** When looking for an appropriate day program for your adult

child, it's important to keep in mind you must prove you have guaranteed funding for their spot in the program. However, obtaining waiver funding can be extremely challenging and require waiting on long wait lists. If requesting a particular day program, your county may be able to provide some waiver funding more immediately to assist funding the program.

- **Waiver funding**, which is provided by the state (and varies state by state), is critical. Waiver funding can help provide future stability and funding for services throughout your loved one's life. The best way to demonstrate a need for waiver funding is to utilize every service offered. Your state, county and administra-

tive entity determines who qualifies for a waiver. By demonstrating your family's commitment and willingness to put in the work to help your child with disabilities, and by trying a variety of services to determine what works, you can increase your child's odds of receiving the waiver they need to support them throughout the remainder of their life.

Navigating the various resources and systems of care can be difficult. But one of the most important things we can do as a community – while we are all on this journey – is to share our knowledge and be there for each other.

If we work together, the road ahead may still be uncertain, but it will be less lonely and overwhelming.

Amy Kelly, MBA, MNM, is the mother to Danny, Annie, and Ryan. Annie is diagnosed with moderate to severe autism, verbal apraxia, intellectual and developmental disabilities, and general anxiety disorder. Amy is the National Director of Family Engagement for Devereux Advanced Behavioral Health, one of the nation's oldest and largest nonprofit providers of behavioral healthcare and serves as a family representative on several special needs boards in the community, locally and nationally. In addition, she participates with other patients and families in efforts supported by the Autism Care Network and serves on an executive committee for the American Academy of Pediatrics to assist children and adolescents with special needs and the importance of quality care.

Parent Advocate from page 34

Establishing a case history, even if you don't have a diagnosis yet, benefits both you and your child in the long run.

- **It's all in the details.** Make sure you provide as much information on your child as possible, and be prepared to advocate for your child's resources and

services. Providing details can help you and your doctor put together the best plan for your child.

- **Ask questions.** You will likely hear phrases and acronyms. Ask questions until you have a clear understanding of the situation.
- **Engage with other parents.** We can all

help each other by sharing our personal journeys. Listen to the stories of what other families have experienced and let them know what you've learned as well.

- **Seek out professional organizations** such as Parent to Parent and INCLUDEnc that support families and connect them to resources for young people with disabilities. Their services

are free and often multilingual.

- **Educate yourself!** Talk to other parents and look online for free tools to help parents navigate resources and advocate for their children to create the best possible outcomes both now and in the future.

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Positive Psychology from page 44

son loves it there! He gets along with everyone, he has peers with whom he can interact. The staff are very comforting and they go to parks, stores, and shop in the community. They help build his skills which he continues to use at home. I don't have that much support in my community. I get support from START/CSIDD and I am grateful."

S:US' START/CSIDD and the Resource Center serve the families and their whole circle of support just as much as the person in crisis seeking services. The foundation of positive psychology and a strengths perspective is intrinsic to how they assess and treat the person in need along with their family members and caregivers. Staff model this foundation in how they interact with the whole circle in helping people identify their strengths and supporting them to stay

strengths-focused, instead of only on their challenges. In the book *Fred and Me: a Willowbrook Survivor's Story*, the professor and sibling of a brother with intellectual/developmental disabilities, Allan B. Goldstein, shares, "Self-esteem can be built even with small tasks." When START/CSIDD and the Resource Center teams treat the person in need, whether it is in their home or at the Center, they build self-esteem one step at a time with inherent value and meaning by witnessing their strengths and helping them to identify, remember, and focus on their strengths on a daily basis. The emphasis on positive psychology helps the participant and their caregivers thrive and flourish, not only when they are receiving support, but also, and just as importantly, when they leave the Center to go out into the world and engage with their community.

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Footnotes

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4. "Authentic Happiness: Using the New Positive Psychology to Realize Your Potential for Lasting Fulfillment" by Martin E.P. Seligman, Ph.D., Atria Paperback, New York, NY, 2002.
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