

Supporting Newly Diagnosed Children and Adults

Parents and Caregivers: What to Do if You Think Your Child is Autistic

By April L. Coleman, PsyD
Licensed Psychologist
Georgia Autism Center

My child has big emotional reactions and seems so sensitive to everything. I am always having to reassure my daughter when we go to new places or meet new people. My son wants to make friends so bad, but he has such a hard time knowing how to play with others. My daughter gets upset every time I take her in public restrooms. My child does not care if others play with him; he can play by himself for hours at a time. I don't know if our child understands what we tell her because she does not talk. These comments and concerns are just some of many that parents and caregivers have shared when we have met for the first time to discuss a possible autism assessment.

Often times, parents and caregivers share with me that their child is displaying "unusual" behaviors and not knowing what the behaviors are stemming from. There are other times when parents and caregivers have expressed being mainly concerned about their child's communication skills and/or social interactions and not know-



ing where to begin to help their child with further developing these skill areas. These concerns and behavior descriptions typically lead to us having a discussion around ASD and how to best proceed to address their concerns.

ASD is a developmental condition that is characterized by differences in social communication and interaction, restrict-

ed interests, and repetitive behaviors. A variety of behaviors can manifest on the autism spectrum, and each autistic child has a unique set of abilities. Thus, autistic children can look very different in their functional abilities, communication skills, interpersonal relationships, and stereotyped behaviors. ASD is prevalent across the world, and the most recent research

shared by the Centers for Disease Control and Prevention (CDC) indicated that as of 2021, ASD was occurring in 1 in 44 children.² Some autistic children show signs of future challenges within the first few months of their life. In others, behaviors may not appear until 24 months or later. Some autistic children seem to develop typically until between 18 and 24 months old, and then they may stop developing new skills and abilities; other children may lose the skills they once had.³ There are various signs of ASD, which include:

- Avoiding eye contact
- Not responding to his or her name by 12 months old
- Trouble initiating or maintaining conversation or conversations focus on a preferred topic of interest
- Not pointing at objects to show interest by 14 months
- Repeating words or phrases over and over
- Having delayed speech and language skill

see What to Do on [page 24](#)

How My Autism Diagnosis Helped Me Accept Myself and Lead a Happier Life

By Claire Jack, PhD
Autistic Therapist
and Training Provider

Throughout my life, I have faced significant challenges. These were most notable as a child, particularly in terms of social and sensory issues. My sensory issues used to be extreme. I couldn't bear to be in a room where any cupboard doors were open, the sight of certain fruits caused me strong anxiety because I would imagine what their skin would feel like, and such sounds as the scraping of plates were enough to send me running. I suffered migraines from the age of five and spent at least one day a week lying in the darkness waiting for the pain and nausea to pass. My social issues were debilitating. I hated being anywhere other than home and, with the exception of a few friends my own age, couldn't stand coming into contact with other people. I was labelled as "shy" because I rarely opened my mouth and had no idea what to say or what the conversation was about. I worried incessantly about anything it was possible to worry about, and needed a very clear idea about what



was happening in my day to help me avoid going into a tailspin.

Some of these issues lessened slightly as I got older. Most of my issues remained, but I became highly skilled at camouflaging the levels of distress I experienced. When I discovered alcohol, it allowed me to present a front which effectively allowed me to hide who I was and what I was going through, to the extent that I "passed" as be-

ing nothing out of the ordinary. I also used alcohol as a coping mechanism, for my severe anxiety and to keep me going when I experienced exhaustion and burnout.

My university years were fueled by anxiety and addiction, and I experienced a complete breakdown in my twenties, after failing to receive the degree mark I'd worked towards for the preceding four years. After that, I muddled through life,

displaying a pattern of short-lived relationships and careers, which usually came to abrupt ends, after my anxiety became too overwhelming, or I fell out with a manager.

By the time I'd trained as a therapist and started a successful practice, I had begun to shape a life which had enough flexibility to meet my mental needs in a healthier way. Ongoing therapy also helped me implement solutions to my issues and to look after myself better. However, instinctively, I felt that there was a missing piece of the puzzle.

After a visit to a new therapist, which was prompted by the fact that I was struggling with managing a change in my circumstances and with daily responsibilities, she suggested that I might be autistic. Initially, I was shocked. I knew nothing about autism and certainly didn't feel that I fitted with what I did know. However, she set me on a path, initially, to finding out as much as I could about autism and finally to receiving a diagnosis, in my late forties, which confirmed that I was autistic.

The first few months following my diagnosis were tumultuous, and it took me a while to come to terms with it. One day I'd feel like I had all the answers I'd been

see Happier Life on [page 25](#)

Mental Health News Education Board of Directors

Chair

Rachel A. Fernbach, Esq., Executive Director and General Counsel
New York State Psychiatric Association

Vice-Chair

Yvette Brissett-André, MPA, Executive Director and CEO
Unique People Services

Secretary

Peter D. Beitchman, DSW, LMSW, Principal
Behavioral Health Consultation

Treasurer

Keri Primack, CFP, Managing Director, SVP, Senior Client Advisor
Quent Capital, LLC

Members of The Board

Anita Appel, LCSW, Senior Health Care Consultant
Sachs Policy Group

Mary Brite, LCSW, CASAC, Chief Compliance Officer
Outreach

Constance Y. Brown-Bellamy, MPA, President and Co-Founder
Advantage Mosaic Group

Jonathan P. Edwards, PhD, LCSW, ACSW, Program Consultant
New York City Department of Health and Mental Hygiene

Ann-Marie K. Foster, MPA, FACHE, President and CEO
Phoenix Houses of New York/Long Island

Debbie Pantin, MSW, MS-HCM, President and CEO
Outreach

Barry B. Perlman, MD, Past President
New York State Psychiatric Association

Jorge R. Petit, MD, President & CEO
Services for the UnderServed

Joshua Rubin, MPP, Principal
Health Management Associates

Jarod Stern, Senior Managing Director
Savills

Kimberly Williams, MSSW, President and CEO
Vibrant Emotional Health

Founding Chairman

Alan B. Siskind, PhD, LCSW

Executive Staff

Ira H. Minot, LMSW, Founder

David Minot, Executive Director and Publisher

Autism Spectrum News Editorial Board

Cindy Alterson, PhD, BCBA, Principal of Devereux NY CARES
Clinical Director, Devereux Advanced Behavioral Health-New York

Joel Bregman, MD, Psychiatrist
United Community & Family Services

Joseph D. Buxbaum, PhD, Director
Seaver Autism Center - Icahn School of Medicine at Mount Sinai

Susan Cortilet-Jones, MS, LMHC, Integrative Wellness Coach for Adults
Discovering Your World, Corp.

Lynda Geller, PhD, Founder, Spectrum Services
A Cooperative of Independent Practices & Organizations, New York, NY

Michael Gilberg, Esq.
Special Education Attorney, NY/CT

Ami Klin, PhD, Director
Marcus Autism Center

Becca Lory Hector, CAS, BCCS
Autism, Neurodiversity, & Inclusion Consultant/Speaker/Author/Advocate

Cecelia M. McCarton, MD, Founder and Executive Director
The McCarton Foundation, The McCarton School (for Autism)

Judith R. Omidvaran
Autism Parent Advocate, New York

Theresa Pirraglia, Co-Founder and Board Member
FECA, The Foundation for Empowering Citizens with Autism

Howard Savin, PhD, Chief Clinical Officer
First Children Services

Pat Schissel, LMSW, New York Director
Asperger/Autism Network (AANE)

Alison Singer, President
Autism Science Foundation

Fred Volkmar, MD, Professor
Yale Child Study Center

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

Dianne Zager, PhD, Head of School Emerita, Shrub Oak International School
Professor Emeritus, C.W. Post, Long Island University

Autism Spectrum News is a Quarterly Online Publication of Mental Health News Education, Inc., a 501(c)(3) Nonprofit Organization

All inquiries regarding advertising, sponsorships, and submitting an article should be directed to:

David Minot, Executive Director and Publisher

(978) 733-4481 • dminot@mhnews.org • 460 Cascade Drive, Effort, PA 18330 • www.AutismSpectrumNews.org

Mental Health News Education, Inc. does not endorse the views, products, or services contained herein. We are not responsible for omissions or errors. Mental Health News Education, Inc. is not responsible for articles submitted to us without the final approval of the organization’s Executive Director, CEO, or Public Relations Department. All articles and advertisements are subject to final approval by our Editorial Board. We reserve the right to edit any article sent to us.

Disclaimer of Endorsement and Liability: The information, opinions and views presented in Autism Spectrum News (ASN) reflect the views of the authors and contributors of the articles and not of ASN, the Editorial Board, or its publisher. Publication of articles, advertisements, or product information does not constitute endorsement or approval by ASN and/or its publisher. ASN and/or its publisher cannot be held responsible for any errors or for any consequences arising from the use of the information contained in this publication. Although every effort is made by the Editorial Board and the publisher to see that no inaccurate or misleading data, opinion or statement appear in this publication, the data and opinions appearing in articles including editorials and advertisements herein are the responsibility of the contributors concerned. The publisher and the Editorial Board accept no liability whatsoever for the consequences of any such inaccurate or misleading data, information, opinion, or statement.

Copyright © 2023 Mental Health News Education, Inc. All rights reserved. Content contained in this publication may be reproduced for one-time personal use. However, anyone wishing to reproduce and distribute any content from within this publication for purposes other than personal use must request this intention in writing directly to the publisher. Failure to do so will be in violation of the copyright held by this publication.

Table of Contents

Supporting Newly Diagnosed Children and Adults

- 1Parents and Caregivers: What to Do if You Think Your Child is Autistic
- * 1How My Diagnosis Helped Me Accept Myself and Lead a Happier Life
- 9The Importance of Telediagnostics in ASD Diagnosis and Treatment
- 10Sharing an Adult Autism Diagnosis with Family, Friends, and Community
- 11Breaking Down Barriers: Diagnosing Autism with NODA Telehealth
- 13Supporting Parents of Children Recently Diagnosed with Autism
- 14An Overview of the Screening and Diagnosis of Autism in Children
- 15Next Steps After an Autism Diagnosis: Acceptance, Advocacy, Treatment
- 17Education Program for Parents of Children with Newly Diagnosed Autism
- 18Challenges in the Diagnosis and Treatment of Older Autistic Women
- 18Rates of Autism Increase, But Numbers Don’t Paint the Full Picture
- 19Screening and Diagnosing Autism Spectrum Disorder in Young Children
- * 20Late-Diagnosis and Camouflaging in People Assigned Female at Birth
- * 20Why Didn’t My Pre-Diagnosis Clinicians Consider an Autism Diagnosis?
- * 21How to Get Unstuck After Receiving an Adult Autism Diagnosis
- * 21I Was Finally Diagnosed with High-Functioning Autism, Now What?
- * 23A Tale of Two Diagnoses: Older Adults and School-Age Children

Supporting Children and Their Families

- 4Person-Centered Early Intervention Program: A Whole Family Approach
- 6Teaching Play to Children with Autism
- * 1711 Compassionate Parenting Tips for Families with Autistic Children
- 19Empowering Caregivers Through an Innovative Peer Navigator Program

The Transition to Adulthood and Adults

- 8The Daniel Jordan Fiddle Foundation for Adult Autism Summit
- 12Listening is Key to Supporting Families and Caregivers

An Interview with Autism Advocates

- * 16An Interview with a First Lady with a Degree in Special Education

Neurodiverse Relationships

- 22Neurodiverse Couples: Making Meaningful Moments of Every Day
- 22Uncovering Neurodiversity in a Relationship

Technology and Healthcare

- 23Virtual Reality is Making Healthcare More Accessible to Autistic Patients
- * Article written by an Autistic Adult

Editorial Calendar

Summer 2023 Issue
Legal Issues and the Law
Deadline: June 1, 2023

Fall 2023 Issue
Supporting Families and Caregivers
Deadline: August 30, 2023

Winter 2024 Issue
Understanding and Accommodating Varying Sensory Profiles
Deadline: December 6, 2023

Spring 2024 Issue
Navigating the Health Care System
Deadline: March 5, 2024

Contact us for information about [advertising](#) and [article submissions](#)

Stay Connected with ASN

Find over 1,200 autism articles and 60 back issues at
www.AutismSpectrumNews.org



Autism Spectrum News Update

AutismSpectrumNews.org

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



Since 2008, Autism Spectrum News has been
your trusted source of science-based autism education,
information, advocacy, and quality resources.

Please Support the Resources Advertised in This Issue!

AHRC New York City	College Living Experience	Melmark
Behavior Therapy Associates	Daniel Jordan Fiddle Foundation	NODA - Remote Autism Diagnosis
Berklee Institute for Accessible Arts Education	Devereux Advanced Behavioral Health	Services for the UnderServed (S:US)
Catalight	First Children Services	Tara C. Fappiano, Esq.
Center for Career Freedom	GoMo Health	Westchester Jewish Community Services (WJCS)

Person-Centered Early Intervention Program: A Whole Family Approach

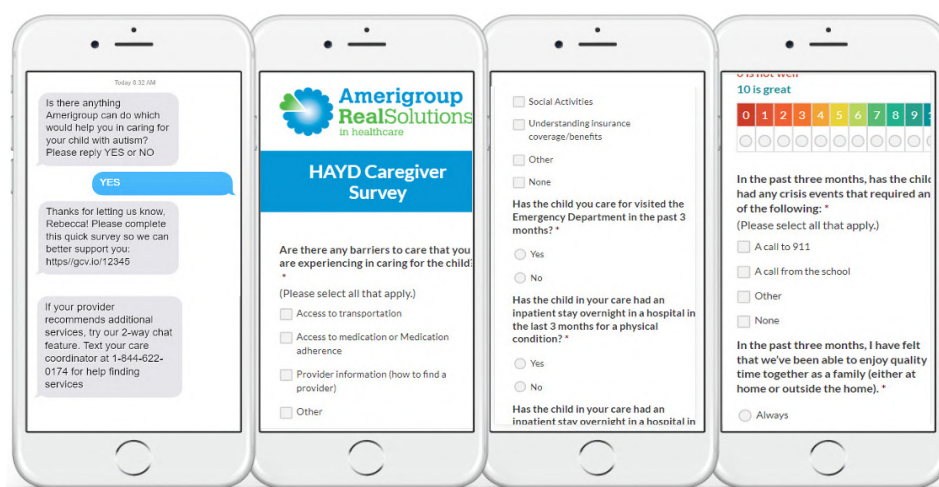
By Danielle Nabinger, MSW,
Amerigroup Georgia,
Rebecca Lyons, MPH,
and Shelley R. Schoenfeld
GoMo Health

The prevalence of autism is at an all-time high. Today, we all seem to know a parent of a child who has been diagnosed with autism spectrum disorder (ASD). According to estimates from the CDC, the rate of autism has more than tripled over the span of two decades: from one in 150 in 2000, to one in 44 children by 2022 (Malik-Soni et al., 2022).

Autism, also known as autism spectrum disorder, is defined by the Centers for Disease Control and Prevention as a “developmental disability that can cause significant social, communication, and behavioral challenges.”

A Statistical Snapshot:

- ASD affects children of any race, socioeconomic status, or ethnic group.
- Boys are four times more likely to be diagnosed than girls.
- Children who have a sibling with autism are more likely to have autism as well, especially twins.
- Autism can be identified as early as infancy, although most children are diagnosed after the age of two. There is no medical test to diagnose autism, so physicians observe a child’s behavior and development to make a diagnosis.



All caregivers are surveyed monthly to assess their support needs. A “Yes” response triggers a link to complete the “How Are You Doing” survey to focus on needs, with appropriate resources being sent in response.

icians observe a child’s behavior and development to make a diagnosis.

The American Academy of Pediatrics (AAP) recommends all children be formally screened for autism spectrum disorder at their 18-month and 24-month-old well-child visits; however, they also recommend that pediatricians begin monitoring babies by observing their behaviors beginning with the child’s first well-child visit.

“It is those observations - in combination with family history, health examinations, and parents’ perspectives - that help pediatric primary health care providers identify children at risk for ASD.”
- American Academy of Pediatrics

Why the Significant Increase in Autism Diagnoses?

There are several reasons for the sharp increase in autism diagnoses. Over the last decade, better diagnostic tools have been developed and the definition of autism has been expanded to include a ‘spectrum’ of criteria and associated behaviors. As a result of these factors and the rise of accessible information on the internet, there is a much greater awareness of autism among the general population as well as health-care professionals. Experts in the field also point to changes in insurance legislation requiring health plans to cover autism services as another major factor increasing the prevalence of autism diagnoses (Thompson, 2023).

Effectively Parenting a Child with Autism: Deep Understanding and Patience

Maintaining routines and structure can be grueling for parents. Ensuring regular respite and care breaks is essential. Self-care in the short term will support both child and parent/caregiver well-being in the long-term (Smith et al., 2022).

Early detection, intervention, and support are key for impacting the core symp-

toms and life course of children with autism and their parents and caregivers. Parents and caregivers are encouraged to discuss concerns and observations with the pediatrician.

Accessing quality health, dental, and behavioral health care for children with autism is a huge challenge in nearly every community. Treatment comes in many different forms, from mental health therapy to occupational, physical, and speech therapies. Sometimes medications can be helpful for other conditions or symptoms related to ASD, like mood problems or the inability to focus.

Finding providers who are knowledgeable about ASD and have made accommodations to support families dealing with autism can be challenging - even more so if seeking providers who accept public and commercial insurance. Oftentimes, when such providers are within network, there are long waiting periods for appointments.

Unique Challenges with Self-Care for Caregivers of Children with Autism

A study published in Clinical Practice and Epidemiology in Mental Health in July 2018 found that parents of children with autism reported a higher level of psychosocial distress and less social support than their counterparts with children with Down syndrome and, the more commonly diagnosed, type 1 diabetes (Picardi et al., 2018). Additional support at the caregiver-level is needed to avoid caregiver burnout and to allow parents and caregivers to continue to fulfill the role to the best of their abilities.

Since 2018, the stressors have only continued to mount for all parents. Living through a global pandemic and all its ramifications has taken a toll on parents. The American Psychological Association (APA) reported in 2021 that 48% of parents experienced an increase in stress levels that year in comparison to their pre-pandemic stress levels.

Beyond the inherent stress and distress of parenting, especially in a post-pandem-

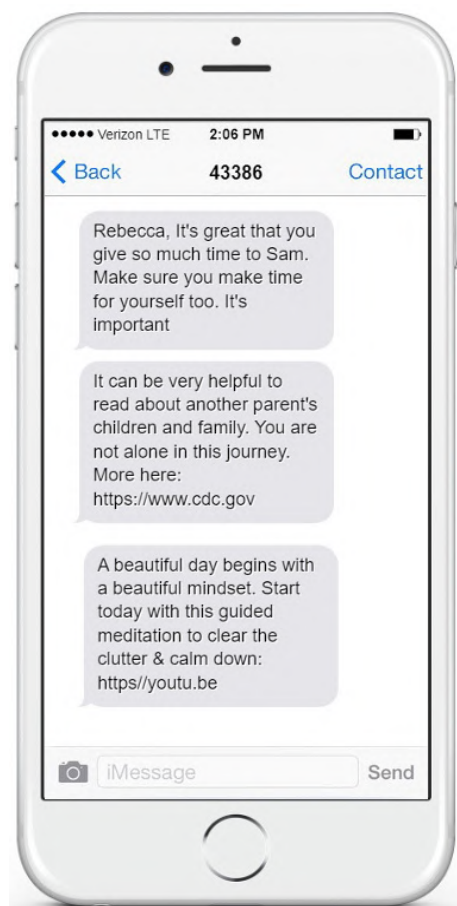
ic world, parents of children with autism are at increased risk to develop depression and anxiety than their counterparts not affected by autism. A 2019 geographically targeted study of 180 mothers of children with autism found that 80.2% met diagnostic criteria for anxiety, as assessed by the General Anxiety Disorder-7 (GAD-7), an industry-standard test for measurement of anxiety, and 72.5% had significant depressive symptoms, as assessed by the Patient Health Questionnaire-9 (PHQ-9), a questionnaire that assesses depression severity (Zhou et al., 2019). This is staggering considering the 6.8% baseline prevalence of depression among all parents in the same geography (Li et al, 2021). Additionally, they found a positive association between both the anxiety and depression scores, and the child’s severity of core autism symptoms. The mothers of children with more-severe symptoms were more depressed and anxious than those with children with less-severe symptoms. Therefore, we concluded that improving the core symptoms in the child is then a sound strategy to improve the mental health of their caretakers.

It is this logic that inspired the development of a two-pronged approach to supporting families touched by ASD. We sought to support the parents through a virtuous cycle in which we help them to manage the core symptoms of their child’s autism while also addressing their mental health - which will then improve their ability to care for their child and themselves.

For more information about the Amerigroup Early Intervention Personal Concierge Program and other digital health management programs, please visit <https://gomohealth.com/campaigns/dei-in-healthcare/> or text DEI to 43386.

The GoMo Health Person-Centered Digital Health Management Solution

We partnered with GoMo Health to create the *Early Intervention Concierge Program*. This mobile engagement program was created to ensure that all Amerigroup members on the autism spectrum receive the appropriate support and resources at the earliest point of intervention. We also made special accommodations to the program to support the unique needs of foster families in our membership to better track children in the foster care system, specifically the care they are under, and be sure these helpful resources are being delivered to those active caregivers. In addition to providing education, resources, navigation, and support to caregivers (including birth parents, foster parents, adoptive parents, and other guardians) to help their child with autism, the program has an entire component



A sampling of messages participants receive once enrolled in the caregiver stress support track

see Program on page 25



Want to Close Gaps in Care?

Evidence-based Autism Spectrum Early Detection and Intervention Concierge Program

An integrated digital health management program proven to:

- + Support parents and caregivers of children with autism by addressing psychosocial and physical health
- + Identify potential developmental delays for children under four years of age
- + Reduce adverse events and cost of care
- + Enable care coordinators to improve productivity and increase joy in practice



Text **DEI** to **43386**
or scan this QR code to
experience the programs.

Message & data rates may apply. Text HELP for info; STOP to cancel.
Your information will not be sold or used for any other purpose.



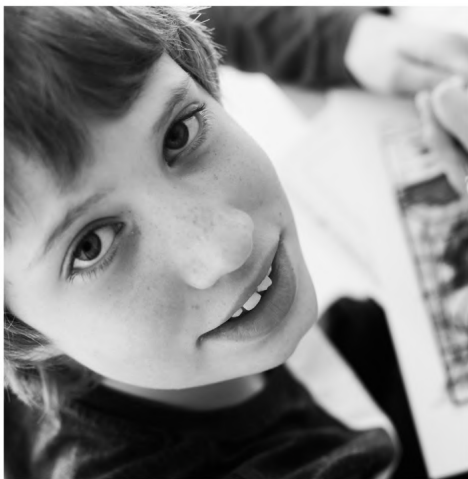
84,900

members enrolled in the
early detection program
(pre-diagnosis)



5,407

program participants
with an autism diagnosis
enrolled in the early
intervention program



17%

of those enrolled have
already indicated a
need for additional help
from care coordinators
via the program



99.6%

program retention rate



GET IN TOUCH

📞 1 (848) 467-4560

🌐 gomohealth.com

✉ info@gomohealth.com

Teaching Play to Children with Autism

By Laura Wilhelm, MS, BCBA, LABA
Director of Early Intervention
Melmark New England

Play has been focused on as a pivotal skill for young children, as it is an important context for both cognitive development and social connection. For these reasons, play is a primary focus of instruction for children with developmental delays and disabilities. Pretend play is a social skill that emerges early in typically developing children and has been shown to be an important contributor to the development of a child's social and language skills (MacDonald et al., 2005, 2009). For typically developing children, play often emerges in a developmental sequence of simple manipulation, discrimination between toy materials, combining or constructing toy materials to make something new, pretend play, and sociodramatic or thematic play (Lifter, 2000). Lifter argues teaching play skills following this developmental sequence will result in more rapid acquisition and increased generalization of play skills.

According to Lifter (2000), pretend play begins to develop around 17 to 19 months and is defined in 4 ways:

1. The child extending familiar actions to a doll or stuffed animal figure, with the child as agent of the activity (e.g., animal walks, drinks, jumps, or any character plus an action such as running, flying, talking),
2. The child relating objects to their self, indicating a pretend quality to the action (e.g., brings empty cup to mouth as if to drink),
3. Play including substitutions with or without objects, paired with a specific play sequence,
4. And/or the child adopting various familiar roles in play theme (e.g., playing house) or arranging the environment to create a scene (e.g., crash cars or trains).

Unlike typically developing children, children with autism often exhibit persistent deficits in social communication and social interaction across multiple contexts. Additionally, children with autism often engage in restricted, repetitive patterns of behavior, interests, or activities. This is a core diagnostic feature of an autism spectrum diagnosis. Play behaviors exhibited by children with autism are often characterized by repetitive behaviors and a lack of pretend or symbolic quality (MacDonald et al., 2005; Lifter, 2000). Further, children with autism often invariably respond in the context of play (Bancroft et al., 2016). A child with autism may develop a strong preference for one toy (Wetherby et al., 2004) and avoid choosing other stimuli associated with a play activity (Lalli et al., 1994). If these repetitive patterns of behavior go untreated, they can persist at a substantially higher rate than that of their same age peers (MacDonald et al., 2007).

Many behavioral teaching procedures have been shown to effectively teach pre-



Laura Wilhelm, MS, BCBA, LABA

tend play skills to children with autism including discrete trial training, pivotal response training, in-vivo modeling, and video modeling. Discrete trial training (DTT) often involves breaking down a skill into smaller steps. Prompting, fading, and reinforcement procedures are often included and are contingent on the child's responding. DTT techniques have been shown to be effective in teaching a variety of play skills, ranging from simple object manipulation (e.g., Eason et al., 1982; Greer et al., 1985; Nuzzolo-Gomez et al., 2002; Santarcangelo et al., 1987) to complex play themes such as socio-dramatic play (e.g., Lifter et al., 1993). Pivotal response training (PRT) is a manualized training procedure geared toward increasing a child's motivation in order to teach important skills. PRT has been shown to be effective in teaching sociodramatic play skills with adults as play partners (Stahmer, 1995; Thorp, Stahmer & Schreibman, 1995). In-vivo modeling often involves in-the-moment modeling of the target response and is often paired with prompting and reinforcement procedures. This method closely replicates how children learn in the natural environment by observing and imitating familiar adults and peers. In-vivo modeling has been shown to be an effective procedure for teaching cooperative play (Goldstein & Cisar, 1992; Jahr et al., 2000). Video modeling often involves a presentation of a video showing models engaged in a target response. The video often serves as the prompt and no reinforcement procedures are necessary. Video modeling has been shown to be effective in teaching pretend play (MacDonald et al., 2005), reciprocal pretend play (MacDonald et al., 2009), and sociodramatic play (Dauphin et al., 2004; MacManus et al., 2015). These procedures are all effective in building play skills and have unique applications and advantages depending on the instructional context.

One area noted as a limitation in the play literature is the lack of generalization observed following training of play skills. In order to establish pretend play repertoires in young children with autism, teaching procedures that promote generalization must be used. The use of matrix training has been shown effective in increasing

generalization across play sets (MacManus et al., 2015) as well as teaching socio-dramatic play skills (Dauphin, Kinney, Stromer, and Koegle, 2004). More research in developing repertoires of pretend play in young children with autism is needed.

Overall, play is a central component of a young child's life. It is an important contributor to the development of a child's social skills and language skills (MacDonald et al., 2005, 2009), making it an essential skill to assess and teach when working with a young child with autism. Many effective procedures exist for teaching such skills. The outcomes of variability within play and generalization across materials and contexts are important to consider.

For more information, please visit Melmark New England's website at www.melmarkne.org, or contact Laura Wilhelm via phone at (978) 654-4300 or via email at lwilhelm@melmarkne.org.

References

- Bancroft, S. L., Thompson, R. H., Peters, L. C., Dozier, C. L., & Harper, A. M. (2016). Behavioral variability in the play of children with autism and their typically developing peers. *Behavioral Interventions*, 31(2), 107-119. <https://doi.org/10.1002/bin.1438>.
- Dauphin, M., Kinney, E. M., Stromer, R., & Koegel, R. L. (2004). Using video-enhanced activity schedules and matrix training to teach sociodramatic play to a participant with autism. *Journal of Positive Behavior Interventions*, 6 (4), 238-250. <https://doi.org/10.1177/10983007040060040501>.
- Eason, L. J., White, M. J., & Newsom, C. (1982). Generalized reduction of self-stimulatory behavior: An effect of teaching appropriate play to autistic children. *Analysis and Intervention in Developmental Disabilities*, 2(2-3), 157-169. [https://doi.org/10.1016/0270-4684\(82\)90016-7](https://doi.org/10.1016/0270-4684(82)90016-7).
- Goldstein, H., & Cisar, C. L. (1992). Promoting interaction during sociodramatic play: Teaching scripts to typical preschoolers and classmates with disabilities. *Journal of applied behavior analysis*, 25(2), 265-280. <https://doi.org/10.1901/jaba.1992.25-265>.
- Greer, R. D., Saxe, C. D., Becker, B. J., & Mirabella, R. F. (1985). Conditioning histories and setting stimuli controlling engagement in stereotypy or toy play. *Analysis and intervention in Developmental Disabilities*, 5(3), 269-284. [https://doi.org/10.1016/0270-4684\(85\)90015-1](https://doi.org/10.1016/0270-4684(85)90015-1).
- Jahr, E., Eldevik, S., & Eikeseth, S. (2000). Teaching children with autism to initiate and sustain cooperative play. *Research in Developmental Disabilities*, 21(2), 151-169. [https://doi.org/10.1016/S0891-4222\(00\)00031-7](https://doi.org/10.1016/S0891-4222(00)00031-7).
- Lalli, J. S., Zanolli, K., & Wohn, T. (1994). Using extinction to promote response variability in play. *Journal of Applied Behavior Analysis*, 27, 735-736. <https://doi.org/10.1901/jaba.1994.27-735>.
- Lifter, K. (2000). Linking assessment to intervention for children with developmental disabilities or at-risk for developmental delay: The Development Play Assessment (DPA) Instrument. In K. GitlinWeiner, A. Sandgrund, & C. Schaefer (Eds.), *Play diagnosis and assessment* (2nd edn, pp. 228-261). New York: Wiley.
- Lifter, K., Sulzer-Azaroff, B., Anderson, S. R., & Cowdery, G. E. (1993). Teaching play activities to preschool children with disabilities: The importance of developmental considerations. *Journal of Early Intervention*, 17(2), 139-159. <https://doi.org/10.1177%2F105381519301700206>.
- MacDonald, R., Clark, M., Garrigan, E., & Vangala, M. (2005). Using video modeling to teach pretend play to children with autism. *Behavioral Interventions*, 20(4), 225-238. <https://doi.org/10.1002/bin.197>.
- MacDonald, R., Green, G., Mansfield, R., Geckeler, A., Gardenier, N., Anderson, J., & Sanchez, J. (2007). Stereotypy in young children with autism and typically developing children. *Research in Developmental Disabilities*, 28(3), 266-277. <https://doi.org/10.1016/j.ridd.2006.01.004>.
- MacDonald, R., Sacramone, S., Mansfield, R., Wiltz, K., & Ahearn, W. H. (2009). Using video modeling to teach reciprocal pretend play to children with autism. *Journal of Applied Behavior Analysis*, 42(1), 43-55. <https://doi.org/10.1901/jaba.2009.42-43>.
- MacManus, C., MacDonald, R., & Ahearn, W. H. (2015). Teaching and generalizing pretend play in children with autism using video modeling and matrix training. *Behavioral Interventions*, 30(3), 191-218. <https://doi.org/10.1002/bin.1406>.
- Nuzzolo-Gomez, R., Leonard, M. A., Ortiz, E., Rivera, C. M., & Greer, R. D. (2002). Teaching children with autism to prefer books or toys over stereotypy or passivity. *Journal of Positive Behavior Interventions*, 4(2), 80-87. <https://doi.org/10.1177%2F109830070200400203>.
- Santarcangelo, S., Dyer, K., & Luce, S. C. (1987). Generalized reduction of disruptive behavior in unsupervised settings through specific toy training. *Journal of the Association for Persons with Severe handicaps*, 12(1), 38-44.
- Stahmer, A. C. (1995). Teaching symbolic play skills to children with autism using pivotal response training. *Journal of Autism and Developmental Disorders*, 25, 123-141.
- Thorp, D. M., Stahmer, A. C., & Schreibman, L. (1995). Teaching sociodramatic play to children with autism using pivotal response training. *Journal of Autism and Developmental Disorders*, 25, 265-282.
- Wetherby, A. M., Woods, J., Allen, L., Cleary, J., Dickinson, H., & Lord, C. (2004). Early indicators of autism spectrum disorders in the second year of life. *Journal of autism and developmental disorders*, 34(5), 473-493. Retrieved from:10.1007/s10803-004-2544-y

Melmark

Mission First. *Every Individual, Every Day.*[®]

Melmark is a multi-state human service provider with premier private special education schools, professional development, training, and research centers.

We are committed to enhancing the lives of individuals with autism, intellectual and developmental disabilities and their families by providing exceptional evidence-based and applied behavior analytic services to *every individual, every day*.



Tyler working on reading skills with Kelly Anglin, Special Education Teacher, at Melmark New England



Carrie working on her lesson plans with her teacher, Anna Eisenberger, M.Ed., at Melmark Pennsylvania



Simeon enjoying a walk with Melmark Carolinas
Director of Program Administration and Clinical
Services, Brad Stevenson, Ph.D., BCBA-D

NEW ENGLAND

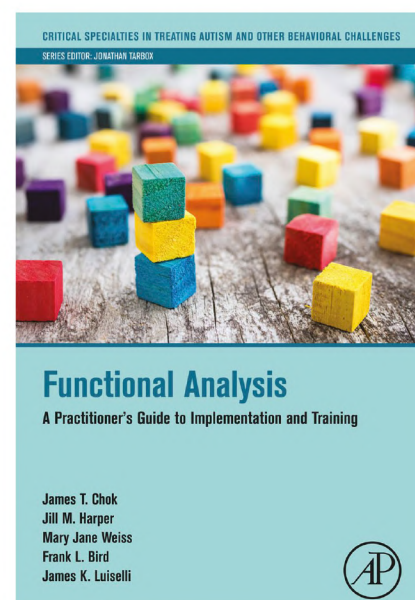
461 River Road
Andover, MA 01810

PENNSYLVANIA

2600 Wayland Road
Berwyn, PA 19312

CAROLINAS

Pineville Church of the Nazarene
8614 Pineville-Matthews Road
Charlotte, NC 28226



Functional Analysis

A Practitioner's Guide to Implementation and Training

James T. Chok
Jill M. Harper
Mary Jane Weiss
Frank L. Bird
James K. Luiselli



Melmark clinicians have published the textbook, *A Practitioner's Guide to Implementation and Training*, now available in hard copy and e-book versions.

WWW.MELMARK.ORG

LET'S FOCUS ON ADULT AUTISM!

THE DANIEL JORDAN FIDDLE FOUNDATION FOR ADULT AUTISM BREAKTHROUGH SUMMIT

Tuesday, April 18, 2023
10:30AM-3:45PM EST

REGISTER NOW
Virtual Event

THE DANIEL JORDAN
FIDDLE FOUNDATION
FOR ADULT AUTISM
TRAILBLAZING SINCE 2002

Autism does not end with childhood, it is lifelong. Most publicly funded services end for autistics when they reach the age of 18. With over 5.4 million autistic adults in the US, it's time we have a platform to discuss this topic of adult autism.

Thanks to their generous sponsorship, [The Daniel Jordan Fiddle Foundation for Adult Autism Breakthrough Summit](#) will be held on April 18, 2023 ([register here](#)). A diverse array of panelists will provide insights in areas including but not limited to employment, housing, postsecondary and support systems including guardianship.

Autism is characterized by social and communication challenges and in some instances accompanied by co-occurring conditions. In the U.S. 1 in 44 are diagnosed with boys being diagnosed 4 times as often as girls. This means that no matter if you have a child with autism, a family member on the spectrum, or know of someone with autism, you will know of someone with autism in your lifetime making awareness events like this only that much more imperative. Autism is also lifelong with over 5.4 million autistic adults in the U.S.

This event spearhead by Dr. Kerry Magro a 35-year-old internationally known

speaker on the autism spectrum who has spoken at over 1150 events worldwide in the past 12 years. Kerry hopes to bring in a personal perspective to highlight the significance of this topic.

The Daniel Jordan Fiddle Foundation for Adult Autism Breakthrough Summit will take place on Zoom and will be \$10 for professionals, \$5 for autistic self-advocates and free for current students. To register for this event as a student you must register here with a valid .edu email address. You will receive a link to the Zoom event via email after registering. If you cannot attend the day of the event as part of your registration fee you will receive a

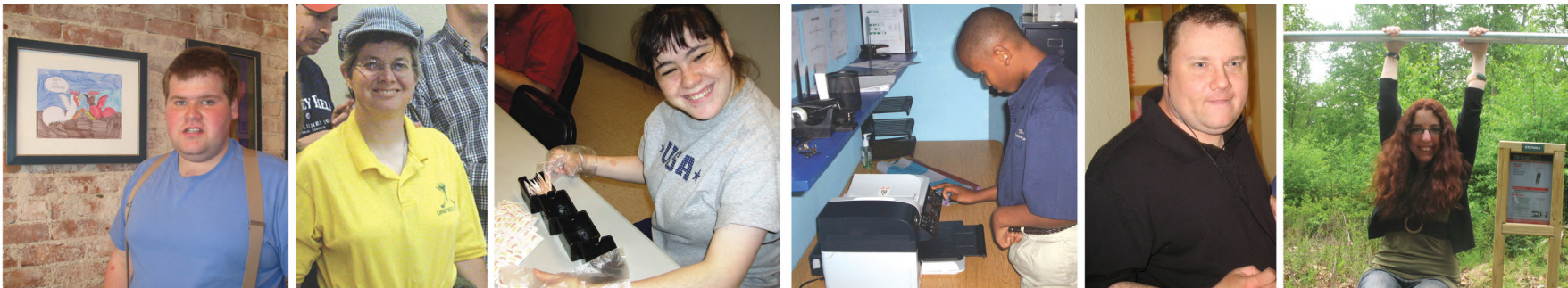
free video download of Summit link for INTERNAL USE ONLY post event. If applicable from presenters/panelists we will also provide a free download of all Summit PowerPoint presentations and handouts from the day.

Those who attend the entire summit on 4/18 will receive a certificate of completion. Personalization requests of the certificate can be sent to Kerrymagro@gmail.com

To register for this virtual event, please visit www.eventbrite.com/e/the-daniel-jordan-fiddle-foundation-for-adult-autism-breakthrough-summit-tickets-562384606497.

If you have any questions on the event email Dr. Magro at Kerrymagro@gmail.com.

THIS IS WHAT SUCCESS LOOKS LIKE



THIS IS WHAT AN ADULT WITH AUTISM LOOKS LIKE!

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

The Daniel Jordan Fiddle Foundation Adult Autism Endowed Funds are trailblazing research, housing, jobs, public policy, family support, artistic expression and community life for adults with autism worldwide today, and for generations to come.

Learn more about **The Daniel Jordan Fiddle Foundation Endowed Funds** at Yale University, Brown University, Rutgers University, Arizona State University, and the University of Miami by visiting our website www.djfiddlefoundation.org. Stay inspired by our Daniel Jordan Fiddle Foundation Leaders in Adult Autism, signature programs and international leadership.

To make a donation, please visit bit.ly/3OB59fx





CATALIGHT™

Shaping the future of ASD care



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

Join our journey.

catalight.org

The Importance of Telediagnostics in ASD Diagnosis and Treatment



**By Nina Rudnick, PsyD
Lindsey Sneed, PhD, BCBA-D
Catalight**

The COVID-19 pandemic brought significant challenges and opportunities for psychologists conducting diagnostic evaluations for people with suspected autism spectrum disorder (ASD). While there had been research on telediagnostics for ASD, at the start of the pandemic these procedures had not been widely applied or accepted as valid means of diagnostic practice. For this reason, many families were told they had to wait for an evaluation until it could be conducted within the health guidelines set forth by the CDC and local government. This significantly increased already long wait times for families. In addition, referrals for individuals suspected of having ASD continued to rise as many families now had more time at home with their child than ever before. This intensive time together gave caregivers insights into their children's social skills and communication – leading some families to wonder if their child had ASD.

With the increase in referrals for ASD evaluations and stated restrictions of COVID-19 related to sheltering-in-place, the field of psychology was put into a position to adapt in order to meet the ever-growing need of their communities. Prior to the pandemic, all ASD evaluations were conducted in person, but with unprecedented times came a need to adjust our process. As the statewide shelter-in-place order was extended in California, it became obvious to some psychologists that adapting to the current reality would include teledagnostic services. Our task was to provide high-quality and thorough teledagnostic evaluations.

There are relatively few psychologists with specialized training in ASD diagnostics and those numbers are even lower in rural and underserved communities. Telediagnostics provides a pathway for families to receive an evaluation who otherwise would not be able to or would need to be put on a lengthy waitlist. ASD diagnosis opens the door to appropriately targeted services and can improve the quality of life for individuals and their families.

Research on telediagnostics commenced before the pandemic, demonstrating good results with high acceptability of the procedures by participants (Juárez et al., 2018; Alfuraydan et al., 2020). Of utmost importance, a high agreement was found between face-to-face and teledagnostic administrations for young children suspected of having ASD (Stavropoulos et al., 2022). With this research in place, we developed a battery of assessments mirroring our previous in-person procedures. This battery was aligned with the available research and provided insight into the individual's cognitive, social-emotional, and behavioral presentation, as well as created a space to observe any restricted and repetitive patterns of behavior. Once initiating our teledagnostic program, we saw exponential advancement in our capacity to provide quick and accessible services, drastically shortening the families' wait times and increasing our ability to serve individuals who may have otherwise fallen through the cracks.

For young children suspected of having ASD, telediagnostics offers psychologists the opportunity to observe the child in their natural environment with their caregiver, where children are most comfortable. This allows for a clear picture of what happens in real-world situations. Upwards of 70% of people with ASD experience some form of anxiety (White et al., 2009), and having the option to provide a teledagnostic evaluation where the person can participate from their most familiar environment can decrease stress and anxiety regarding the whole diagnostic experience. Additionally, we have found that there are limiting factors in requiring patients to come into offices for evaluations. Some of these factors include a lack of transportation, severe behavioral or emotional challenges that limit comfort in going into offices, certain disabilities, long distances to drive for the evaluation and high gas prices. Telediagnostics can truly address the historic inequity in quality care and diagnostic evaluations.

Reflecting on these last two and a half years it is now difficult to imagine a clinical world without telediagnostics because

see Telediagnostics on page 25

Sharing an Adult Autism Diagnosis with Family, Friends, and Community

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

The successful British author Matt Haig spent a lot of time in self-reflection at the height of the pandemic. During this time, at 46 years of age, he was newly diagnosed with Attention Deficit Hyperactivity Disorder (ADHD) along with having Autism Spectrum Disorder (ASD). In light of being diagnosed only recently in middle age, he understood much more his lifelong enthusiasm and propensity to adhere to routine along with his chosen profession of writing fiction which requires a regular daily practice for him. He viewed his lifetime habits as ways to cope with feeling “...a little bit different without ever having understood why...” prior to his diagnoses.¹ Quieter time spent during the pandemic along with practicing more self-compassion has helped him adjust. He shared, “One of the few great things about middle age is you have an acceptance of who you are and a kindness toward yourself. In the olden days left-handed people were told to hold the pen with their right hand, but they were always left-handed; maybe it’s the same with autism. Maybe there’s a lot of things where you try to be a round peg and you’re actually a square peg and that’s fine. You just therefore create more square



holes.”¹ Cultivating self-compassion along with routine and habits that help promote acceptance and comfort helped the author Matt Haig adjust to his new diagnoses. These qualities of self-compassion, acceptance, kindness, and comfort have helped others live with and share with their community their diagnosis of ASD, an Intellectual and/or Developmental Disability (I/DD), with their family members and loved ones who support them.

When interviewing people supported

by S:US who live with ASD or I/DD and their family members, these similar themes of acceptance, self-compassion, empathy, sensitivity, and kindness were mentioned often. Valerie, a woman who has I/DD and attends an S:US Day Habilitation Program in Brooklyn, NY, shared, “...having I/DD doesn’t bother me. We’re all human beings. We all have needs and it doesn’t bother me. I live with it, I deal with it the best that I can, and I don’t let it affect me. Nothing else to do. When something both-

ers me, I give myself space, quiet time, I stay home...listen to some music, mostly gospel – it makes me happy and motivates me. I will also tell my staff and talk to Yvette (the Program Director at my day habilitation program). When I’m upset, I go to them and tell them; they’ll listen to me and help me with my situation, they talk to me and that helps.” Being around others who listen, care and make space for feelings or hard moments that arise, helps people with disabilities. Dr. Robert Joseph, an S:US Psychologist, stated “...all people are different...have different strengths and weaknesses. We need to accept our differences and make space for our differences.”

In the article “Sharing an Autism Diagnosis with Family and Friends,” psychologist Mandi Silverman, Psy.D., notes, “We often say that children with autism are like snowflakes, no two are the same. Just because one child with autism looks and sounds one way does not mean that another child will.”² Each person with ASD has a spectrum of behaviors, with different types of symptoms, onset, and level of severity. It is important to seek out good medical care, therapeutic treatment to build skills for the person with the disability, and connect to resources and social support. Hope, a mother who has an adult son with ASD and lives in a home managed by S:US reflected, “It is important to let go of ASD

see *Sharing on page 27*

Do you have a passion for helping others?

S:US offers a full spectrum of housing, wellness, and supportive services for people with intellectual/developmental disabilities. We are dedicated to helping people with I/DD live up to their fullest potential by creating opportunities for meaningful relationships, full integration into their community, and personal growth. We are hiring for the following positions to support the health and well-being of the people we serve.

- Assistant Program Directors
 - Direct Support Professionals
 - Program Directors
- Psychologists
 - Registered Nurses & Licensed Practical Nurses
 - Social Workers

Full-time positions at multiple locations throughout New York City. Excellent health benefits. Generous paid vacations and holidays. Flexible schedules. Ongoing training and career advancement opportunities.

Join our team and change lives.
Visit sus.org/careers or email SS-HRRecruiter@sus.org to apply.



Breaking Down Barriers: A Guide to Autism Diagnosis with NODA Telehealth

By Martin Costello
Autism Advocate

If you are the parent or guardian of a child on the autism spectrum, you know firsthand how frustrating and time-consuming it can be to get a diagnostic assessment for your child. The process often involves long wait times, multiple in-person appointments, and a lot of uncertainty. Thanks to recent advancements in telehealth technology, parents now have access to a faster and more convenient way to get their child assessed for autism.

Telehealth acceptance has been steadily increasing in recent years, with more patients and clinicians opting for virtual appointments over in-person visits. This trend has only accelerated during the COVID-19 pandemic, as many families were unable or unwilling to visit clinics in person and clinicians were prevented from having patients visit their clinics.

The benefits of telehealth go beyond convenience. Aided by innovative telehealth platforms and experienced clinicians, parents can now accelerate their child's assessment when they use video conferencing and other telehealth tools from their home. For example, if the parent and child are comfortable doing so, a recording of the child's behavior can be shared with a trained, diagnostic clinician.



This alternative way of pursuing a diagnostic evaluation can be a faster and more efficient than traditional in-person assessments, the standard of care that families have been following for decades.

What is NODA?

NODA™ stands for the Naturalistic Observation Diagnostic Assessment and

is an evidence-supported hybrid (synchronous and asynchronous) telehealth platform that supports families seeking faster, quality diagnostic assessments for autism, particularly those living in underserved areas. What has emerged is potentially the most prospectively research-based telehealth method to help young families who suspect their child should be evaluated for autism.

How NODA Works:

- Parents download the [NODA app](#) and set up a secure account. Then, the NODA app prompts them to complete a diagnostic history questionnaire and then record and upload short videos of their child in various situations at home: mealtime, bedtime, playtime with others, and playtime alone.
- Experienced clinicians then view the videos, tag behaviors relevant to a diagnosis of autism, and NODA organizes these tags according to the DSM-5 and virtually meets with the family (occasionally more than once)
- The clinician renders a diagnosis and provides a complete diagnostic assessment report to the patient's family.

What Parents Can Expect:

There are a few steps parents can expect when they use NODA to get their diagnostic assessment done:

1. Usually after the child has been screened "positive" by their pediatrician or other referring source, the family can register on the NODA app where they fill out an adaptive behavior assessment and

see NODA Telehealth on page 26

NODA - Founded by Parents, for Parents

The origins of researching autism diagnosis and telehealth may go back to 1995, when Medical device industry executive and dad Ron Oberleitner and his wife Sharon began "losing our son" (15-month-old Robby) is the only way they could describe it.

Robby's body was still intact and growing, but 180 degrees different from his two older brothers' development years earlier. Robby started losing the few FIRST words he had learned (flower, dada, mama), and instead, started to shriek, tantrum and cry for hours on end seemingly every day. He stopped eating and began to pick at his food instead, and at a moment's notice, may run out of the house naked to go... anywhere. The changes to Robby affected him on a daily basis and the discomfort could last several hours, until he passed out (it seemed). Robby's parents took him to their family pediatrician several times after witnessing Robby's increasingly distressing and indescribably torturous behavior. That overlapped with a decline in his ability or interest to interact with his mom and dad. Eventually his interaction with others dissolved as though it was never there. To anyone who observed Robby at that time, he seemed to be in constant pain and discomfort, and in his own world.

As it would happen with any family, the Oberleitners would take trips so that Robby could be evaluated by different "medical specialists" with whom they shared their concern about Robby's erratic behavior and sleeplessness. As Robby's situation grew increasingly concerning, Ron's




Robby at 7 years, after being diagnosed with Profound Autism at 3 ½ years

work responsibilities raised an interesting thought. Ron's position included oversight of novel health care initiatives that studied how surgery patients could safely be evaluated post-operatively from the safety of their home via Skype or secure videoconferencing. Patients could also get tertiary expert opinions by forwarding photos of post-operative wounds. While carrying

see NODA on page 26

IS IT AUTISM?




DIAGNOSTIC ASSESSMENT



www.RemoteAutismDiagnosis.com

Listening is Key to Supporting Families and Caregivers and Leads to Better Outcomes

By Trudy Ann Pines, MSEd
Assistant Principal
AHRC New York City’s
Middle/High School

Supporting families and caregivers is a lifelong learning process as children and young adults with autism spectrum disorders (ASD) typically undergo many changes. When providing workshops to families about accessing services, I began to consider the question of how we can support them further, as simply providing information does not seem to be enough.

A Chance to Be Heard

Parents and caregivers must be given the opportunity to be heard so educators and practitioners can better understand their children’s lives, goals, and dreams. The impact of a child’s developmental disability or other mental health issues can truly impact parents’, caregivers’, and family functioning (Prendeville & Kinsella, 2019). Family functioning plays an important role in understanding parental interactions with children diagnosed with developmental disabilities. Understanding their interactions may help educators and practitioners develop an approach,



or needed interventions, to enhance their day-to-day functioning at home and determine future valued outcomes (Prendeville & Kinsella, 2019). Parents and caregivers often struggle to obtain access to health, social and financial support (Doherty et al., 2020). Their socioeconomic status may pose limitations in advocating for their children due to their work schedules, financial resources, and lack of access to information about their children’s rights and entitlements (Doherty et al., 2020). Such factors can affect their family functioning

and their child’s transition to adult life.

Focusing on the Person in Future Planning

Generally, students transitioning from school to adulthood can pose challenges. For students with ASD, the process can be overwhelming, while families and caregivers often face systemic barriers in accessing adult day services, benefits, and entitlements upon transitioning from educational services (McGinley et al., 2021). Such barriers include a lack of knowledge about several transition tasks which may affect students’ access to community inclusion and the workforce. Person-centered planning emerges as an approach for future planning. This allows parents, educators, practitioners, and service providers to assess, explore, determine, and implement valued outcomes for their children who require support. Such an approach has promoted ongoing support to parents and caregivers of children with ASD and other developmental disabilities.

Collaboration Leads to New Vision

Person-centered planning refers to the process of articulating the care and support needs of individuals with developmental disabilities in a manner of pursuing and achieving their goals that is collaborative (Heller, 2019). It is rooted in the social values of equality and access to the community for individuals with developmental disabilities whereby decisions are based upon the principles of inclusion, choice, and independence (Taylor & Taylor, 2017). This approach aims to place children and young adults at the center of planning and decisions that affect them. When they are actively involved in person-centered planning, it is believed that their attitudes, behavior, and learning contribute positively to the community. When and how do parents and caregivers decide about the future for their children and young adults?

Seeing Children Through a Different Lens

When engaging in person-centered planning with parents and caregivers, it is important to explore their children’s profiles in terms of who they are, their aspirations and dreams, prior to determining future

valued outcomes. Self-awareness is key to goal setting in person-centered planning. As parents and caregivers reflect on their children’s capabilities, they begin identifying what is important to their child and the supports he or she will require to contribute to society. During such exploration, parents, caregivers, and practitioners see their children through a different lens.

A parent once told me during a person-centered planning meeting, “I have never thought of seeing my son from a different perspective; I tended to focus so much on his deficits in certain areas of his life. This meeting opened my eyes to see his potential in other areas and other possibilities, such as attending college.”

As parents and caregivers interact in a natural way, there is a strong sense of engagement and inner reflection of themselves. Their conversations may lead to setting valued outcomes for their children that might seem unrealistic to others or goals that could be attainable.

The goal-setting process is rooted in transforming their children’s dreams into goals and objectives. Goals and objectives based on their children’s wants and needs and supported by parents, caregivers, and service providers, can lead to set activities and a timeline that allows their children to accomplish them effectively. In a transition meeting, a student completed a picture of his life through person-centered planning by including both graphic and written descriptions of his preferred place to live, work and other dreams he wanted to accomplish. Parents and caregivers were able to picture and reflect upon his vision from a different perspective: his own perspective.

Person-centered planning has indeed evolved toward an empathic approach that empowers and motivates children and young adults with developmental disabilities, as well as their parents and/or caregivers. With the opportunity to articulate a vision, parents and caregivers consider different paths, and engage in natural conversations centered on their children. Over time, this approach has improved the relationship between parents/caregivers and their children, while promoting respect and dignity, which forges a deeper emotional bond.

Trudy Ann Pines, MSEd is an Assistant Principal at AHRC NYC Middle/High School in Brooklyn and serves as a Care Manager for Care Design New York. She also was a school counselor at AHRC NYC Middle/High School for 14 years. She earned her master’s degree in School Counseling and Educational Leadership at Brooklyn College of the City University of New York and is currently completing her doctoral degree at St. Thomas University. Her research interest includes social and emotional learning in special education and transition services for students with developmental disabilities post-COVID-19 pandemic. Trudy Ann resides with her family in Brooklyn. In her free time, she runs outdoors, practices journal writing, and spends quality time with her daughter.

see Listening on page 29



Stand for Something.

Advocate for people who are neurodiverse to live full and equitable lives.

For support, resources, or to donate
visit **AHRCnyc.org** or call **212-780-2500**



Raymond Ferrigno, Board President
Marco Damiani, Chief Executive Officer



Engaging and Supporting Parents of Children Recently Diagnosed with Autism

By Georgia Efthimiou, MA, BCBA,
Kristen Daneker, MS, BCBA,
Brandon Sierchio, MA, BCBA,
and Howard Savin, PhD
First Children Services

No parent wants to learn that their child is autistic. Hopes and dreams for a neurotypical child are mostly abandoned and replaced by fear, uncertainty and, often, despair. Thus, effective professional intervention must begin with active listening to grasp the parent perspective on their child's special needs, degree of parent's emotional dysphoria and other salient issues in family dynamics. This process productively enables formation of an effective alliance between clinicians and parent(s) to begin addressing the needs and challenges for a newly diagnosed child or adult with autism.

An Autism Spectrum Disorder (ASD) diagnosis for parents with young children can be isolating. There are many added responsibilities that parents are not always prepared to pursue for their children. Parents often feel that the burden that comes with this diagnosis is too high. They often feel that they have limited access to resources they need. As parents embark on the journey to secure support for a loved one, it is important to educate oneself, practice self-care, and prepare to be an active part of the child's treatment. Education and training have been proven to help alleviate some of these feelings for parents as they become more familiar with Applied Behavior Analysis (ABA) and learn the tools to manage their child's behavior. Beginning treatment as soon as possible is paramount. As a person grows, they form routines and develop behaviors that are reinforced, sometimes inadvertently, by parents and others. Some of those routines and behaviors may be quite challenging in nature and can result in a child being stigmatized or prevented from participating in activities with their neurotypical peers.

Today, pediatricians are trained to screen children achievement of developmental milestones. If they seem to fall behind, they refer parents to neurologists, or developmental specialists, where they can further evaluate their child. From there, appropriate diagnostics can be made. If a child is under 3 years of age, Early Intervention Services are almost always recommended and are available in every state. Once an autism diagnosis is obtained, parents are given a prescription for ABA services. At that point, the parents must look for resources on their own, whether state funded or through their personal insurance provider.

Behavior Analysts are educated to not only treat a child with Autism but also to treat and work actively with the child's parents or caretaker. The expectation is that parents will participate in their child's treatment from the onset of services on a weekly or monthly. Once specific skills are mastered, or behaviors reduced, a Board Certified Behavior Analyst (BCBA) will work with the families to utilize these skills and strategies outside of therapy ses-



sions. For progress to be sustained, caregivers must continue to transpose the work that the clinicians provide into home and community settings. Research shows that parental involvement is crucial for maximizing the child's progress.

ABA therapy will focus on addressing the autistic child's skills deficits and challenging behaviors. An evaluation is completed at the outset of treatment to assess individual deficits and incorporate the child's strengths into a treatment plan. Parental input is also incorporated into daily programming. The goal is for the child to be able to be a part of family life, with minimal support, by the end of services. In addition to ABA services, parents may be encouraged by the child's physician to seek additional services such as Physical Therapy, Occupational Therapy, and Speech Therapy. ABA providers will work hand in hand with outside providers as part of an interdisciplinary treatment approach. A behavior intervention program, no matter how well written, is only as effective as the people who are implementing it. This requires training and consistency across all settings including the home and community. With ABA therapy, services may be provided in the home, in the community as well as clinic-based services.

Reducing ABA therapy hours, or recommending discharge, can leave many families feeling apprehensive or anxious, even when their child has made remarkable progress throughout the course of treatment. ABA therapy becomes intertwined with the family's daily routine and structure, and most families value the consistency and predictability of having additional support and resources available to them as needed. Discharging from services does not have to be a scary process for families and continuing to provide regular parent training throughout the service fading stage is a help.

It is important that families and clinicians have transparent conversations about long-term goals and hopes of outcomes for ABA therapy early on to ensure that reasonable expectations are discussed and agreed upon. Similarly, criteria to fade direct ABA therapy hours and ultimately criteria to discharge from services should be

interventions that were once predominantly overseen and implemented by trained clinicians. Once effective interventions may need to be reconsidered if they prove to be ineffective in a different setting or when implemented by different people. Interventions may look different when run predominantly by the family, and caregivers should feel empowered to speak up if something is not working.

The final stage of discharge involves touch points between the family and clinician to assess continued stability and the need for any additional supports after direct services have ended. The clinician will provide the family with a discharge summary outlining their child's progress on long-term goals, a summary of treatment and outcomes, clinical recommendations for ongoing support, and information on additional community resources the family can look into should the need arise for services again in the future. While medically-based ABA therapy is not intended to be a lifelong therapy, a child may need direct ABA therapy again even after successful discharge if new challenges occur that require a higher level of care again. It is not uncommon for a child to have several cycles of ABA therapy during transitional periods in their life.

see *Supporting Parents* on [page 26](#)



Family is at the heart of everything we do.

STRIVE Autism Care Continuum

STRIVE integrates interdisciplinary behavioral health treatments and other therapeutic services all under one roof. Services take place in center, home, and community settings.

What we offer:

- Autism Assessments
- Applied Behavior Analysis
- Behavioral Parent Training
- Individual Counseling
- Social Skills Groups
- Support Groups for Parents and siblings

 www.firstchildrenservices.com  888-966-0746



An Overview of the Screening and Diagnosis of Autism Spectrum Disorder in Children

By the Center for Disease Control and Prevention (CDC)

Diagnosing autism spectrum disorder (ASD) can be difficult because there is no medical test, like a blood test, to diagnose the disorder. Doctors look at the child’s developmental history and behavior to make a diagnosis.

ASD can sometimes be detected at 18 months of age or younger. By age 2, a diagnosis by an experienced professional can be considered reliable.¹ However, many children do not receive a final diagnosis until much older. Some people are not diagnosed until they are adolescents or adults. This delay means that people with ASD might not get the early help they need.

Diagnosing children with ASD as early as possible is important to make sure children receive the services and supports they need to reach their full potential.² There are several steps in this process.

Developmental Monitoring

Developmental monitoring is an active, ongoing process of watching a child grow and encouraging conversations between parents and providers about a child’s skills



and abilities. Developmental monitoring involves observing how your child grows and whether your child meets the typical developmental milestones, or skills that most children reach by a certain age, in playing, learning, speaking, behaving, and moving.

Parents, grandparents, early childhood education providers, and other caregivers can participate in developmental monitoring. CDC’s [Learn the Signs. Act Early.](#)

program has developed free materials, including *CDC’s Milestone Tracker* app, to help parents and providers work together to monitor your child’s development and know when there might be a concern and if more screening is needed. You can use a [brief checklist of milestones](#) to see how your child is developing. If you notice that your child is not meeting milestones, talk with your doctor or nurse about your con-

cerns and ask about developmental screening. Learn more about *CDC Milestone Tracker* app, milestone checklists, and other parent materials.

When you take your child to a well visit, your doctor or nurse will also do developmental monitoring. The doctor or nurse might ask you questions about your child’s development or will talk and play with your child to see if they are developing and meeting milestones.

Your doctor or nurse may also ask about your child’s family history. Be sure to let your doctor or nurse know about [any conditions that your child’s family members have](#), including ASD, learning disorders, intellectual disability, or attention deficit/hyperactivity disorder (ADHD).

Developmental Screening

Developmental screening takes a closer look at how your child is developing.

Developmental screening is more formal than developmental monitoring. It is a regular part of some well-child visits even if there is not a known concern.

The American Academy of Pediatrics (AAP) recommends developmental and behavioral screening for all children during regular well-child visits at these ages:

see CDC Overview on [page 27](#)



Advocate.
Mediator. Litigator.
Conflict Resolution.

Advocacy and dispute resolution
in the areas of special education,
disability, discriminatory
conflicts and more.

For a free consultation visit:
<https://tarafappiano.com/contact/>



Devereux | UNLOCKING
ADVANCED BEHAVIORAL HEALTH HUMAN POTENTIAL™

Devereux Advanced Behavioral Health changes lives –
by unlocking and nurturing human potential for people living
with emotional, behavioral or cognitive differences.

We support children and adults with autism spectrum disorder in the development of
communication, social and independence skills needed to realize fulfilling, productive and
socially connected lives. Our programs and services utilize evidence-based strategies,
including positive behavioral supports and applied behavior analysis.

LEARN MORE
DEVEREUX.ORG | (800) 345-1292

Next Steps After an Autism Diagnosis: Acceptance, Advocacy, and Treatment Options

By Salli Shon, LCSW, BCBA, LBA-CT
and Caitlan Freeman, MS, BCBA, LABA
Autism Care Partners

The road to diagnosis can be long and uncertain. For some, the news of diagnosis brings validation and hope. For others, it can lead to even more uncertainty. In either situation, it is important to seek support and guidance to navigate a path forward. It can be difficult to muddle through all of the information, emotions, and clinical options that often accompany news of the diagnosis, however, the true path forward begins with understanding.

In order to meet criteria for a diagnosis of Autism Spectrum Disorder (ASD), an individual must present with developmental concerns in the following areas: persistent deficits in social communication and social interactions across multiple contexts and restricted and/or repetitive patterns of behavior, interests, or activities. These concerns must be present in early development, cause clinically significant impairment, and not be accounted for by intellectual disability or global developmental delay (American Psychiatric Association, 2013). Though this clinical definition is very clearly defined, each individual given a diagnosis of ASD is different. Everyone



has unique strengths and struggles, and the discussion around diagnosis should highlight these complexities. Initially, conversation about the diagnosis should highlight an individual's strengths while also providing valuable information in areas where they may need support.

Initial news of a diagnosis can bring about a variety of emotions and it is important to hold space for those feelings. In the same way each individual presents

uniquely, interpretation of a diagnosis is nuanced by each family and individual's circumstances and perspectives. Ultimately, this diagnosis provides information that helps to understand an individual and their needs. It is also a roadmap to identify and gain access to a variety of supports that will help them to thrive in their daily lives. It does not change who the child or individual is or imply they will lead any lesser quality of life. As parents and practitioners,

it is our job to change the narrative around an ASD diagnosis by helping shift the conversation from symptoms that need to be remediated or cured, to unique and individual areas requiring our acceptance and support to thrive.

Next steps following diagnosis should focus on understanding the person's individual needs and meet them where they are. The path for a young child will differ from a school aged child and even more so for adults.

Pre-school age children will benefit from early intervention through a birth to three program offering Autism specific interventions. Treatment models utilizing principles of Applied Behavior Analysis are evidence-based. They have demonstrated effectiveness in the acquisition of skills and reduction of harmful behaviors. Examples of ABA interventions comprise Natural Environment Teaching (NET), Discrete Trial Teaching (DTT), Pivotal Response Training (PRT), and Skill Based Training (SBT) (National Autism Center 2006-2017). Because Autistic children are diverse and unique, it is best to have an approach that is flexible and comprehensive, including Occupational Therapy and Speech and Language programs. Young children, prior to entering school, can

see Next Steps on page 29



Transition to college. Pursue a career.
Build a life away from home with
College *Living* Experience.

ACADEMIC SUPPORTS | INDEPENDENT LIVING INSTRUCTION
SOCIAL COACHING & COMMUNITY | CAREER DEVELOPMENT



START YOUR TRANSITION!
ExperienceCLE.com | 800.486.5058



Westchester Jewish
Community Services

Provides Comprehensive Behavioral Health Services
via Telehealth and In-Person

- Dialectical Behavior Therapy
- Trauma Treatment for Child and Adult Survivors of Sexual Abuse and Domestic Violence
- Specialized Counseling for College Students
- Co-Occurring Substance Use and Mental Health Disorder Treatment
- Intensive Outpatient Services
- School-Based Mental Health Clinics
- Specialized Therapy for People with Intellectual and Developmental Disabilities
- Therapeutic Social Skills for Children, Adolescents, and Adults on the Autism Spectrum
- Bereavement Services
- Peer-led Wellness Groups

Contact: Leslie Hernandez, Director of Admitting
(914) 737-7338 x 3119

www.WJCS.com

845 North Broadway, White Plains NY 10603



Autism Around the World: An Interview with a First Lady with a Degree in Special Education and “Autism Belize”

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

She doesn't flinch...“We need money! We need a lot of money. We need a lot of training, and it costs a lot of money...We're not lost. We're not this little country that has our heads in the sand. Every time somebody suggests to me 'Let's have a Special Education summit!' It upsets me...because I feel they want to rehash and rehash, same/old and same/old, and talk, talk, talk, talk,...We know what our issues are, we know how to fix them.”

Armed with a degree in Special Education from the University of Chicago, Her Excellency, Mrs. Rosanna Briceño, is no typical “First Lady.” Her passion for autism and other disabilities contains no optics; and her frustrations...no filter. Though the picture of approachability, she is constantly lurching her frame forward from the sofa, thrusting her arms to drive home her points.

Her Excellency was first exposed to Special Education at age 18 and quickly realized it was her mission. Laughing, she states, “That was thirty-five years ago, and I have since been called an ‘old soldier’ many times.”



Her Excellency, Mrs. Rosanna Briceño, First Lady of Belize, with Christy Castillo Almeida, the Founder of Autism Belize

I have been given an unprecedented hour with her and her “partner-in-crime” (both in and outside the Belizean school system), Christy Castillo Almeida, the Founder of Autism Belize.

One of my many “hats” in the autism world tasks me to both inform, and gain

exposure for the work of fledgling, but workaholic, autism organizations in Central and South America. Because of their economic challenges they often look to us for leadership, as too often amongst the overwhelmed there is an obligation to emulate the autism developments that have

occurred in the US. But when they are so overwhelmed, it is hard for them to see that based on our relatively privileged economy, we are actually no great example. We in the U.S. are still engulfed in *unlearning* so many mistakes. So if challenged economies starting at baseline can somehow avoid the comic/tragic pitfalls of vaccine theories, punitive ABA, and the messaging of organizations like Autism Speaks, they could theoretically surpass us.

Here in Belize this latter role is unnecessary. Powerhouses Almeida and Mrs. Briceño need no such education. They are more than advanced enough in their comprehension of all that has occurred. They have done the feasibility work. They know what they need, and their need is great. Belize has only 1 SLP (Speech and Language Pathologist) working full time in the entire country. They have no full-time OTs, BC-BAs, FloorTime Therapists, or Play Therapists. Their insurance companies won't insure for autism - not even for basic health or the cost of an official diagnosis. In this land of around 420,000 Creole, Mestizo, East Asian, and Maya, there is only one special needs school (containing 11 classrooms) and only 20 special education classrooms in 14 regular education locations throughout the country. In these

see *Autism Belize* on [page 28](#)

Building Your Career is Personal.

1 on 1 Online Instruction at home!

Convenient, stress-free, private.

Free/no tuition/gov't paid. Free loaner laptops.

Your choice of your own personal NYSED licensed Instructor.



1hr classes, 8am-8pm, 7 days/week

Rolling enrollment. Start anytime.

Earn your Certificate in Microsoft Word, Excel, Outlook, PowerPoint, Keyboarding & other work skills demanded by most Employers (Indeed.com)

Learn at your pace, take 3-7 months, no deadlines.

And, the Center, in Partnership with Jawanio, Yonkers, will make sure you get a well paying job; PT/FT, close to your home.

Call/text/email Lizzie to arrange for an interview:

914-557-1318 cell, lizzie@freecenter.org

Start your career path today!



The Center for Career Freedom

185 Maple Ave, White Plains, NY 10601

• 914-288-9763 • Freecenter.org •

14yrs & up

We love
Students
with
Special
needs!

Berklee Institute for Accessible Arts Education (BIAAE)

Arts Education Programs
Graduate Programs in Music Education and Autism
Professional Development

berklee.edu/BIAAE



Behavior Therapy ASSOCIATES

ESTABLISHED 1979

www.BehaviorTherapyAssociates.com

Providing comprehensive clinical, consulting, and school-based service for children through adults, families, schools, and organizations.
Michael C. Selbst, PhD, BCBA-D
Executive Director

732.873.1212
info@BehaviorTherapyAssociates.com
35 Clyde Road, Suite 101
Somerset, NJ 08873

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

Mindy Appel, LCSW, ACSW, LMFT

Bank United Building
5300 W. Atlantic Avenue - Suite 408
Delray Beach, Florida 33484

appelmindy@gmail.com • www.mindyappel.com

(561) 926-7858

Parent Education Program for Families of Children with Newly Diagnosed Autism

By Daniel Magin, BA,
Kristin Christodulu, PhD,
and Jane Ann Worlock, MSEd
University at Albany Center for
Autism and Related Disabilities

The proliferation of misinformation related to autism spectrum disorder has been an issue for decades and one that capitalizes on the vulnerabilities of the population at which it is targeted (Capuano & Killy, 2020). The most infamous example of the harm that misinformation in the autism community can pose comes from the widely debunked idea that vaccines are the main cause of autism (Roozenbeek & Van der Linden, 2022). As this theory has spread its way through the public consciousness, it has contributed to the decision of thousands of parents to opt out of getting their children vaccinated (Roozenbeek & Van der Linden, 2022). Even after the results of countless studies have emphatically proved this idea wrong, it has continued to loom in the public consciousness with 13% of a recent sample of 500 parents believing the idea that vaccines were a likely major cause of ASD and 30% of this sample believing the idea that a large amount of resources should continue to go towards the investigation



of vaccines as the cause of autism (Fischbach et al., 2016).

The threat of misinformation seems to be rising with the ease at which it is spread through technology. Indeed, the Surgeon General of the United States recently issued an advisory to warn the public about the growing danger that misinformation poses to US Public Health (Office of the Surgeon General, 2021). With the ever-increasing capacity of misinformation to

reach its target audience through social media and related technology, it is more important now than ever that parents and families have access to trusted experts in the field to provide them with reliable and accurate information on which they can base their decisions related to their recently diagnosed autistic family member.

While technology has its risks in relation to the spread of misinformation, it can also be leveraged by professionals to enable ac-

cess to trusted and evidence-based information for families who recently received a diagnosis of autism spectrum disorder. As the internet has become the most common resource for parents and caregivers to use when seeking out information related to their child's neurodevelopmental disorder, professionals and health-care providers must provide information through this medium for it to reach as many families as possible (Chan et al., 2017). Furthermore, they must do so in a way that both refutes the misinformation that families may have consumed in the past and inoculates families against misinformation that they may be exposed to in the future (Smith & McDonald, 2017). One way of doing this is to provide families with evidence-based information about autism and to briefly and directly address the common misinformation that families may be exposed to, as well as the potential motivations behind the agents spreading the misinformation (Smith & McDonald, 2017). However, it is imperative that in the process of doing so, scientists and professionals strike a careful balance between labeling the misinformation as such and overly repeating the trope associated with the misinformation, which could inadvertently reinforce the audience's belief in the false idea (Smith & McDonald, 2017).

see Parent Education on page 29

11 Compassionate Parenting Tips for Families with Autistic Children

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

Few people realize the challenges of being a parent, until they become one. Now, imagine the added challenges of parenting an autistic child which is becoming more common as the number of children diagnosed with an autism spectrum disorder (ASD) increases. According to the Centers for Disease Control and Prevention, in the United States, the prevalence rates of autism spectrum disorder increased from 1 in 150 children in 2000 to about 1 in 68 in 2012 (Centers for Disease Control and Prevention [CDC], 2012). A more recent study by the Centers for Disease Control and Prevention (CDC; 2020) suggested that in some areas of the country, the prevalence of ASD was closer to 1 in 54 children.

A crucial time to support parents is after a diagnosis when parents are overwhelmed by and focusing on the challenge of "what do I do?" Many parents search online for the best therapies or ask others about best parenting practices. I am here to say that autistic children do not need a perfect parent, they need a positive and accepting one.

The aim of this article is to give parents a glimmer of hope, emphasizing 11 compassionate parenting strategies and focusing on the joyful moments during a



crucial time when parents are focusing on the challenge of "my child is autistic, what do I do?"

1. Allow the feelings and emotions - Parents, after receiving an autism diagnosis, experience a plethora of emotions before they accept their child's diagnosis. Many parents move through emotions like Kubler-Ross' (1980) stages of grief; grieving for what might have been followed by a plan of action. Having an autistic child may not fit your perspective of what your family should look like, it

may feel like you have a square peg to fit into your family circle. You will mourn and that is okay. Give yourself the time and space.

2. Realize you are good enough - My opinion, all parents of autistic children should receive a merit badge in parenting. Raising an autistic child is like learning a foreign language - but in parenting. It is challenging and sometimes overwhelming. Parents utilize numerous resources to help their child developmentally, but they still worry they are not doing a good enough

job. Your child does not need the perfect parent, they need a happy and supportive one. Raising an autistic child is difficult, but it is empowering and will make you a better person.

3. Build your support village - When you begin learning about autism, there are moments when you will feel lonely and lost. You will learn more from your "support friends and family" than an autism expert. Simply talking to and listening to others who are raising autistic children can be life changing. They get it! It is so comforting to talk with others who get it and support you, especially during times when you feel overwhelmed or isolated. You are not alone in this journey.

4. Your child's differences are what make them unique - Even though your child interprets the world differently, that's not a bad thing. This is the beginning of an eye-opening journey. Their perspective of the world is amazing; they will show you there are different ways or even better ways to solve problems. Yes, they may have challenges due to their neurodiversity, but they can cope with these challenges with proper support.

5. Autism is your child, but it does not define your child - Your child is not defined by a single diagnosis, they are special

see Parenting Tips on page 34

Challenges in the Diagnosis and Treatment of Older Autistic Women

By Mary P. Donahue, PhD
Owner/Psychologist
Mindful Paths Psychological Services, LLC

Autism has a unique neurological structure with a wide variety of expressions. This diversity of strengths, challenges, and experiences is why autism is considered a spectrum disorder. It's also what makes it challenging to diagnose and treat because the myriad of symptoms manifested in any given autistic person at any time on any calendar day is different.

Historically, autism is better identified in males than in females (Leedham, 2020). Reasons may be that: males tend to act externally when frustrated, measures of autism traits have been normed on mainly male samples, and females express autistic traits differently (Bargiela, 2016). Even some educators can identify autism in males easier than in females, despite observing the exact same scenario (Whitlock, et. al., 2020). There may also be an implicit bias toward women as autism and co-occurring disorders are often misdiagnosed in women as personality or mood disorders (Muller, 2019). In addition, females can have a higher social motivation, greater capacity for friendship, and internalize angst as compared to males (Bargiela, 2016). Lastly, women are adept at using camouflaging as a coping skill.



Camouflaging is a safety strategy where an autistic person suppresses their autistic characteristics so they appear “normal” and are accepted by mainstream society. It takes an extreme amount of energy to constantly suppress natural behaviors. It also means that the autistic person is not known as themselves but, rather, as the projected persona. This leaves the autistic person without a sense of self or of belongingness. Masking, then, can derail appropriate diagnosis.

Another difficulty in diagnosing females is how autistic people communicate. They're generally direct, literal thinkers, so asking a patient, “How are you doing today?” can elicit one answer with two meanings: The patient responds with “good,” indicating little trouble to the provider but actually meaning “in the moment” to the patient. She may have been immobile yesterday or sleepless over the last few weeks, but that's not “today.” Next, as women tend to internalize expe-

riences and be very cooperative, she may outwardly appear to be getting along well in the observable moment but is internally exhausted and flooded. Cognitive processing might be slower, made worse by painful environmental stimulation. Her processing can be restrained as providers push to gather information. She may look disinterested or uncooperative or may be masking well. She is not, however, revealing her true self. Thus, diagnosis and subsequent treatment goals are miscalculated.

One critically important diagnosing tool, however, is the expertise and understanding of the clinician. This requires humility and mindfulness. It can be a tricky process to elicit the information you're exactly looking for when communicating outside your norm. The best tool an assessor can have is to learn not only what autism is, but how it manifests in real life for that patient. Being open minded and setting aside preconceived notions is a start. The practitioner is their own best instrument.

Treatment

Research reveals considerably little about how to specifically support or treat the needs of autistic women. Thus, “evidence-based” doesn't always apply. Treatment can also be complicated by the medical model, wherein treatment seeks

see *Older Women* on [page 35](#)

Rates of Autism Increase, But Numbers Don't Paint the Full Picture

By Kate Wallis MD, MPH
and Eileen M. Everly, MD
Children's Hospital of Philadelphia
(CHOP)

Headlines over the past 20 years have signaled ever-increasing [recognition](#) of autism spectrum disorder (ASD). Now, in a new [article](#) published in *Autism*, our team describes our own estimates of how many children across Children's Hospital of Philadelphia's (CHOP) Primary Care Network have been diagnosed with ASD. What we found highlights the importance of tracking and unpacking the numbers of diagnoses to identify areas for continued improvement. This includes improving data collection for communities - such as Asian American families - that have been excluded from other studies of autism prevalence or whose needs have been obscured when categorized as “other.”

What We Found

We found that almost 1 in 31 children, or 3.2% of our population, met our diagnostic definition for autism. This number is higher than [some national data](#), but in line with a more recent [study](#) published in the last year. The median age at which a diagnosis was documented was 3.93 years. We are encouraged that more than half of our



population was diagnosed before age 4, as we know that early diagnosis, which can provide early access to needed supports, can help children learn new skills.

We were also encouraged that our team found fewer racial, ethnic, and socioeconomic disparities in ASD diagnoses than we might have expected based on historical data. For decades, Black, Hispanic, and other minoritized racial and ethnic children, as well as children from families with lower incomes were known to experience

delayed and missed diagnoses of ASD. We found that after adjusting for other factors, children who identified as Black, Hispanic, White, or had other or multiple races were diagnosed at the same rates and ages. Similarly, socioeconomic vulnerability did not affect rates or ages of diagnosis.

However, children who identified as Asian had higher rates of ASD diagnosis compared to children from other racial groups - 5.4% of Asian children (or 1 in 19 children) were diagnosed with autism. As

this was an exploratory study, there is much more to do to understand these results.

Race and ethnicity are psycho-social constructs. As such, history suggests that when differences in autism prevalence between racial or ethnic groups are found, or are found to change, it is due to differences in identification rather than in underlying biology. Thus, our differences in rates of diagnoses compared to historical findings could be due to differences in internal clinical processes or in the social influences of health. For example, children may have differences in how they access and use health care services, or in the care they receive.

It's important to view this data not as a conclusion, but as information we can use to ask the next right question as we continue to put equity at the forefront of our care.

What Can Our Teams in Research and Primary Care Learn from This Study?

First, the rates of ASD across the CHOP Care Network can be used to help ensure we have the capacity to meet the needs for this large group of children with ASD.

While our data on age of diagnosis is promising, we can do more to continue to improve early identification and access to services. A new model, known as the Autism Care Champions in Primary Care, seeks to train primary care providers at

see *Autism Rates* on [page 31](#)

Screening and Diagnosing Autism Spectrum Disorder in Young Children

By Jennifer Shannon, MD
Executive Medical Director and Child,
Adolescent, and Adult Psychiatrist
Cognoa

Given the complex nature of autism spectrum disorder (ASD), its diagnosis can be challenging. Unlike conditions where biomarkers such as those found with a blood test can provide a definitive diagnosis, diagnosing ASD requires clinical observation and interpretation of a child's behavior and developmental history. Screening and diagnostic tools can be utilized to aid the clinician's assessment, but no tool should be used as a "stand-alone" diagnostic. The clinician must assess each child's presentation and make a diagnosis based on whether the Diagnostic and Statistical Manual of Mental Disorders - Fifth Edition (DSM-5) criteria for ASD are met ("Screening and Diagnosis of Autism Spectrum Disorder" | CDC; "Diagnostic Criteria | Autism Spectrum Disorder (ASD)" | CDC).

Children with ASD can be identified as toddlers and early intervention can and does influence outcomes. In addition to screening when concerns arise, the American Academy of Pediatrics (AAP) "recommends screening all children for symptoms of ASD" through a combination of standardized autism-specific screening tests at 18 and 24 months of age and gen-



eral developmental screening at 9, 18, and 30 months of age visits (Hyman, et al 2020).

ASD Screening Tools

A screening tool is used in the general population in individuals *without* symptoms to identify those at risk. The goal of a screening tool is to enable earlier identification of concern and does not provide a diagnosis (Bovbjerg 2020; "Screening and Diagnosis of Autism Spectrum Disorder" |

CDC). For ASD, examples of commonly used screening tools available include the Modified Checklist for Autism in Toddlers (M-CHAT-R/F), Screening Tool for Autism in Toddlers and Young Children (STAT), and Rapid Interactive Screening Test for Autism in Toddlers (RITA-T) ("Screening and Diagnosis of Autism Spectrum Disorder" | CDC; "RITA-T Research" | Boston Children's Hospital), with M-CHAT-R/F being the most studied and widely used in toddlers in the primary care setting (Hyman, et al 2020).

ASD Diagnostic Tools

A diagnostic tool is used in individuals *with* symptoms, concerns, or those for whom *screening has identified an area of concern* to assess the probability or likelihood that an individual may have a particular condition. Examples of ASD diagnostic tools include Autism Diagnostic Observation Schedule-Second Edition (ADOS-2), Autism Diagnostic Interview-Revised (ADI-R), Childhood Autism Rating Scale-Second Edition (CARS-2) ("Screening and Diagnosis of Autism Spectrum Disorder | CDC" n.d.; "(CARS™2) Childhood Autism Rating Scale™, Second Edition" n.d.) and Canvas Dx. These tools have been clinically validated in varying individual populations and most are routinely used by specialist clinicians (Randall et al. 2018; Megerian et al. 2022). To date, Canvas Dx, is the only AI based diagnostic device that has received FDA marketing authorization for ASD (FDA. 2021).

A tool's performance can be evaluated based on the following characteristics (Bovbjerg 2020):

- Sensitivity – The ability of the tool to correctly identify individuals who truly have ASD

see Screening on page 31

Empowering Caregivers Through an Innovative Peer Navigator Program

By Sarah Vejnaska, PhD,
Samantha Hochheimer, MS,
Suzannah Iadarola, PhD,
Melanie Pillecchia, PhD, BCBA, NCSP,
Connie Kasari, PhD,
and Aubyn Stahmer, PhD

After a child receives an autism diagnosis, caregivers begin to look for appropriate services and supports. This journey requires them to navigate a very complicated service system. Caregivers are usually tasked with coordinating their children's medical, educational, and community-based services across different systems of care. Research looking at this process finds that family quality of life improves when families have their service needs met (Jones et al., 2017). However, caregivers of autistic children report greater unmet service needs than caregivers of children with other developmental concerns (Chiri & Warfield, 2012), and greater difficulties in accessing and dissatisfaction with care (Carbone et al., 2010).

Families from historically marginalized groups, individuals living in poverty and/or in rural areas, and those for whom English is not their first language have even greater challenges navigating these systems. They often experience lower quality care (Bilaver et al., 2020; Jafarabadi et al., 2021, Stahmer et al., 2019).



Mind the Gap is an AIR-B project to connect families with support services in their area and to put families with a recent diagnosis in a better position

The Autism Intervention Network
on Behavioral Health

The AIR-B ([Autism Intervention Research Network on Behavioral Health](#)) addressed these challenges by developing a family navigation program called Mind the Gap (MTG), intended for families who have been historically underserved or delayed in accessing services (Iadarola et al., 2020). AIR-B uses a community-partnered participatory research approach that includes collaborating with community partners, including Federally Qualified Health Centers, schools, and family members, who helped develop MTG (Wallerstein et al., 2017).

Mind the Gap

MTG is a program delivered by peer navigators - caregivers of children on the autism spectrum or with other developmental delays with personal experience navigating

the service system. Peer navigators receive training in collaborative coaching strategies designed to empower caregivers by helping them learn to connect with service providers and to grow their service networks for their children on the autism spectrum, post-diagnosis. Caregivers meet with their peer navigators up to 12 times across three months to set goals related to service access and their own self-care strategies. The peer navigators support families in accessing MTG resources that include videos, activities and information related to understanding autism, navigating the service system, advocacy strategies, talking with one's family about autism, caregiver self-care strategies, and other online resources to assist caregiver understanding of child development. These resources are [freely available in English and Spanish](#).

MTG's family-driven programming allows for one-on-one direct support, setting this program apart from many typical com-

munity practices. Sue Mustard, a peer navigator from Starbridge, noted, "[The] 'peer to peer' or 'parent to parent' connection [is] so important. That is something that often is not present when working with many providers... I wish that I'd had access to a navigator and the MTG resources when my child was young, and I'm so happy to be able to provide that to others."

A pilot study of the program matched nine caregivers across the US with MTG trained peer navigators (Iadarola et al., 2020). After the MTG program, caregivers demonstrated increased knowledge of autism and identified their relationship with their peer navigators as the most beneficial feature of the program. Pat Schreiber, currently a peer navigator from Warmline Family Resource Center shared, "One mother I worked with stated that it was such a relief to connect with a parent who 'gets it,' who has walked some of the same pathways and endured some of the same challenges. This shared experience seemed to give her hope that a pathway to progress and better outcomes might exist and that she wasn't alone in trying to follow it."

Results from a larger randomized-control trial with 112 caregivers comparing outcomes between one group given access to MTG materials, and another given access to these materials and working with a peer navigator are forthcoming.

see Peer Navigator on page 33

Late-Diagnosed Autism and Camouflaging in People Assigned Female at Birth

Britt Boylan (They/Them)
Student Pursuing an MA in Mindfulness-Based Transpersonal Counseling
Naropa University

It is becoming increasingly understood that there are marked differences in autism between genders. This has led to people assigned female at birth (AFAB) to being diagnosed in adolescence or adulthood at a higher rate compared to people assigned male at birth (AMAB) (Wood-Downie et al., 2020). I was diagnosed autistic in November 2021 at twenty-six years old. It came after being misdiagnosed with type two bipolar disorder in 2015 and being “treated” for that on varying medications with no improvement. I started to suspect I was misdiagnosed in 2019 when I did not have any “hypomanic episodes” despite stopping all medications due to contraindications with pregnancy. It was not until mid-2021 that my therapist and I began exploring alternative diagnoses. Over five months, she evaluated me for autism until finally diagnosing me.

This did not come as a surprise to my family or me, but I was surprised to hear that my family suspected I was autistic but chose not to have me evaluated when I was younger. Due to this, I developed intense masking (a.k.a. camouflaging) skills that allowed me to “fit in” the best I could, but



Britt Boylan (They/Them)

forced me to internalize all my struggles related to autism. It has taken over a year, and a neurodivergency-affirming therapist, to begin the “unmasking process.” This has involved: understanding my mask, unlearning the parts that do not serve me, and learning how to live authentically.

A growing body of research suggests negative consequences from long-term camouflaging (Wood-Downie et al., 2020). It is a “risk-marker for suicidality” and

camouflaging makes recognizing autism in AFAB people much more difficult than AMAB people (Wood-Downie et al., 2020, p. 1354). Another issue is the diagnostic criteria for autism is not inclusive of the ways AFAB people express their autistic traits (Hull et al., 2020). There are theories as to why autistic AFAB people are missed in childhood or misdiagnosed and that includes social factors and camouflaging (Hull et al., 2020). Depending on the

society, there are different expectations of girls versus boys. Self-regulation, for example, can be a challenge for autistic people, but especially for AFAB people who have the strong tendency to camouflage and internalize, which again is correlated with poor mental health outcomes later in life (Wood-Downie et al., 2020).

As discussed in Lockwood-Estrin’s (2021) article, there are several barriers to AFAB people receiving an autism diagnosis, one of which being behavioral problems. They argue that “...females diagnosed with ASD needing additional behavioral problems to improve their chances of receiving a diagnosis,” (Lockwood-Estrin et al., 2021, p. 456). The same behavioral problems between young AFAB and AMAB people are not being seen because there are different societal expectations of each group. Lockwood-Estrin’s article also states that young boys were often more “aggressive and hyperactive” compared to young girls who “exhibit staring and seizure-like activities” (Lockwood-Estrin et al., 2021, p. 456). Ironically, the Center for Disease Control and Prevention (2022) lists “hyper- or hypoactivity to sensory input...” as a diagnostic criterion for autism (Center for Disease Control and Prevention, 2022). The hypoactivity aspect is largely ignored as it is common in AFAB presentations (Lockwood-Estrin et al., 2021).

see Late-Diagnosed on page 30

Why Didn’t My Pre-Diagnosis Clinicians Bring Up the Possibility of Autism?

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

So much was lost as a result of not knowing for so long. Lost happiness, because of having to contend with unanswered questions as to why I faced such daunting challenges which none of my peers seemed to be facing. Lost time, during which I lived without a complete picture of who I truly am, during which my sense of self remained compromised. Lost opportunities which I was denied due to there being no diagnosis, from which I would have benefitted had they presented themselves. So much that was lost during those years of my life as an unidentified autistic.

Better late than never, but still. I paid dearly for not finding out until 40. As I ruminate on this matter, I cannot help but look back on my pre-diagnosis clinical experiences and attempt to explain to myself why not one of these clinicians said a word to me about the prospect of autism. I don’t blame them for my late identification as an autistic, even though their silence on this matter is the singular reason why the issuance of a diagnosis was, to say the least, delayed.

My now deceased mother was a clinician. After working as a social worker at a



Sam Farmer

mental health center and a counselor for a school district helping students with emotional challenges, she went into private practice as a marital and family therapist. One night at the dinner table, she admitted something which made an impression on me and which I will never forget. She confessed that no matter how hard she might try, she would not be able to save a married couple she was counseling from what her instincts told her was inevitable divorce. Her tone while talking about this case was one of realism, of honesty, and without guilt, knowing that the outcome she saw

coming would not be her fault if it did in fact come to pass.

It was then that I came to realize that the extent to which a clinical process can help a client has its limits. Not every dysfunctional relationship can be fixed. Not every challenge can be resolved. Not every diagnosis that is waiting to be made is, in fact, accurately made. In that moment, I admired my mother’s capacity to understand and open up about her own limitations as a clinician. As such, I don’t blame my late identification as an autistic on my pre-diagnosis clinicians. I do believe that they acted according to what they viewed as my best interests and did their best to position me for greater happiness and success, as I’m sure my mother did for her clients. These types of actions are not blame-worthy. The outcome I wanted, and which I was eventually granted, would simply have to wait.

As I look back on my earlier clinical experiences through my late-identified autistic lens, I wonder about the following:

- Perhaps an autism diagnosis was too much to expect of those clinicians with whom I worked in the 1980’s and 90’s. Back then, autism was not being diagnosed the way it has been in recent years, and not nearly as often. The only person I knew at the time who had been identified as autistic exhibited challenges that seemed more extreme than mine and had unique abilities that greatly exceeded

those of my own. Furthermore, I knew another individual who faced challenges similar to mine and who, like me, was not diagnosed until considerably later in life.

- Was I actually adept enough at masking my autism to falsely lead the pre-diagnosis clinicians into believing that I was neurotypical? Before I figured out how to love who I am, feel comfortable in my own skin and bring out more of my genuine, authentic self, masking was a survival strategy upon which I depended in order to “fit in,” to delude myself into thinking I was just like everybody else and to please others as a way to avoid confrontational situations. Perhaps all of those years spent masking were collectively sufficient at persuading these clinicians to only see who I wanted them to see rather than the real me.
- Did my pre-diagnosis clinicians not possess enough knowledge of autism or practical experience with autistic clients to have their eyes open to the possibility of it or to be able to suspect or diagnose it with certainty? Maybe it did cross their mind that I should explore the possibility of autism, though they chose to say nothing because they didn’t feel the confidence that is required to take that kind of leap.

see Pre-Diagnosis on page 24

How to Get Unstuck After Receiving an Adult Autism Diagnosis

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

When I was diagnosed ASD level 1 at age 42 and realized what the staggering number of undiagnosed autistic women my age* must be, my first thought was of all the untapped talent that was out there in the world like misplaced dynamite. There was world-changing potential just waiting to be activated.

Now, I'm 52, I work for an autism and neurodiversity services non-profit, and am the happiest I've ever been. I still struggle with executive function, but it's no longer a mystery. I still think about all of the autistic women my age and wonder: are they feeling any better? If those women were like me, they were held back by unresolved trauma, contorted thinking, and the energy-hemorrhage of masking - which arose from growing up undiagnosed autistic in a world organized for neurotypical people.

For me, learning that I'd had a different operating system all along finally unlocked the potential of the twenty years of recovery and therapy work that I'd done. I've still got plenty to do, but I'd like to share some of the things I did, post diagnosis, to reclaim a more authentic self, and heal a lot of the trauma that kept me from enjoying life and managing my emotions.



Johanna R. Murphy, MFA

I realized that I was stuck; the injustices and humiliations of my childhood still ruled my day-to-day reactions. My inner self was still waiting for a trusted adult to come and validate my experience and correct the injustice. It was time for me to become my own trusted adult and **validate** my own experiences.

Getting Unstuck

I **grieved** for my childhood self and

worked on letting go of the pain and anger that held me back by developing a perspective I could live with: It was the 70s and 80s and no one knew better. That may not be an excuse, but it is a reason. I now have life experience teaching and raising kids and I know it is very hard, even with the best information, best resources, and best intentions.

I **repaired** my grief and perspective simultaneously. I was in an MFA Program for nonfiction narrative when I was diag-

nosed autistic. I had to produce a manuscript - a memoir - to complete the degree. It took a few years. I wrote until it truly was the past, instead of an ever-present shadow over my life. I got unstuck.

Forget everything you learned about blending in, forget that you aren't allowed to like all the weird things you liked as a kid. **Remember** the things from childhood that gave you deep, uncomplicated joy. After I was diagnosed, I asked myself to remember the happiest I had ever been as a child. For me it meant reconstructing my childhood 45s collection, buying a bass, and learning all the basslines that brought me such joy. That joy was permission to repair my relationship with music and my natural instincts about how I ought to live.

Reappraise your notions of what you can and can't do. I asked myself what sort of support I had needed for my hidden disabilities when I was young. Could I get that support now? For me, the element that most profoundly affected my soul was dyscalculia - specifically the element of it that impacts reading musical notation. No amount of focus helped. What I could read one day was a jumble the next. This was unspeakably shameful for me, and it completely ruled out music school because at that time a sight-reading audition was the application process.

I realized that the way I had learned to

*see **Get Unstuck** on [page 34](#)*

I Was Finally Diagnosed with High-Functioning Autism, Now What?

By Annie Kent, MA
Mental Health Systemic Advocate/
Educator, and Recently Diagnosed
"Aspie"

I suspected I was on the Autism Spectrum for over 20 years before I finally received a diagnosis. Like many people with high-functioning autism, my autism went unnoticed because I was intelligent enough to succeed in school and my autistic traits were not seen as neurodivergent, but as learning disabilities, anxiety, and depression.

I was a lonely kid, who didn't really fit in. Like many female Aspies, I can recall being the last called on in gym class for team activities. I had a few friends but "lost" most of them as my parents moved from city to city, state to state. As I got older, I found it increasingly hard to adjust to new neighborhoods and new schools and started to withdraw more into my own little world.

Upon entering University at age 16, I thought all my problems were solved. I fell in love with the study of Human Psychology, but my social skills deteriorated. Not only was I several years younger than my classmates, but I would go to class, eat lunch alone in whatever hiding spot I could find, attend more classes, and then head home to complete assignments.

My reality existed entirely in my mind, and I let no one in. I could not find mean-



Annie Kent, MA

ingful employment. I returned to University a few times, but, for the most part, had little interest in the course content, little motivation to succeed and obtained average grades - with no job at the end of it all. My depression became so severe, I begged my psychiatrist for a lobotomy!

No One Noticed My Autistic Traits

In contrast to my studies in clinical psychology and related social sciences in

which I excelled, my failures should have triggered a medical professional to refer me for Autism testing. With the knowledge of neurodivergence available today, I hope other girls fare better.

About twenty years later, after researching and educating myself about Autism Spectrum Disorders, I found a psychologist, herself autistic, who conducted the formal assessment. An MD's signature made it official. I was deeply relieved. Finally, I had the missing pieces to a puzzle that had confounded me and the many physicians I had seen.

Incorrectly Diagnosed

Despite asking about Autism for two decades, the diagnoses I received included:

- Schizoaffective disorder
- Anxiety
- Borderline Personality Disorder
- Schizophrenia
- Demonic Possession¹
- Dissociative Identity Disorder
- Dependent Personality Disorder
- Obsessive-Compulsive Disorder

- Temporal Lobe Epilepsy
- Schizoid Personality Disorder
- Bipolar Disorder
- And my "favorite:" Angel Eyes and a Lost Soul (yes, seriously)

Finally, a Diagnosis

Being diagnosed validated my experiences and improved many aspects of my life. I finally feel *real*. I am happier, but success is elusive. I blame COVID-19 and the dearth of affordable supports for newly diagnosed adults in my geographically isolated community.

"Now What" Is the BIG Question

My current psychiatrist is focusing on my coexisting attention deficit disorder, and some of my impairments do overlap with ADHD, which is also a neurodiversity. I experience *dyspraxia*: "a neurodevelopmental disorder of movement and coordination in which messages sent from the brain to the muscles are interrupted."¹ The term derives from *Praxis*, which is "the ability to combine information from the environment and successfully perform actions to completion."³ Occupational

*see **Now What** on [page 30](#)*

Neurodiverse Couples: Making Meaningful Moments of Every Day - Having a Good Afternoon

By Grace Myhill, MSW
Director, Peter M. Friedman
Neurodiverse Couples Institute
AANE

Every day there are countless opportunities for partners to create small connecting moments to enhance emotional connection in their relationship. Taking advantage of these little moments can make for big changes in your relationship dynamics. “Having a Good Afternoon” is the second of the series called “PFA Tips: Neurodiverse Couples: Making Meaningful Moments of Everyday.” Part one was [Having a Good Morning](#), and part three will be “Having a Good Night.”

Spending the Day Apart

Out of Sight Doesn’t Have to Mean Out of Mind - When you spend the day away from your partner, just because you are physically separated, doesn’t mean you have to feel apart emotionally. Letting your partner know you’re thinking about them, even when you’re apart, makes them feel loved and cared about. You can connect with your partner verbally or nonverbally. Mix it up, there is no right way to communicate, as long as it is comfortable for you both.



Something as simple as a text saying, “I’m thinking of you” lets your partner know you are happy they are part of your life. A wink emoji text sends a flirty message. A message that confirms the schedule of the day like “Do you need me to pick up anything on my way home?” or “I’m confirming that you are in charge of the carpool today,” reinforces that together, as a team, you are taking care of the re-

sponsibilities of your shared life.

When partners are in touch during the day, they are reassuring each other that they are on each other’s mind, and in each other’s hearts, even when apart.

Spending the Day Together

Being Together Doesn’t Automatically Mean Feeling Togetherness - When you

and your partner spend an unstructured day at home, it is easy to get hyper focused on whatever you are doing, and take your partner for granted, overlook them, or tune them out altogether. You may not even realize it, but your partner might feel ignored or worse yet, invisible, so remember to seek out moments to connect.

When you cross paths with your partner, give a nod or a soft touch or an “I’m looking forward to dinner with you.” If you haven’t seen them all day, poke your head into their space - give them a big smile or a quick hug, ask how their day is going, offer to get them a beverage, make them lunch or a snack that you enjoy together if possible, or let them know that you are there if they need you. Figure out what type of intimate communication, and how much of it, works for both you and your partner.

Having Fun, Together - When your day includes spending time together, make sure you pick an activity that meets your and your partner’s needs and expectations. You may have different ideas about what would be a fun activity so you may decide to take turns. If you like silent walks in nature and your partner likes chatty, fast paced walks, you can alternate or divide the walk so that everyone’s needs are met.

see [Good Afternoon on page 33](#)

Uncovering Neurodiversity in a Relationship

By Leslie A. Sickels, LCSW
Clinical Social Worker

Neurodiversity in a partnership signifies that partners’ brains are wired differently from one another. When a couple learns that someone has a diagnosis of Autism Spectrum Disorder (ASD), it can fundamentally shift the way they view their relationship. While there are inherent challenges that can arise when neurodevelopmental differences exist, many couples report feeling relieved to know there is a reason they are having misconnections. Uncovering neurodiversity in a relationship can help couples begin to understand their neurological differences, recognize how and when ASD is coming up in their relationship, and develop concrete tools to improve their connection.

Understanding Neurodiversity

In neurodiverse couples counseling, many couples report years of difficult interactions without having a context for why they are having miscommunications and unfulfilled needs. For many couples, this can lead to incorrect assumptions about their partners’ intentions, care, and even commitment to the relationship. However, once a couple recognizes a partner is on the spectrum, it can transform



these assumptions and act as a road map to repair the relationship. From a neurodevelopmental lens, everyone’s brains are wired differently during their early development, which informs how people think about themselves, others, and the world (American Psychiatric Association, 2013). It also shifts how people approach things and engage with others. Recognizing and embracing that fundamental differences exist when two people look at the world differently is the first step in shifting a relationship dynamic. Using the language of “neurodiverse partners” communicates

that both partners brains are different from one another, and each are responsible for working to improve their relationship.

Identifying Neurodiversity

Once a couple understands and begins to embrace this critical piece of information about neurodiversity, they can work on identifying how ASD is coming up in their unique partnership. Many couples seek out neurodiverse couples therapists, support groups, books, or other resources to begin to recognize how neurodiversity

is arising for them (AANE Resources for Adults, 2023). Dr. Stephen Shore, who is an autistic professor, writer, and advocate, is famously quoted for saying “If you’ve met one person with autism, you’ve met one person with autism,” which highlights that while there are core diagnostic features for all individuals diagnosed with ASD, they manifest in a variety of ways for each person on the autism spectrum. Thus, there are also a myriad of ways that neurodiversity can come up in a partnership and each couple must consider how it is emerging in their relationship. For example, there may be regular miscommunications during conversations, differences in emotional or intimate needs, challenges in one’s ability to begin and execute tasks, and in many other areas of a close relationship. When a couple can identify that something is coming up because of differences in neurological wiring, they are grounding these interactions in neurodiversity instead of becoming upset, frustrated, or angry with their partner. Shifting the way one or both partners are thinking about their relationship allows them to break out of negative patterns and cycles.

By acknowledging how neurodiversity is relevant for them, partners can begin to ground in *good intentions*, which means their actions are well-meaning towards one another. When someone views their partner

see [Neurodiversity on page 32](#)

Virtual Reality: A Tool for Making Healthcare More Accessible to Patients with Autism

By Evelyn Chan, MD
CEO and Founder
SmileyScope

For patients with autism, getting healthcare is often a struggle. My views in healthcare were heavily influenced by watching my brother, who was non-verbal and autistic, and my mother navigate the healthcare system with much difficulty. He, like many patients with autism, struggled with doctor visits so much that he missed out on much-needed care.

It's estimated that 1 in 44 children have a form of autism spectrum disorder (ASD).¹ Although the United States has made strides in improving awareness about ASD, there is still much to be improved on how they receive healthcare. Virtual reality (VR) is hoping to help with that.

How Virtual Reality Helps with Healthcare Anxiety

Children with and without autism often have needle phobia. This can make routine procedures unbearable and can lead to healthcare anxiety. It is not uncommon for a child to need to be restrained in order to administer a shot or vaccine safely.

One of my patients suffered from ex-



treme needle phobia. We decided to leverage the power of virtual reality to improve his experience. Virtual reality in pain management takes advantage of how our brain processes pain. If we were able to change a patient's negative perception of a needle procedure we could also change their negative reaction. VR does this by transporting them to a different environment - such as an undersea water adventure. While the

injection site was being prepared, all he could see and feel were waves and fish nibbling on his arm - both of which he loved. Surrounding him in a safe and calm environment allowed him to be fully vaccinated with less fear and pain.

This method is called procedural choreography, where real-world negative and painful stimuli are replaced by virtual stimuli filled with positive and friendly images.

How Virtual Reality Helps with Phobia Management

Virtual reality can also offer a safe space to manage the phobias of those with autism. Common phobias of those with autism are often fear of crowded places or small, enclosed spaces - such as MRI machines. It causes what they call sensory overload, where intense stimulus overwhelms them beyond an ability to cope.

Virtual reality allows them to be exposed to their phobia in a controlled environment. For patients with autism who have to undergo MRI, virtual reality is used to slowly expose them to a stimulated MRI and assess their ability to withstand the procedure. This can reduce their fear and anxiety and lessen the need for them to be sedated.

Studies have shown that virtual reality has drastically improved the healthcare experience. Clinical trials are showing with the use of VR there is a 60% reduction in pain, a 40% reduction in anxiety, and cut in half the need to physically restrain patients for needle procedures.² Caregivers have seen an improvement in their child's experience as well, with caregivers rating their child's distress levels 75% less than caregivers whose children did not receive virtual reality.

see Virtual Reality on page 30

A Tale of Two Diagnoses: Older Adults and School-Age Children

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

When I was first diagnosed with Asperger Syndrome in late 2000 at 44 years, I was already a middle-aged adult.

For most of my life, I had always felt that I was different from most people my age in a variety of ways, not to mention frequently reminded of such by others (usually in a very unpleasant manner). The diagnosis, at long last, explained the reasons for this. As such, it was nothing less than the explanation that I had been searching for my entire adult life (at least since adolescence). Consequently, I was elated to receive it. During my years of involvement with the adult autism community, particularly by attending and facilitating support groups, I have found this to also be the case for a vast number of autistics who are past a certain age.

For much younger individuals (particularly adolescents of middle-school or high-school age), this can be a very different story. That is the time of life when socialization and social skills become much more important than they had ever been. Being told that they are living with a condition that can impair their social functioning is literally the last thing that they want to hear. An eleven-year-old in mid-



Karl Wittig, PE

dle school will not be nearly as receptive to such as I was at the age of 44, and will certainly not feel the sense of relief that I did. These two cases need to be dealt with in very different ways.

Older Adult Diagnoses

In the context of ASD diagnosis, I generally define an older adult as someone who entered adulthood before the advent

of increased public awareness about Asperger Syndrome, so-called "high-functioning" autism, and the autism spectrum in general. Such awareness increased dramatically during the first two decades of the 21st century, but prior to that time, knowledge of these was anything but common, even among mental health professionals. In fact, the diagnoses did not even exist in the U.S. until 1994 with the publication of DSM-IV. The result of this is that anybody who came of age prior to the first several years of the 21st century was, almost by definition, undiagnosed because the diagnosis was not even known during their childhood.

The more fortunate in this population, including myself, were never diagnosed with any condition, particularly when they were "twice-exceptional" and had unusual scholastic or other abilities, or simply did not have serious enough impairments or severely inappropriate behaviors to warrant any such kind of diagnosis. Others, however, were often misdiagnosed with different conditions, ranging from milder ones like ADHD to more serious mental illnesses (the term "emotional disturbance" was often used for children). They were treated for conditions that were not even present, sometimes using ineffectual methods that often did much more harm than good (e.g., powerful psychiatric medications). In any case, these individuals rarely received appropriate treatments that

might have actually improved the quality of their lives. For that matter, the real nature of their deficits and challenges was never even recognized.

The fortunate few of us who were able to "stumble" onto the correct diagnosis when it finally became available constituted an even tinier fraction of the overall adult ASD population. They came to it by a variety of means. Some, like me, had learned about autism through the media, ranging from popular portrayals (e.g., Rain Man) to documentaries, news reports, articles, books, etc., (I managed to find a local bookstore with a small section of books about autism) to the internet (which resulted in an explosion of information) and recognized striking similarities between the individuals depicted and ourselves. Others were identified by a family member (an older sister, for instance) who had somehow encountered autism and recognized that their relative exhibited many of the traits. A substantial number of adults were also identified when their children were diagnosed on the autism spectrum and either they or the professionals working with their children recognized that they themselves exhibited the same traits (ASD is well-known to have a strong hereditary component); there is said to be an "army" of adult autistics who arrived at their diagnoses in this manner.

see Two Diagnoses on page 32

What to Do from page 1

- May appear to lack empathy
- May struggle with pretend play
- May prefer to be alone than play with peers
- Can struggle with initiating and maintaining friendships
- May memorize random facts about one topic and/or engage in intense play with one item
- Rigidity about transitions, time, travel, daily routines, feeding, and placement of objects
- Atypical body movements, such as flapping, spinning, body rocking, tense body movements, toe-walking, finger-flicking, and finger twisting/crossing

The Assessment Process

Over the past several years, there has been more attention given to ASD, and parents, caregivers, and professionals are likely paying more attention to possible developmental differences associated with ASD. Therefore, it is important for parents and caregivers to know how to go about obtaining an ASD diagnosis and what to do once a diagnosis is received, as the entire process can be quite overwhelming and confusing and contribute to families feeling lost and alone when they have limited knowledge. As a parent or caregiver, if you suspect that your child may have ASD, then it is best to act as early as possible by talking with your child's primary care physician or pediatrician to get an autism assessment completed. Once you have obtained a referral for an autism assessment or have sought out an autism specialist on your own, then you want to keep the following in mind as you prepare for the assessment and throughout the duration of the assessment process.

- Prior to attending any appointments, talk with those who have already worked with your child. This may include teachers, therapists, or medical specialists. Have these individuals write down their observations or prepare a letter for you to provide at the time of the assessment.¹
- Keep your own log of your observations of your child. You can use this log as a reference at the time of the initial assessment appointment when asked to share your concerns and reasons for seeking out the ASD assessment.¹
- Ask someone from your support system to attend assessment appointments with



April L. Coleman, PsyD

you and your child. It can be helpful to have an additional person take notes while you are talking with the autism specialist and who can help you keep track of decisions made.

- While waiting for an ASD diagnosis, do not wait to obtain services. If your child is younger than 3 years old, go ahead and connect with your local early intervention program. If your child is older than 3 years old, make contact with the early intervention special education department within your local school district.³

Participation in an ASD assessment will either confirm or disconfirm the diagnosis and help you determine what supports and interventions would benefit your child and your family. Your physician would be able to give you a referral to an autism specialist, which can be a child psychologist or developmental pediatrician. Once connected with the autism specialist, be prepared to participate in an interview to provide as much information as possible about your child and family history (e.g., social skills, language and communication, physical health, family dynamics, etc.) and to provide any relevant medical, school, and/or mental health records. You may be directly asked what makes you suspect your child has ASD, so think about this and be prepared to answer as best as possible. The assessment will also address your child's developmental functioning, cognitive ability, adaptive functioning, and social communication and interaction through direct play observation, classroom observations, and rating scales completed by you and teachers. It is also strongly recommended that you seek a full medical examination, including pediatric neurology,

vision, and hearing, to determine if there are any associated medical conditions that may be contributing to your child's developmental differences.

Once the evaluation is complete, you will receive a written report with results of the evaluation. This report may tell you that your child has ASD, where your child falls on the autism spectrum, and include specific recommendations for next steps. The report can also say that your child does not have ASD or that there is not enough information at the time to give an ASD diagnosis. With the latter case, another evaluation may be needed when your child is older.⁴ If the autism specialist does not believe your child has ASD, but you still have concerns, it is okay to ask for a second opinion. In such circumstances, never let your concerns get dismissed.

Once your child has received an ASD diagnosis, schedule a follow up appointment with the autism specialist to discuss the results of the assessment and to ask any questions you have about the written report you receive. You also should read and learn as much as you can about therapies and supports to address your child's specific needs, and be sure to build your support network, including participation in autism parent support groups and forums and seeking out family support to help you make sense of all of the information you have received.⁴

Dr. April L. Coleman is a Georgia licensed psychologist and the clinical training site coordinator at the Georgia Autism Center in Peachtree Corners, Georgia. She is also a published author and speaker. She has been working in the mental health field for 16 years and has been in private practice for the past 9 years. Dr. Coleman specializes in the comprehensive assessment of Autism Spectrum Disorder (ASD), specific learning differences, Attention-Deficit/Hyperactivity Disorder (ADHD), and anxiety. She works with individuals aged 12 months through young adulthood. Dr. Coleman speaks at various school and agency events in which she educates parents and caregivers about the common signs of ADHD, ASD, specific learning differences, and anxiety; when it is time to seek support from a qualified professional for an assessment; and what next steps should be once the assessment process is complete and diagnoses are shared.

Dr. Coleman enjoys working with families from diverse backgrounds and circumstances. She has worked in a variety of settings, including schools, community mental health clinics, community service boards, child advocacy centers, specialized treatment centers, social service agencies, and private practice. She has also collaborated with institutions to conduct

assessments within residential treatment facilities, within juvenile detention centers, within foster homes and group homes, and for the Georgia Division of Family and Children Services. With her years of experience, Dr. Coleman's clinical work extends beyond the assessment process and also involves providing support, guidance, and consultation to parents and caregivers post diagnosis to ensure that the families' needs are met as best as possible.

Dr. Coleman is a former clinical psychology graduate level professor of five years in which she taught child and adolescent psychopathology and life span development, and she led a diagnostic assessment seminar for students within the child and family curriculum. She also is the current practicum site supervisor for graduate level students at Mercer University and the University of Georgia. Dr. Coleman is a graduate of Georgia State University and The Georgia School of Professional Psychology. She holds a Bachelor of Science degree in Psychology and a Master of Arts and Doctor of Psychology in Clinical Psychology. Dr. Coleman resides in Metro Atlanta with her husband and their 2-year-old daughter.

More information about Dr. Coleman and how to connect with her can be found at www.draprilcoleman.com and www.georgiaautismcenter.com.

Footnotes

1. Action for Children. (2022, May 11). What should I do if I think my child has autism? Support for Parents from Action For Children. Retrieved February 7, 2023, from <https://parents.actionforchildren.org.uk/additional-needs-disabilities/understanding-additional-needs/autism/>
2. Centers for Disease Control and Prevention. (2022, March 2). Data & statistics on autism spectrum disorder. Centers for Disease Control and Prevention. Retrieved February 7, 2023, from <https://www.cdc.gov/ncbddd/autism/data.html>
3. Pratt, D. C., Tomlin, D. A., Minshawi, D. N., & Boyce, G. (n.d.). What to do if you suspect your son or daughter might have an autism spectrum disorder. Indiana Resource Center for Autism. Retrieved February 7, 2023, from <https://www.iidc.indiana.edu/irca/learn-about-autism/what-to-do-if-you-suspect-your-son-daughter-might-have-an-autism-spectrum-disorder.html>
4. Signs of autism in children: What to do. Raising Children Network. (2022, October 25). Retrieved February 7, 2023, from <https://raisingchildren.net.au/autism/learning-about-autism/assessment-diagnosis/autism-signs-in-children-what-to-do>

Pre-Diagnosis from page 20

- Did some or all of them suspect autism yet refrain from disclosing their suspicion because of the social stigma that surrounds it? If so, I can imagine them not wanting to scare me or lead me into a state of depression. Those of us who are stigmatized often face pronounced emotional and mental health vulnerabilities. It seems to me that a discussion between a suspecting clinician and the client about the prospect of autism be-

comes more likely, and easier to have, if the stigma doesn't exist. This is what neurodiversity self-advocates including me are working toward. The prevailing narrative needs to change.

Shortly before my 40th birthday, my wife and I agreed that there might be more to me than my auditory processing learning difference and that this was worth investigating. Eventually I would learn from one of my pre-diagnosis clinicians that a neurological evaluation might shed light

on any challenges or diagnoses that were there the whole time but of which I wasn't yet aware, and sure enough it did just that. The revelation of autism felt like quite a gut punch when I first noticed it in the neuropsychologist's final report, though it would eventually prove to be both beneficial and transformative.

Even though my pre-diagnosis clinical journey concluded later than I would have preferred, and deserved, at least it led me to a diagnosis when it was meant to happen, I suppose. Better late than never. All

is well that ends well.

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.

Happier Life from page 1

looking for throughout my life. Another day I'd feel shocked and even embarrassed. At times, I felt depressed that I had struggled so much and for so long, and aggrieved for the life I might have had if I'd had the awareness I'd recently gained. I liked knowing that there was a reason for the issues I faced but I didn't like labelling them as autistic. For a long time, I found it very hard to reconcile the facts that I'd lived a whole life, was a mother, a wife, a business owner, and I had autism. I didn't quite know how to use the information in a productive way.

As I let the diagnosis sink in, though, I found that I had started to think about things differently. Instead of constantly trying to find a solution to my issues, and criticizing myself for being less able than most people when it came to certain situ-

ations, I found myself accepting that certain situations were fundamentally harder for me to deal with. The funny thing was that, once I accepted that certain things were harder for me than they were for most people, I found some of those things became a bit easier. By not trying to reach unattainable standards, I found ways of being which were ok. And I was ok with that. One example was how I interact socially. After my diagnosis, instead of pushing myself to keep my mask up all the time, I allowed myself to admit if I was lost in a conversation, or to say something silly or ask for clarification without that leading to hours of rumination.

For the first time in my life, my anxiety levels reduced significantly. Post-diagnosis, there simply wasn't so much stuff to worry about. I knew why things were difficult; the frustrating mysteries of my life had disappeared. I knew when I needed

help and how to help myself.

Most importantly, I now accept *myself*. I'm proud of what I've achieved. I'm proud of a brain which processes things in the way it does. I don't see my autism as inhibiting me in any way. It's always been there. But now, I can acknowledge it and take ownership of the way I process and understand the world.

Claire Jack, PhD, is an autistic therapist and training provider who provides life coaching for autistic women. Claire is the author of "Women with Autism: accepting and embracing Autism Spectrum Disorder as you move towards an authentic life," "Level 1 Autistic Teens: A solution-focused approach to parenting," and "Raised by a Narcissist: 7 steps to healing the wounds of a toxic childhood." For more information, visit www.drclairejack.com or email claire@academyinnermind.co.uk.



Claire Jack, PhD

Program from page 4

focused specifically on the caregiver's well-being and mental health. The caregiver support track includes tailored messaging, resources, and education based on each individual's level of need for psychosocial support.

Upon enrollment in the program, participants (in this case, caregivers of Amerigroup's members with autism between the ages of 0-18) are asked a series of questions to gauge the types of resource/support needs their children have. Additionally, the questions assess the amount of support they need in coping with the stress and challenges associated with their role as a caregiver. Prompt questions include, "In the past three months, how often do you feel you've been able to enjoy quality time together as a family?" and, "On a scale of 0-10, how would you rate your overall stress level?" Participants who indicate that they enjoy family time infrequently or never and/or those who indicate stress levels greater than five are automatically contacted by Amerigroup care coordinators (who are notified via 'smart' escalation logic) who use **GoMo Chat™** (a HIPAA compliant text-based communication system) and/or phone to contact the caregiver

directly and work towards de-escalation and avoidance of adverse events.

These same questions are asked again quarterly using the GoMo Health How Are You Doing (HAYD) survey to continuously check-in with members, as overall stress levels and emotional health can change quite frequently. This quarterly check-in also allows assessment of program engagement and its effects on stress levels over time.

In addition to triggering contact from Amerigroup care coordinators, responses to these questions allow participants to enroll into additional program messaging tracks that provide extra support, education, and resources for those with more significant psychosocial needs and stressors. While content is pulsed out in a logic-based, pre-defined cadence, participants are also able to text in simple keywords that trigger specific in-the-moment content anytime, anywhere. This allows caregivers to receive support within their lived environment and in their specific moment of need.

Since the program's launch in July 2022, electronic patient reported outcomes data (ePRO) has been collected and indicates strong program impact including:

- 39% reduction in emergency department (ED) visits

- 66% reduction in inpatient stays
- 8% reduction in crisis events
- 9.25% increase in caregiver-reported child well-being
- 4.8% increase in caregiver-reported family quality time
- 19.2% increase in caregiver confidence in caring for their child with autism.

Danielle Nabinger, MSW, is a Consultant with Amerigroup Georgia. Rebecca Lyons, MPH, is Senior Project Manager and Shelley R. Schoenfeld is Chief Strategist at GoMo Health. For more information about the Amerigroup Early Intervention Personal Concierge Program and other digital health management programs, please visit <https://gomohealth.com/campaigns/dei-in-healthcare/> or text DEI to 43386.

References

Li, Wen; Yang, Yuan; Liu, Zi-Han; Zhao; Yan-Jie; Zhang, Ling; Cheung, Teris; et. Al. The first national action plan on depression in China: Progress and challenges. *The Lancet Regional Health Western*

Pacific. 2021 Feb.

Malik-Soni, N., Shaker, A., Luck, H. et al. Tackling healthcare access barriers for individuals with autism from diagnosis to adulthood. *Pediatr Res* 91, 1028–1035 (2022). <https://doi.org/10.1038/s41390-021-01465-y>

Picardi A, Gigantesco A, Tarolla E, Stoppioni V, Cerbo R, Cremonte M, Alessandri G, Lega I, Nardocci F. Parental Burden and its Correlates in Families of Children with Autism Spectrum Disorder: A Multicentre Study with Two Comparison Groups. *Clin Pract Epidemiol Ment Health*. 2018 Jul 31;14:143-176

Smith, Melinda, M.A., Segal, Jeanne, Ph.D., Hutman, Ted, Ph.D., Help Guide: Helping Your Child With Autism Thrive. HealthGuide International, Dec. 22, 2022

Thompson, Dennis, Childhood Autism Diagnosis Is Getting Better, But Not for Everyone. *HealthDay News*, Jan. 26, 2023

Zhou, Wensu MDa; Liu, Dan MPHb; Xiong, Xiyue PhD*, Xu, Huilan PhDa*. Emotional problems in mothers of autistic children and their correlation with socioeconomic status and the children's core symptoms. *Medicine* 98(32):p e16794, August 2019.

Telediagnosics from page 9

it opens up access to care so readily, fitting into individual's and family's lives. While there will be times when telediagnostic is clinically contraindicated, or a telediagnostic service will require in-person follow up, it appears to our organization that this will become more the exception than the rule. Post-pandemic, many families are now more comfortable and knowledgeable about an array of telehealth services as research is continuing to be published regarding the effectiveness of telehealth services across disciplines and services (e.g., psychotherapy, parent training, coaching). However, there are families who would still prefer to be seen in-person due to their discomfort of managing the technology necessary for a successful telediagnostic session or not having sufficient space to engage in the play behavioral observation. Organizations should be conducting a thorough screening of patients and their caregivers to determine if they would be best suited for an in-person evaluation. If

that screening does not occur, the family may miss valuable time due to needing to schedule follow-up visits or receiving incomplete evaluations.

In summary, telediagnosics demonstrates high agreement to in-person ASD evaluations, meaning that no matter how the evaluation is completed, as long as the psychologist is trained and knowledgeable about ASD and the evaluation procedures, the results will be the same. We know that many families experience a long wait between receiving a referral for an ASD evaluation and receiving the services. Research consistently shows that early identification and intervention are critical for positive outcomes in acquiring speech (Ben-Itzhak & Zachor, 2007; Tiura et al., 2017). Catalight has found that our high-quality ASD telediagnosics are able to reduce those wait times for evaluation and behavioral health therapies and increases treatment access to individuals in underserved communities.

Nina Rudnick, PsyD, is Director of Be-

havior Health at Catalight Care Services. Lindsey Sneed, PhD, BCBA-D, is Vice President of Clinical Excellence at the Catalight Research Institute. For more information, email research@catalight.org.

References

Alfuraydan, M., Croxall, J., Hurt, L., Kerr, M., & Brophy, S. (2020). Use of telehealth for facilitating the diagnostic assessment of Autism Spectrum Disorder (ASD): A scoping review. *PLOS ONE*, 15(7), e0236415. <https://doi.org/10.1371/journal.pone.0236415>

Ben-Itzhak, E., & Zachor, D. A. (2007). The effects of intellectual functioning and autism severity on outcome of early behavioral intervention for children with autism. *Research in Developmental Disabilities*, 28(3), 287–303. <https://doi.org/10.1016/j.ridd.2006.03.002>

Juárez, A. P., Weitlauf, A. S., Nicholson, A., Pasternak, A., Broderick, N., Hine, J.,

Stainbrook, J. A., & Warren, Z. (2018). Early Identification of ASD Through Telemedicine: Potential Value for Underserved Populations. *Journal of Autism and Developmental Disorders*, 48(8), 2601–2610. <https://doi.org/10.1007/s10803-018-3524-y>

Stavropoulos, K. K.-M., Bolourian, Y., & Blacher, J. (2022). A scoping review of telehealth diagnosis of autism spectrum disorder. *PLOS ONE*, 17(2), e0263062. <https://doi.org/10.1371/journal.pone.0263062>

Tiura, M., Kim, J., Detmers, D., & Baldi, H. (2017). Predictors of longitudinal ABA treatment outcomes for children with autism: A growth curve analysis. *Research in Developmental Disabilities*, 70, 185–197. <https://doi.org/10.1016/j.ridd.2017.09.008>

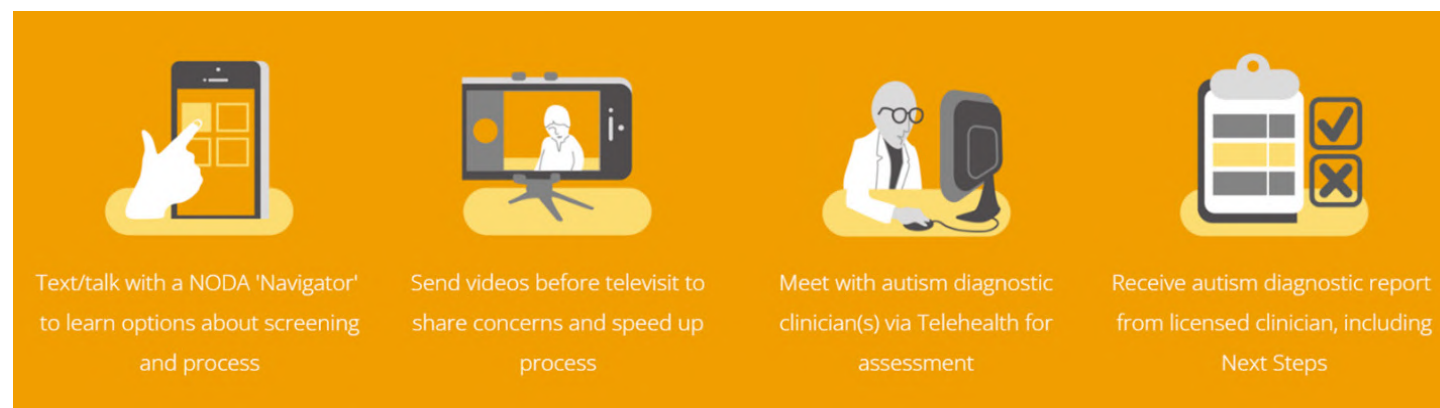
White, S. W., Oswald, D., Ollendick, T., & Scahill, L. (2009). Anxiety in Children and Adolescents with Autism Spectrum Disorders. *Clinical Psychology Review*, 29(3), 216–229. <https://doi.org/10.1016/j.cpr.2009.01.003>

NODA Telehealth from page 11

development history questionnaire. They then follow instructions to capture and share clinically-guided video examples of their child's behavior in and around their home.

2. A licensed NODA diagnostic clinician who is already trained to assess autism in-person will receive the in-home behavior specimen collection (videos and developmental history) via their secure access to the NODA Telehealth platform. During their analysis, this clinician may interact with the family through the NODA app if more data is requested. The NODA clinician analyzes each video sample and *clinically tags* all atypical and typical behaviors based on his/her clinical judgment, and the platform correlates these tags to DSM-5 criteria if applicable.
3. (Since 2021) The NODA Clinician will then use a novel real-time telehealth tool that enables him/her to interact with families via video chat, so he can gather more history and potentially analyze / archive additional naturalistic behavior data. At this juncture, the clinician can usually educate families about their findings and recommended next steps.
4. The NODA clinician then can provide a thorough report of findings via a diagnostic assessment report that the families can access from their NODA app. These reports are instrumental to qualify the child for intervention services if warranted.

With family consent, referring providers, insurance payors, and treatment clinicians can be included in the distribution of



this diagnostic assessment report. A *NODA report* can also provide a list of local or online treatment centers, which could jumpstart the process of matching a diagnosed child with a specific treatment provider.

Any telehealth program used to deliver healthcare for any health condition operates more effectively when the clinicians make their clinical decisions with the same degree of confidence relative to an in-office visit. Several prospectively-executed research studies funded by the National Institutes of Health confirm that clinicians have a high level of confidence when using NODA to evaluate patients. Most families do not consider a virtual exam as inferior to an in-office visit. As one family described their experience to one of the clinics that now uses NODA for all diagnostic assessments during and post-pandemic, “We just got a diagnosis from the *Southwest Autism Research & Resource Center (SARRC)*. The wait time was really short, everything was done over the phone or on the computer, and everyone I spoke with was really pleasant to work with. We were very happy with them!” That is the goal for any telehealth technology provider, especially

when it involves a more efficient way to collect and analyze data for one of the most important moments in finding life-changing solutions for their child.

By following the NODA protocol, families can save time and reduce stress by avoiding long travel times and waitlists associated with in-person assessments. NODA also allows *clinicians* to perform assessments while they are traveling, after clinic hours, on weekends, and it has the added benefit of clinicians observing the individual in the patient's natural setting when behaviors occur and/or via a video chat. This new way of gaining evidence for a diagnostic assessment has the potential to revolutionize the way autism diagnoses are made and provide families with earlier access to intervention services.

For more information, visit <https://behaviorimaging.com/NODA>.

References

Matthews NL, Abowd GD, Rozga A, Fein DA. Medical and Healthcare Applications. In: O'Brien HL, Rogers WA, Fisk AD, editors.

Handbook of Human-Computer Interaction in Healthcare. Springer; 2010. pp. 563–580.

Nazneen N, Matthews N, Smith CJ, Rozga A, Abowd GD, Oberleitner R, Arriaga RI. Supporting in-home collection and sharing of behavior specimens for diagnostic assessment of children with autism. *J Biomed Inform.* 2015 Aug;56:147-57. doi: 10.1016/j.jbi.2015.05.006. Epub 2015 May 18. PMID: 26002838; PMCID: PMC4541279.

Oberleitner R, Ball J, Gillette D, Naseef R, Stamm BH. Technologies to lessen the distress of autism. *Journal of Aggression, Maltreatment & Trauma.* 2006 Jan 1;12(1-2):221-42.

Smith CJ, Rozga A, Matthews N, Oberleitner R, Nazneen N, Abowd G. Investigating the accuracy of a novel telehealth diagnostic approach for autism spectrum disorder. *Psychol Assess.* 2017 Mar;29(3):245-252. doi: 10.1037/pas0000317. Epub 2016 May 19. PMID: 27196689; PMCID: PMC5116282.

Southwest Autism Research Center (Phoenix, AZ) Letter from the President / CEO – February, 2023.

NODA from page 11

out his job responsibilities, Ron was struck by the thought that this technology could be implemented for his and other families who, along with their children, were experiencing an increasingly difficult situation. There was always a hounding thought, “Why aren’t we doing this to help doctors see what’s happening in our home?”

Robby was ultimately diagnosed with autism in 1996. That led directly to the formation of Princeton Autism Technology by Ron and Sharon Oberleitner. The family formed a nonprofit that collaborated with autism doctors to assess if and how *telehealth images* could expedite and improve access to healthcare for families with autistic children. Several pilot studies with interested autism centers showed the promise of what parents can provide if asked to send video data, and agencies including NIH, Dept of Defense, and private autism foundations started funding pilot projects.

After developing telehealth applications for treating children with autism showed great promise to help get their own son



The Oberleitners at the annual autism research meeting (INSAR) in Rotterdam, Netherlands in 2018

treatment for his challenging behaviors, Ron and Sharon organized a multi-disciplinary team of diagnostic clinicians, academic researchers, technologists, parents

plinary team of diagnostic clinicians, academic researchers, technologists, parents

of children with autism, and other medical device industry veterans to create a telehealth platform to enable what is now known as the Naturalistic Observation Diagnostic Assessment (NODA™). What has emerged is the most prospectively research-based telehealth method to help young families who have suspect that their child should be evaluated for autism.

NODA was developed in conjunction with Georgia Tech University, Southwest Autism Research and Resource Center (Phoenix, AZ), and several other leading academic research partners, and is proving conclusive for over 88% of children when compared to the conventional In Person Assessments (IPA).

Since the pandemic, NODA has helped thousands of families connect remotely to diagnostic doctors, and there are now over 1,000 clinicians who've received online training for NODA, and more than 40 clinics in 20+ states in 5 countries who have incorporated NODA into their practice. The app has been translated into Japanese, Sweden, Arabic (Saudi Arabia), and Spanish for international uses and underserved US populations.

Supporting Parents from page 13

Once a child is diagnosed with autism, a multitude of services and visits become centered around the identified child. As illustrated, this typically triggers a substantial increase in caretaker responsibilities

ties and expenses. This scenario can often leave neurotypical siblings feeling isolated, worried, and insecure about the new family dynamic. Siblings need to have a good grasp on revised circumstances and experience ongoing parental support. Parents, too, need support while rising to

the time and transportation needs of their autistic child. It's essential for parents to structure time off, and alone time, where possible, to support their adult relationships and emotional equilibrium as they move forward with their revised everyday life.

Georgia Efthimiou, MA, BCBA, is Northern New Jersey Regional Director; Kristen Daneker, MS, BCBA, is Pennsylvania Regional Director; Brandon Sierchio, MA, BCBA, is Southern New Jersey Regional Director; and Howard Savin, PhD, is Clinical Advisor at *First Children Services*.

Sharing from page 10

stereotypes. One needs to be flexible and creative. All techniques do not work for all people with ASD. My son is different like everyone else.” If people in one’s family or social circle do not understand the diagnosis, feel overwhelmed or have difficulty coping with the diagnosis, then accompanying loved ones for appointments with medical and treatment providers, along with becoming more informed through good psychoeducation, can help people cope, adjust, learn more about enhancing the skills and capabilities of the person living with the disability, along with how best to provide support.²

Jajaida Gonzalez, Vice President of S:US’ Day Habilitation Services, shares, “It is important to see abilities in everyone; challenges of a person evolve and shift since a diagnosis was given to them, whether it was recently given or from years ago. A person at 25 years of age can have a lifetime, many years of education and good support and can become so capable. Family members (and the wider community) can carry the initial experience of the diagnosis throughout their lives. They need to see or be open to seeing the evolution, shifts and growth that can happen throughout the life of their loved one who lives with a disability and realize all of the possibility... that a person with a disability can embody, can become.”

Jajaida models this sense of open-mindedness and open-heartedness, empathy, and compassion for participants who attend S:US’ day habilitation programs, their family members and advocates, along with her staff. “People are far more than their diagnosis and symptoms. It is always better to meet the person, learn who they are now, interact with them, observe them, and to try new things with them. It is so important to meet them at the stage of life where they are now. There is a profound impact that education, support, and life experiences have on each person and helps each person learn, evolve, expand, and grow as a human being.”



Lori Lerner, LMSW, RYT-200 hr.

For over 20 years, Yvette McBean has worked with adults with disabilities including ASD and I/DD in both residential settings and day habilitation programs at S:US. Currently, Yvette serves as the Program Director at Valerie’s day habilitation program. Over the years, Yvette has learned that “...everyone is special in their own unique way. For me – due to my creativity, patience, sensitivity, and flexibility – I am able to tap into what works for the people that I support who live with a disability. At the end of the year, I will often ask the participants of my program, ‘What do you want for the new year? What do you want to accomplish?’ I value and respect them and they are important to me. What they say matters and I, as the Program Director, plus my team of Direct Support Professionals (DSPs) try to weave in their wishes into our programming for the year.” It is with this strong sense of attunement and communication that people at her program feel acceptance, compassion, kindness, and empathy. Tasha, Valerie’s friend and another participant in the same program, feels a lot of kindness

and compassion from Yvette and her staff. She shared, “There are good people here in this program and I get good support from them. They work with us, help us learn more, give us good coping skills, learn how to talk about stuff and not fight, get along with people, go on trips, learn how to cook meals like jerk chicken, and talk about relaxation and anger management. When I get mad now, I don’t fight, I talk about it and take a walk.” The coping skills that Tasha and her peers have learned from Yvette and her team of DSPs have helped them nurture a sense of acceptance, compassion and kindness for themselves, their peers, and their community.

Marcus Gutierrez, a Quality Intellectual Disability Professional (QIDP), at the same program managed by Yvette, comes to the field embodying sensitivity, respect, and awareness both as a professional and as a father of two sons with ASD. He shares, “As a staff person, I need to be really sensitive and aware of certain things for the people that I support with a disability. Some have great support, rich support systems with family, friends, and people who check up on them. And some have little to no support system which makes things really hard, magnifies everything. It makes me want to learn more and be more aware of what they deal with... be more sensitive overall to people everywhere and people living with a disability. I want to be mindful, respectful, and more compassionate of what a person deals with. As a parent, I know that my two sons need a lot of support – physically, emotionally – and they need my attention. They need my help on how to live every day, they make me want to be more responsible, more attentive to their needs and raise my awareness of how conscious I am with them. I wear many hats – teacher, supporter, parent – to support them and to help them be as integrated into society as much as possible.”

It is with kindness, compassion, mindful awareness, acceptance, and empathy that people living with a disability – whether it be ASD, I/DD, or another disability

– develop coping skills, evolve, and grow towards what they want to pursue so that they can be fully integrated into their communities and the larger society. Several parents and family members who were interviewed for this article expressed that they are enormously grateful about the increase of awareness about people living in the community with ASD, I/DD, or another disability, and feel this greater sense of inclusivity, sensitivity, and ease when they encounter other people with a disability and when they are out with their loved one with a disability in their community.

In his book *Books for Living*, the author Will Schwalbe writes about the book *Wonder*, which focuses on a main character with a disability, and how it reminds us to embody kindness. He writes, “Choose kindness. Whenever there’s a choice – and we are faced with such choices almost every minute of every day – this is what the book...[*Wonder*]... would have us remember... the challenge after reading this book is to wonder if, in fact, we are choosing kindness – and to try to challenge ourselves to live more kindly.”³ When sharing a diagnosis of ASD, I/DD or a disability along with living with a disability, an adult needs acceptance, compassion, empathy, sensitivity and kindness in order to thrive and flourish in their milieu and in their community.

Lori Lerner, LMSW, RYT-200 hr., is Coordinator of Family and Wellness at Services for the UnderServed (S:US). Ms. Lerner may be contacted by email at llerner@sus.org or by phone at (917) 408-5366.

Footnotes

1. “Inside the List” by Elisabeth Egan, *The New York Times*, January 15, 2023.
2. “Sharing an Autism Diagnosis with Family and Friends” by Rachel Ehmke, Child Mind Institute, January 30, 2023.
3. *Books for Living* by Will Schwalbe, Alfred A. Knopf, New York, NY, 2016.

CDC Overview from page 14

- 9 months
- 18 months
- 30 months

In addition, AAP recommends that all children be screened specifically for ASD during regular well-child visits at these ages:

- 18 months
- 24 months

Screening questionnaires and checklists are based on research that compares your child to other children of the same age. Questions may ask about language, movement, and thinking skills, as well as behaviors and emotions. Developmental screening can be done by a doctor or nurse, or other professionals in healthcare,

community, or school settings. Your doctor may ask you to complete a questionnaire as part of the screening process. Screening at times other than the recommended ages should be done if you or your doctor have a concern. Additional screening should also be done if a child is at high risk for ASD (for example, having a sibling or other family member with ASD) or if behaviors sometimes associated with ASD are present. If your child’s healthcare provider does not periodically check your child with a developmental screening test, you can ask that it be done.

[View and print a fact sheet on developmental monitoring and screening](#)

Developmental Diagnosis

A brief test using a screening tool does not provide a diagnosis, but it can indicate whether a child is on the right development track or if a specialist should take a closer

look. If the screening tool identifies an area of concern, a formal developmental evaluation may be needed. This formal evaluation is a more in-depth look at a child’s development and is usually done by a trained specialist such as a developmental pediatrician, child psychologist, speech-language pathologist, occupational therapist, or other specialist. The specialist may observe the child give the child a structured test, ask the parents or caregivers questions, or ask them to fill out questionnaires. The results of this formal evaluation highlight your child’s strengths and challenges and can inform whether they meet criteria for a developmental diagnosis.

A diagnosis of ASD now includes several conditions that used to be diagnosed separately; autistic disorder, pervasive developmental disorder not otherwise specified (PDD-NOS), and Asperger syndrome. Your doctor or other healthcare provider can help you understand and navigate the diagnostic process.

The results of a formal developmental evaluation can also inform whether your child needs early intervention services. In some cases, the specialist might [recommend genetic counseling and testing for your child](#).

View the original source of this article [here](#).

References

1. Lord C, Risi S, DiLavore PS, Shulman C, Thurm A, Pickles A. Autism from 2 to 9 years of age. *Arch Gen Psychiatry*. 2006 Jun;63(6):694-701.
2. Hyman SL, Levey SE, Myers SM, Council on Children with Disabilities, Section on Developmental and Behavioral Pediatrics. Identification, Evaluation, and Management of Children with Autism Spectrum Disorder. *Pediatrics*. 2020 Jan;145(1).

Autism Belize from page 16

classrooms they have a total of 54 teachers working with more moderate to significantly challenged. Most of these teachers got one class in Special education during their schooling.

But Briceño has stuck with a strategic plan. And training teachers is a huge part of it.

“We need to get teachers that are not only passionate, but have the right attitude. We need to work on attitudes. Changing their attitudes.” If it’s just a job?... We need culture change!”

Almeida cuts in:

“10 years ago we were in denial. We did 24 teacher trainings last year, which is good, but then you sometimes go into their classroom, and you go, ‘Where’s the visual schedule?’”

Briceño returns:

“(The teachers) know a lot more than they think they do, and that’s why a lot of it also has to do with the implementation... At some point we have to get them to be open to new ideas...(Even) the principals now are open. They’re not saying ‘no’ anymore. But they need a lot of support and training.”

For a short while, the interview then turns into a conversation between Briceño and I. We trade “That is not ‘inclusion’” stories from our consulting backgrounds. Briceño shares with me how they’re creatively enticing trainers from abroad in exchange for free vacations...

And on autism?

“It’s not a taboo subject anymore... Parents are demanding the appropriate education for their children. Once they understand that it’s not the end of the world. That this is a behavior... We’re understanding more of why the children behave this way.”

She has inexplicably gone over her frustrations far more than expected. So, I ask what she is proud of. The answer? Her, her team, and the work of the Ministry of Education. *“Over the last 3 years we have out surpassed all the work of the past.”*

The focus then turns to Christy Almeida, whom I know somewhat prior from several emails and a training I once gave her organization, albeit through Zoom. She’s astonishing: A single mom with a 15-year-old, adult-sized, non-speaking son. She is still rebuilding the home that was flooded a few months ago by the last major storm. Given all that, Almeida should be infinitely more fatigued than she is and appears. She too, like Briceño, drives her points home, but unlike the First Lady’s affability, Almeida has a righteous aggression to her passion that is distinctly hers. In my meetings with her, the toughness, the engine, and the intelligent spark dominates. No surprise that when it comes to a “go to” on autism, she’s the one on Belizean TV or radio for a reason.

(Don’t get me wrong: Now a friend, I can attest that) Almeida is fun, but she does not need mutual laughter to enrich or reassure a conversation when it is about serious



H.E. Rosanna Briceño in front of a photo of her husband, Prime Minister John Briceño

subjects.

Briceño: *“Christy does most of the work. She’s passionate! Christy has put her life story on the table!”*

Her Excellency stated that when they first met and Almeida told Mrs. Briceño about her plans for Autism Belize, that the First Lady thought to herself “yeah, yeah, yeah. I’ve heard that before. Let’s see if you (Almeida) can do the follow-up. “*She can, and she did.*”

Almeida chimes in: *“A lot of people say they want to help you, but you don’t know what you don’t know... You know when I go into the Belize airport, they don’t have a family bathroom, they only have the handicap bathroom. I have to take my six-foot-one son in the female bathroom then into the handicap stall. And this has happened more than once that by the time I get out, someone’s reported that... ‘there’s a guy in*

the (female) bathroom.’” Almeida says it always gets worked out, but that, “you can tell that (my situation) has never dawned on them.”

With less than 48 hours’ notice, eight parents from Autism Belize have come to an impromptu sharing session with me at 6 pm on the Wednesday I am there. In relative terms, such numbers are wonderful for a startup such as this. And, as per usual, the attendees are mostly moms.

One could write so much about the value in the relationships these parents have with one another as individuals. But what is so starkly evident is that the real value to them as individuals lies in the collective. And as and in that collective they are good, and also fun. They appreciate the guest (me) and pepper me with questions, but the answers they receive pale in comparison to the reassurance they feel to be with one another. Most know enough about autism to know that the youngsters who might appear like me (or my older son) are far from being diagnosed still in Belize (one or two who came alone gleefully refer to their husbands back at the house as “probably”). They are aware of what is to come.

And they do not let their more-challenged and non-speaking kids make them vulnerable to unhealthy attitudes. They share the stories of celebrated difference as well the challenges. Karate vs. dancing is discussed for one child who is being bullied. A non-speaking 12-year-old girl encountering puberty is surprisingly much more bothered by the new bra than by the menstrual changes to her body. Both dads in attendance don’t know how to *not* overwork...

As always the world over, these autism parents too, need to enjoy life outside their children, and often they will need the help of each other to make that happen. And of course they resist, falling into the (monstrously inaccurate) martyrdom stereotypes of parenting that we are led to believe is noble. Their children, “after all,” cannot



Michael John Carley

be understood or properly cared for by strangers. But even their most challenged children can be understood, if not by the world someday, at least by each other.

I asked one poor dad, Alex, how he can make room for more pleasure in his life. He answers why that’s not possible, and I call him on the fact that he is dodging my question by focusing on what he can’t do, as opposed to what he can do, and everyone laughs knowingly; not because it’s any brilliant insight, but because they all recognize that they would answer similarly. They need more meetings like this.

Almeida made sure there was a feast of sandwiches and chicken fingers for the attendees, and lemonade filled with minced apple pieces to wash it down. But it is almost entirely left untouched. Clearly, their nourishment is each other.

Attitude change costs nothing. But that does not invalidate the need for money that Briceño emphasizes, Training is the sharing of the otherwise hidden healthy attitudes, and strategies. They’re on a roll.

But Belize too, like us, has a two-party system, both of whom have different views on life. Should her husband’s party not win the next election, who knows what will happen to all this progress....

This article was originally published on the [Neurodiversity Press Blog](#) and has been republished with permission.

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.



**Back row left to right: Christy (Almeida), Kirk, Dulce, Alex, Azalia
Front row left to right: Stephanie, Kareesh, Elsie Mae, Roslyn,
and a young man who OD’d on cute pills**

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



**Autism Spectrum News
Update**

AutismSpectrumNews.org

Parent Education from [page 17](#)

The Center for Autism and Related Disabilities at the University at Albany has an ongoing program funded by the Office for People with Developmental Disabilities of New York State that specifically addresses this urgent need in the community and does so in ways that are in line with this model. [The Parent Education Program for Families of Children Newly Diagnosed with Autism](#) is a 5-part, group-based virtual program in which caregivers are provided with evidence-based information on several topics related to autism. These sessions include a general “about autism” session; a session providing caregivers with information related to self-care and coping; a session on evidence-based psychosocial interventions related to autism; a session on accessing services; and a “special topics” session. Throughout these sessions, the group leader introduces the relevant evidence base in a clear and understandable manner, provides the families with strategies for using the information in their daily life, and clearly and concisely refutes common misinformation related to the topic at hand. This is done in a respectful way and the group leader encourages the families to ask any questions that they may have throughout each session. This model is in line with common recommendations for countering misinformation in the public health and communication sciences literature (Roozenbak & Van der Linden, 2022). Moreover, the virtual nature of this program allows it to reach individuals across the Capital District of New York State who otherwise may not have had access to evidence-based information like this at a time when they are most in need of it - the period immediately following diagnosis. Furthermore, these families are in the company of other caregivers who share similar experiences and who may be able



Daniel Magin, BA

to share resources with them - a source of information that parents may be especially likely to trust and make decisions based off (Fishbach et al., 2015). As the group leader is present throughout these interactions, she can either endorse the resources shared by the families in the group or guide caregivers towards other, similar, yet more evidence-based resources.

Programs like these have the capacity to fight against the proliferation of misinformation with the dissemination of evidence-based information by trusted experts in the community. Through components like virtual programming and group-formatting, professionals in the field can make information readily available and trustworthy for the families who need it the most. If these sorts of options become more widely accessible and utilized, we can dampen the harmful impact of pseudoscience and misinformation on lives of families across the country and facilitate access to much-needed, useful evidence-based information.



Kristin Christodulu, PhD

Daniel Magin, BA, is a Graduate Assistant, Kristin Christodulu, PhD, is Director, and Jane Ann Worlock, MEd, is Senior Trainer University at Albany Center for Autism and Related Disabilities Parent Education Program. For more information about the Parent Education Program at the Center for Autism and Related Disabilities at the University at Albany, please contact Jane Ann Worklock at (518) 442-4822 or visit our [website](#).

References

- Capuano, A. M., & Killu, K. (2021). Understanding and addressing pseudoscientific practices in the treatment of neurodevelopmental disorders: Considerations for applied behavior analysis practitioners. *Behavioral Interventions*, 36(1), 242-260.
- Chan, M. P. S., Jones, C. R., Hall Jamieson, K., & Albarracín, D. (2017). Debunking: A meta-analysis of the psychological efficacy of messages countering misinformation.



Jane Ann Worlock, MEd

Psychological Science, 28(11), 1531-1546.

Fischbach, R. L., Harris, M. J., Ballan, M. S., Fischbach, G. D., & Link, B. G. (2016). Is there concordance in attitudes and beliefs between parents and scientists about autism spectrum disorder?. *Autism*, 20(3), 353-363.

Roozenbeek, J., & Van Der Linden, S. (2022). How to combat health misinformation: A psychological approach. *American Journal of Health Promotion*, 36(3), 569-575.

Smith, I. M., & MacDonald, N. E. (2017). Countering evidence denial and the promotion of pseudoscience in autism spectrum disorder. *Autism Research*, 10(8), 1334-1337.

United States. Public Health Service. Office of the Surgeon General. (2014). *Confronting Health Misinformation: The U.S. Surgeon General's Advisory on Building a Healthy Information Environment*. U.S. Department of Health and Human Services, Public Health Service, Office of the Surgeon General

Listening from [page 12](#)

References

- Doherty, M., Lynden, B., Lauren, J., Julie, T., & Stanhope, V. (2020). Transitioning to person-centered: A qualitative study of provider perspectives. *The Journal of Behavioral Health Services & Research*, 47(3), 399-408.

Heller, T. (2019). Bridging and aging an intellectual/developmental disability in research, policy, and practice. *Journal of Policy and Practice in Intellectual Disabilities*, 16(1), 53-57.

McGinley, J., Marsack-Topolewski, C., Church, H. L., & Knoke, V. (2021). Advance care planning for individuals with

intellectual and developmental disabilities: A state-by-state content analysis of person-centered service plans. *Intellectual and Developmental Disabilities*, 59(4), 352-364.

Prendeville, P., & Kinsella, W. (2019). The role of grandparents in supporting families of children with autism spectrum disorder:

A family systems approach. *Journal of Autism and Developmental Disorders*, 49(2), 738-749.

Taylor, J.E., & Taylor, J.A. (2017). Person-centered planning: Evidence-based practice, challenges, and potential for the 21st century. *Journal of Social Work in Disability & Rehabilitation*, 12(3), 213-235.

Next Steps from [page 15](#)

receive services in their home or in a clinic. Some centers with an innovative approach are offering social work support to siblings and parents. Clinics typically can offer comprehensive treatment including social skills groups, even for little ones 18-months to 2-years-old. The recommended dose of hours for very young children whose developmental milestones are below that of their chronological age peers are 25 to 40 hours. Although this may be daunting, the hours are spread throughout multiple environments of home, school, and the community.

School-age children will require an Individualized Education Plan (IEP) to access supports at school which include many of the components described for young children. Because autism is a neurodevelopmental disorder that can affect learning, not a learning disorder per se, an ABA

approach is beneficial for teaching school readiness skills, as well as organizational skills and executive functioning skills. ABA accomplishes this by breaking down larger goals and tasks into smaller manageable pieces. Social interaction will remain an area requiring direct targeted teaching. Enrolling in a social skills group will be pivotal for developing reciprocal social interaction skills.

For adults, life might begin to make sense and they are better able to navigate the world in which they live. Not only are they able to understand themselves clearly, people in their lives also become understanding of them. Many teens, young adults and mature adults struggle with social disconnection creating feelings of anxiety and depression. Seeking therapy in these situations is critical to well-being and health and a therapist with training and/or experience in ASD is recommended. Support groups for adults allow for sharing of resources as

well as providing a social connection.

Regardless of where this diagnosis takes place in the lifespan, understanding and accepting it, accessing proper supports, and adapting the environment is crucial in supporting each individual in fulfilling their potential.

Salli Shon, LCSW, BCBA, LBA-CT, is a licensed clinical social worker and the managing BCBA at Autism Care Partners center in Avon, CT. Salli conducts diagnostic evaluations as well as providing social work support to the families. Caitlan Freeman, MS, BCBA, LABA, is a parent of an autistic child and the Managing BCBA at the Autism Care Partners center in Worcester, MA.

Autism Care Partners operates a several multi-disciplinary centers across the Northeast with the mission to empower families to reach their potential through early diagnosis and exceptional, innova-

tive, interdisciplinary care. More information can be found on their website at www.autismcarepartners.com or by calling (800) 679-3609.

References

American Psychiatric Association (2013). *Diagnostic and statistical manual of mental disorders: DSM-5*. 5th ed. Washington, D.C.: American Psychiatric Publishing.

May Institute (2006-2017). National Autism Center's Evidence Based Practice and Autism in the Schools - Comprehensive behavioral treatment for young children.

LeafWing Center (August 20,2019). What constitutes effective intervention for individuals with Autism? The National Research Council's report on effective treatments for Autism still stands True. <https://leafwingcenter.org>

Virtual Reality from page 23

The Future of Healthcare for Patients with Autism

As a healthcare provider, it has always pained me to know that there are those who struggle with healthcare so much that they seek to avoid medical help altogether. As someone who joined healthcare with a mission to serve and help, it was always my goal to find ways to improve the clinical experience for all my patients - especially those who were underserved. The goal of improving the experiences of patients like my brother has always driven my passion for innovation.

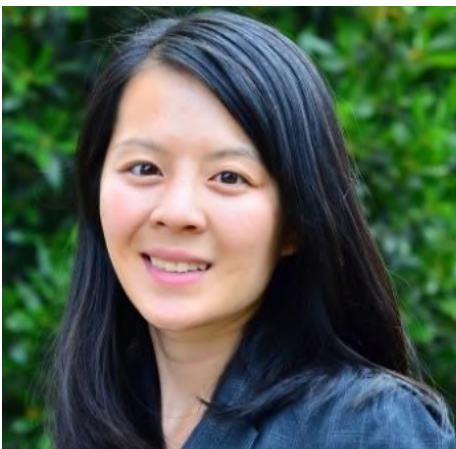
Virtual reality is slowly becoming the standard of care to help reduce pain and anxiety for those who struggle with phobias and healthcare anxiety. VR has the potential to alleviate fears and manage various conditions in children with autism by changing their situational perception and immersing them in a safe and controlled environment.

Evelyn Chan, MD, is the CEO and founder of SmileyScope, a virtual reality solution for needle procedures used by healthcare practitioners. Evelyn is a Medical Doctor (Pediatrics) and a Rhodes Scholar. In 2017, Evelyn took her experience working with children and developed a first-of-its-kind medical VR device. You can learn

more about her on [LinkedIn](#).

Footnotes

- Centers for Disease Control and Prevention. (2022, December 15). Autism and developmental disabilities monitoring (ADDM) network. Centers for Disease Control and Prevention. Retrieved March 9, 2023, from www.cdc.gov/ncbddd/autism/addm.html#:~:text=CDC%20estimates%20that%20about%201,8%2Dyear%2Dolds.
- Chan E, et al. Virtual reality for pediatric needle procedural pain: two randomized clinical trials. J Pediatr. 2019;209:160-167. e4. [[PubMed](#)]



Evelyn Chan, MD

Late-Diagnosed from page 20

It gives me hope that the diagnostic criteria for autism will evolve to be more inclusive of AFAB people or anyone who does not present in a “typical” way. I also hope that as the research evolves, outdated stereotypes will continue to diminish especially amongst clinicians. However, future research is needed to know how much camouflaging truly effects AFAB, late-diagnosed autistic individuals (Hull et al., 2020). Clinicians need to be updated on findings as well, because there is a growing body of literature to suggest that autistics will camouflage during evalua-

tions, which can lead to missed or misdiagnoses (Hull et al., 2020). The current literature suggests that there are real barriers to AFAB people receiving needed diagnoses which leads to poorer mental health outcomes. As clinicians, we can mitigate this by approaching clients through a developmental, multicultural lens that allows them to advocate for themselves and live authentically.

Britt Boylan (They/Them) is a student pursuing their M.A. in Mindfulness-Based Transpersonal Counseling at Naropa University. They have a passion for research and learning and they hope that the re-

search surrounding autism in AFAB people will continue to evolve. Britt can be reached by email at brittany.boylan@naropa.edu.

References

Center for Disease Control and Prevention. (2022, November 2). Diagnostic criteria for 299.00 autism spectrum disorder. www.cdc.gov/ncbddd/autism/hcp-dsm.html

Hull, L., Petrides, K. V., & Mandy, W. (2020). The female autism phenotype and camouflaging: A narrative review. *Review Journal of Autism and Developmental Disorders*, 7, 306-317.

Lockwood-Estrin, G., Milner, V., Spain, D., Happe, F., & Colvert, E. (2021). Barriers to autism spectrum disorder diagnosis for young women and girls: A system review. *Review Journal of Autism and Developmental Disorders*, 8, 454-470. <https://doi.org/10.1007/s40489-020-00225-8>

Wood-Downie, H., Wond, B., Kovshoff, H., Mandy, W., Hull, L., & Hadwin, J. A. (2020). Sex/gender differences in camouflaging in children and adolescents with autism. *Journal of Autism and Developmental Disorders*, 51, 1353-1364. <https://doi.org/10.1007/s10803-020-04615-z>

Now What from page 21

Therapy might help me cope with fine and gross motor deficits.

I struggle with reading social cues; I mask my differences; have issues with *proprioception*, a.k.a. “kinaesthesia...the body’s ability to sense its location, movements, and actions the sense of self-movement, force, and body position,”⁴ and *interoception*, “the feeling of knowing what is happening in your body, for example if you are hungry, thirsty, warm, cold, etc.”⁵

I am socially isolated, and while I enjoy get-togethers with friends from former workplaces, I would welcome additional social support.

If asked, I tell people, “the only things I can do are research and writing.” And I’ve been criticized by others on the spectrum, with comebacks such as, “consider yourself lucky,” and “you could make a career of that.” What those people don’t know is that I write because I struggle with expressive language and nonverbal communication, interpersonal *soft skills*.

Soft skills encompass a wide range of neurotypical (NT) competencies, but principally listening and effective speaking skills, attitude, work ethic, teamwork, leadership qualities, time management, decision making, and conflict resolution. Plus, the ability to control and manage your emotions. These social skills are the qualifications most employers want in employees they retain.

Stigma

Stigma wasn’t a new experience for me, but stress in the workplace, especially dealing with managers, eventually broke me. When I sought support, I received criticism because I couldn’t adequately verbalize the

problems I was facing. In fact, I wasn’t always aware there was a problem, until the manager asked to see me in her office.

Has My ASD Diagnosis Benefited Me?

As I’ve said, I’m happier. Missing pieces have been inserted into the puzzle that is ME. I’m making sense of my past - and the present. On the other hand, I feel as if I’ve been left with almost nothing but Dr. Google and self-help books to help me incorporate this new self-knowledge, or to cope with the traits that set me apart from neurotypicals.

Not Everyone Wants a Formal Diagnosis

My pursuit of a diagnosis was primarily for personal validation. There are adults who view a formal diagnosis as detrimental. If they’re satisfied with their life and career, and embrace their uniqueness, the expense and stress of neuropsychiatric testing may not be worthwhile.

For others, though, an assessment and diagnosis may help them, family members, partners, employers, colleagues, and friends, to understand why their thought processes and life experiences are different, and *potentially* how to fit their square peg selves into NT round holes.

Children

It’s all a matter of choice for adults. However, “a...diagnosis and intervention can benefit children on the autism spectrum and [those] with other developmental disorders. Timely diagnosis is a necessary first step for identifying and beginning appropriate therapies and supports.”⁶

“A cognitive assessment can help determine the [child’s]:

- Strengths,
 - Areas of difficulty, [and strengths],
 - [And] level of intellectual functioning.”⁶
- Given my own journey to diagnosis, if you’re the parent or guardian of a girl who might be exhibiting signs of autism, please ask for a referral for autism testing. While her differences are far more likely to be noticed today, if she’s “high functioning” she may already be masking her symptoms. Her struggles may be dismissed as shyness, a learning disability, behavioral problem, or be overlooked because she doesn’t fit autistic stereotypes.
- My path to an autism diagnosis was fraught with misdiagnoses and the failure to understand that autism manifests differently in boys vs. girls. My discovery journey started with testing for learning disabilities when I was seven and followed a tortuous trail through the DSM before landing on Autism, Level 1. I believe if what we now know had been known and accepted years ago, I probably would have qualified for the support services I needed to be far more independent. The burden of care has shifted from my parents to my spouse, and that affects his health. I’m left pondering the question, *What If?* We’ll grow old and he won’t be able to support my mental health forever. *What happens then?*
- Annie Kent, MA Psychology, spent two decades working in public sector disability, and mental health and addictions advocacy and education. Diagnosed with three closely related forms of neurodiversity, a lack of awareness and understanding led to burn-out and retirement from the field. She remains an active advocate, engaging

remotely with several Autism, ADHD, and Disability organizations and forums. For more information, email Annie at anjo-lie1031@gmail.com.

References

- Kiley, Rachel. *Pastor Greg Locke Slammed For Saying Autism Is Demonic Possession*. God, 27 Jan. 2022, <https://god.dailydot.com/demonic-possession-autism/>.
- Dyspraxia. *Healthdirect*, www.healthdirect.gov.au/dyspraxia. Accessed 8 Feb. 2023.
- What Is Praxis? *Mosaic Health & Rehab, Belgrade MT*, 14 Mar. 2022, <https://mosaicrehabmt.com/what-is-praxis/#:~:text=Praxis%2C%20also%20known%20as%20motor%20planning%2C%20is%20the,often%20break%20praxis%20abilities%20down%20into%20specific%20parts>.
- Santos-Longhurst, Adrienne. “Proprioception: What It Is, Problems, Diagnosis, Treatment & More.” *Healthline*, Healthline Media, 16 July 2019, <https://www.healthline.com/health/body/proprioception>.
- INTEROCEPTION | English Meaning - Cambridge Dictionary. *Cambridge Dictionary | English Dictionary, Translations & Thesaurus*, <https://dictionary.cambridge.org/dictionary/english/interoception>. Accessed 8 Feb. 2023.
- Autism: For Professionals. *Government of Canada*, <https://www.canada.ca/en/public-health/services/diseases/autism-spectrum-disorder-asd/professionals-autism-spectrum-disorder-asd.html>. Accessed 8 Feb. 2023.

Autism Rates from page 18

Care Network sites to diagnose patients in their own practices and facilitate next steps to help families access needed services. Providers in these practices can refer their patients for evaluation if they have a high suspicion for ASD and if those patients meet specific referral criteria. Families can then pursue those assessments in their familiar primary care office, which can increase their comfort and expedite care without having to see a specialist to make the diagnosis.

An extra advantage of this program comes in the form of bi-weekly sessions where the Autism Care Champions can present any challenging cases to an interdisciplinary team of experts for discussion and clarification, building on the successful ECHO models used in various settings.

This consistent and open communication between primary care providers and developmental specialists is instrumental in ensuring that the child is receiving the most comprehensive and up-to-date evaluation possible. As this model grows, our hope is to decrease the median age of ASD diagnosis to have the greatest impact on children and families, and to decrease time between initial referral by a primary care provider and the actual diagnosis. Currently this



Kate Wallis MD, MPH

interval can be as long as 18-24 months, since many developmental specialists have wait lists that long. This model can shorten time to diagnosis to half that, if not sooner.

And finally, ongoing efforts need to continue to center equity. Processes that reduce diagnostic barriers for historically and contemporaneously underserved groups continue to be needed. Additionally, it is necessary to increase equity in



Eileen M. Everly, MD

access to services post-diagnosis to ensure that children's needs are being met in a just and equitable way. For example, half of Asian children and 41% of Latino children in the Philadelphia metro area have at least one parent with limited English proficiency. For these children, interpreting, translation, and bilingual providers play a key role in service delivery.

They say that if you can't measure some-

thing, you can't improve it. This exploratory project to quantify rates and ages of ASD diagnosis can serve as a benchmark as we continue to strive to improve care. It also illustrates the importance of granular data on race and ethnicity. As we aim to seek novel solutions to better meet the needs of children and families with ASD, continuously measuring our impact on diagnostic ages and on racial and ethnic equity will be crucial.

This article has been republished with permission. You may view the original article at <https://policylab.chop.edu/blog/rates-autism-increase-numbers-dont-paint-full-picture>.

Kate Wallis MD, MPH, is a faculty member at PolicyLab at Children's Hospital of Philadelphia (CHOP), an attending physician in CHOP's Division of Developmental and Behavioral Pediatrics, an assistant professor in the Department of Pediatrics at the University of Pennsylvania, and an associate fellow in Penn's Center for Public Health Initiatives. Eileen M. Everly, MD, is a pediatrician at Karabots Pediatric Care Center, West Philadelphia, a CHOP Care Network primary care practice. For more information about PolicyLab at Children's Hospital of Philadelphia, visit <https://policylab.chop.edu/>.

Screening from page 19

- Specificity – The ability of the tool to correctly identify individuals who truly do not have ASD
- Positive predictive value (PPV) – The likelihood that an individual who receives an ASD positive outcome truly has ASD
- Negative predictive value (NPV) – The likelihood that an individual who receives an ASD negative outcome truly does not have ASD

Sensitivity and specificity are “fixed test characteristics” because they do not change, regardless of disease prevalence – how often the disease may occur in a certain population of individuals. The PPV and NPV do change when disease prevalence changes (Bovbjerg 2020). There can be substantial variation in the sensitivity and specificity of ASD tests, likely due to methodological differences and variations in the clinical characteristics of populations recruited (Randall et al. 2018). Therefore, when assessing the performance of a test in the real world, PPV and NPV should also be considered.

Artificial intelligence (AI) and machine learning (ML) technologies are increasingly being used in healthcare. ML is a form of AI where systems have the ability “to learn” using large amounts of data to improve accuracy. Thus, large amounts of data combined with computational power can help improve clinical efficacy by helping improve the accuracy and efficiency of diagnosis and treatment (Ahuja 2019). Considering the diverse and complex symptom presentation in ASD, AI-based tools designed to aid in diagnosis are an active area of research and growth (Shannon, et al. 2022). ML-based diagnostic devices such as software as medical devices (SaMDs) have the advantage that they



Jennifer Shannon, MD

have the potential to improve performance with additional data or real-world use (FDA 2019).

When making an ASD diagnosis, best practices require integration of caregiver reports, behavioral observations, standardized assessments of cognitive, language and functional adaptation, and clinical assessment based on the DSM-5 criteria (Randall et al. 2018). Regardless of the tool selected, no single ASD tool should be used as the basis for diagnosis, and it should be used by clinicians to support rather than replace clinical judgment (“Screening and Diagnosis of Autism Spectrum Disorder” | CDC; Elder et al. 2017).

Dr Jennifer Shannon is a board-certified child, adolescent, and adult psychiatrist passionate about healthcare innovation, particularly as it relates to pediatric mental health. She practices in Bellevue, WA and is also Executive Medical Director at Cognoa. For more information, please contact jennifer.shannon@cognoa.com.

References

Ahuja, Abhimanyu S. 2019. “The Impact of Artificial Intelligence in Medicine on the Future Role of the Physician.” Edited by Matteo Lambrugh. *PeerJ* 7 (October): e7702. <https://doi.org/10.7717/peerj.7702>.

Bovbjerg, Marit L. 2020. “Screening and Diagnostic Testing,” October. <https://open.oregonstate.edu/epidemiology/chapter/screening-and-diagnostic-testing/>.

“(CARSTM2) Childhood Autism Rating Scale™, Second Edition.” n.d. Accessed February 27, 2023. <https://www.wpspublish.com/cars-2-childhood-autism-rating-scale-second-edition.html>.

“Diagnostic Criteria | Autism Spectrum Disorder (ASD) | NCBDDD | CDC.” n.d. Accessed February 9, 2023. <https://www.cdc.gov/ncbddd/autism/hcp-dsm.html>.

Elder, Jennifer Harrison, Consuelo Maun Kreider, Susan N Brasher, and Margaret Ansell. 2017. “Clinical Impact of Early Diagnosis of Autism on the Prognosis and Parent-Child Relationships.” *Psychology Research and Behavior Management* 10 (August): 283–92. <https://doi.org/10.2147/PRBM.S117499>.

FDA. 2019. “Proposed Regulatory Framework for Modifications to Artificial Intelligence/Machine Learning (AI/ML)-Based Software as a Medical Device (SaMD) - Discussion Paper and Request for Feedback.” <https://www.regulations.gov/document/FDA-2019-N-1185-0001>.

FDA. 2021. *FDA Authorizes Marketing of Diagnostic Aid for Autism Spectrum Disorder*. June 2, 2021. <https://www.fda.gov/news-events/press-announcements/fda-authorizes-marketing-diagnostic-aid-autism-spectrum-disorder>.

Hyman, Susan L., Susan E. Levy, and Scott M. Myers. 2020. “Identification, Evaluation, and Management of Children with Autism Spectrum Disorder.” *Pediatrics* 145 (1).

Megerian, J.T., S. Dey, M. Raun, D.L. Coury, M. Lerner, C.J. Nicholls, Kristin Sohl, et al. 2022. “Evaluation of an Artificial Intelligence-Based Medical Device for Diagnosis of Autism Spectrum Disorder.” *Nature Partner Journal- Digital Medicine*. <https://doi.org/10.1038/s41746-022-00598-6>.

Randall, Melinda, Kristine J. Egberts, Aarti Samtani, Rob JPM Scholten, Lotty Hooft, Nuala Livingstone, Katy Sterling-Levis, Susan Woolfenden, and Katrina Williams. 2018. “Diagnostic Tests for Autism Spectrum Disorder (ASD) in Preschool Children.” *Cochrane Database of Systematic Reviews*, no. 7.

“RITA-T Research | Boston Children's Hospital.” n.d. Accessed February 27, 2023. <https://www.childrenshospital.org/research/labs/rita-t-research>.

“Screening and Diagnosis of Autism Spectrum Disorder | CDC.” n.d. Accessed February 9, 2023. <https://www.cdc.gov/ncbddd/autism/screening.html>.

Shannon, J., C. Salomon, T. Chettiath, H. Abbas, and S. Taraman. 2022. “Autism Spectrum Disorder and the Promise of Artificial Intelligence.” *J Child Adolesc Behav* 10 (428): 2.

Shannon, J, Sharief Taraman, Dennis P. Wall, Stuart Liu-Mayo, and Carmela Salomon. 2022. “Optimizing a de Novo Artificial Intelligence-Based Medical Device under a Predetermined Change Control Plan: Improved Ability to Detect or Rule out ASD in General Pediatric Settings.” *Journal of the American Academy of Child & Adolescent Psychiatry* 61 (10, Supplement): S242-243.

Neurodiversity from page 22

as having good intentions, it allows them to have more trust and feelings of connection in the relationship. It gives a couple the opportunity to hold two things true: that their partner has good intentions in the relationship and that due to differences in neurological wiring, those well-meaning behaviors are not always going to have the desired positive outcomes. Sometimes the best of intentions have a negative impact, but when someone believes their partner is coming from a positive place, they are better able to recover from a difficult interaction. An example of good intentions that were misperceived can be seen in the following example:

A man on the spectrum wanted to make a nice dinner for his family to show them how much he loved them. Cooking was one of his passions and he spent all day creating a delicious, multi-course meal. His husband had to watch their children that day without his support. When either their children or his husband would come into the kitchen to talk or try to help him cook, he rejected their efforts. He would not engage in conversation because he wanted the meal to be perfect and did not want to get distracted from the recipes. When it was dinnertime, he was so happy with the outcome of the meal, but his family was frustrated, and the dinner did not go smoothly.

The autistic man was well-intentioned in creating a beautiful dinner for his family but did not recognize the unintended negative impact of the way he was engaging with them throughout the day. His husband was well-intended in trying to help cook but his good intentions had a negative impact as they were viewed as a distraction.



Leslie A. Sickels, LCSW

Once the couple grounded in good intentions, they were able to recognize how neurodiversity came up and make a plan for how they could engage in similar situations differently in the future.

Concrete Tools and Strategies

The next step after receiving psychoeducation about neurodiversity and learning the ways it applies to a specific relationship is to integrate tools to minimize challenges in the relationship. One strategy is for a couple to work on both changing perspectives and behaviors. This requires each partner to either shift the way they are thinking about a situation or how they are engaging in it. In using the example above, the neurotypical husband would benefit from shifting his perspective to see

his partner's good intentions and recognize that he was trying to do something nice for their family to show his love and affection. The partner on the spectrum could work on shifting his behaviors. He could coordinate with his husband to find a good day/time to cook a lavish meal so that it does not have an inadvertent negative impact on the family by putting the burden of childcare solely on his husband.

Another important strategy that can be utilized with neurodiverse couples is related to communication. Since both partners' brains are wired differently, communication should be clear and concrete. In neurodiverse couples work, therapists often describe couples as "speaking different languages," which is due to the differences in neurodevelopmental wiring (Myhill & Jekel, 2015). Many articles are published about difficulties with social communication for individuals on the autism spectrum. These challenges include verbal and nonverbal communication and can all contribute to social difficulties (Denworth, 2018). When a couple is in a relationship, challenges in communication can happen regularly in day-to-day communication. When partners each learn to speak their significant others' language, they can be more effective in connecting with one another.

In addition to paradigm and behavioral shifting and working on communication, there are many other tools that can be integrated into a neurodiverse relationship to support positive changes. Once a couple has identified how neurodiversity is coming up for them specifically, they can target those particular areas of the relationship. This tailored approach allows a couple to focus on the most important areas for them and begin to work toward significant changes in their partnership.

Conclusion

Uncovering neurodiversity in a relationship can help couples begin to work towards understanding and improving their dynamic. It allows a couple to recognize neurodevelopmental differences that are inherent in their relationship and begin to integrate strategies to improve their interactions. The recognition of a diagnosis can fundamentally shift the way a couples views each partner and the interactions between them, and help set the relationship on a more positive and productive track forward.

Leslie Sickels, LCSW, works with neurodiverse couples and individuals on the autism spectrum in New York. For more information about Leslie's therapeutic work and neurodiverse couples therapy visit LeslieSickelsLCSW.com.

References

- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). Arlington, VA: American Psychiatric Publishing.
- Denworth, L. (2018). *Social Communication in Autism, Explained*. Spectrum News. Retrieved from <https://www.spectrumnews.org/news/social-communication-autism-explained/>
- Myhill, G., & Jekel, D. (2015). *Neurology Matters: Recognizing, understanding, and treating neurodiverse couples in therapy*. FOCUS, NASW Massachusetts Chapter.
- The Asperger/Autism Network (AANE). (2023). *Resources for Adults*. Retrieved from <https://www.aane.org/resources/adults/>

Two Diagnoses from page 23

Receiving and Dealing with an Adult Diagnosis

Once an adult is identified, either through self-diagnosis or by another individual, they need to accept the reality of their condition. For many older adults, especially the self-diagnosed who have long been seeking an explanation, this happens almost immediately and is greatly welcomed. For those who are diagnosed by professionals, it may come as something of a surprise and can be received in any number of ways - from acceptance to skepticism to doubt to denial, at least at first; it also may or may not be welcomed, although in my experience I have found that, especially among older adults, the majority eventually if not immediately both accept and welcome the diagnosis.

For those who are identified by a family member, friend, or some other person in their lives, the situation is a bit trickier because it involves giving the suspected individual news that they may not be receptive to, and even suspect the motives of the person giving it to them. One method that I have long suggested is to have another adult on the spectrum disclose their own condition to the individual, giving a comprehensive description of its traits and challenges, and seeing how he or she responds to this. The idea is that the autistic

person appears to simply be sharing a personal aspect of their life and, as such, is less likely to raise any suspicion. I have actually used this method to (I believe) identify a few people who were almost certainly on the spectrum (I am clearly not qualified to make an actual determination) but, alas, were neither receptive nor particularly interested.

Once an ASD adult accepts a diagnosis, I usually recommend that they learn as much about their newly identified condition as possible. For me, this consisted of reading every article, both online and in print, that I could get my hands on, and attending every talk, workshop, and conference that I could manage to get to; in particular, I found that personal memoirs and autobiographical articles by other adults on the spectrum were especially valuable in that they told of experiences, challenges, difficulties, etc. that often were strikingly similar to my own. As such, I strongly recommend these for all newly diagnosed adult autistics.

I especially recommend going to a support group if one is available in the local area. As a result of the COVID-19 pandemic, a number of groups, such as those hosted by Aspies For Social Success (AFSS - www.nyautismcommunity.org) have migrated from in-person gatherings to online meetings. This has made them available to a much wider population, given that many people do not live in proximity to the orig-

inal meeting locations and that a significant portion of the ASD population does not drive. Meeting a group of individuals who have many of the same traits and face many of the same challenges that one does can be an eye-opening not to mention validating experience indeed. In fact, at every meeting that I first attended, I would hear at least one story told or incident recounted which was so much like one of my own experiences that it was uncanny and even scary; this continues to happen occasionally to this day.

Diagnoses of School-Age Children

Giving an ASD diagnosis to a school-age person is, for a number of reasons, very different from doing so for an adult. Nowadays, diagnosis often takes place in early childhood because parents as well as medical and health professionals are much more likely to be familiar with autism, thanks to the recent explosion in public awareness, than they would have been in the past. Clearly, a small child is far too young to receive such a diagnosis; the appropriate age depends on when the individual is ready to receive such information, which in turn depends on many different factors.

Ironically, by the time someone diagnosed in early childhood is old enough to understand the ASD diagnosis, they may also be old enough to not be welcoming of

such. The same is true for someone who is diagnosed when they are already in school. It is just around the time of middle school and early high school that socialization and social skills suddenly become much more important than they had been heretofore. Deficits in these areas, which had at most been a minor liability, can now have devastating effects on the life of a young person. News of a condition that results in such deficits is highly unlikely to be well received. The gifts and benefits that sometimes come with being on the spectrum (e.g., so-called "splinter skills") are little consolation in the face of something as horrific as social isolation and marginalization, not to mention ridicule and bullying. I have personally known individuals who received their diagnosis at a young age and were anything but happy about it. I have also wondered if, had I been told of my condition at that time in my life, I would have been anywhere nearly as relieved or elated as I was when I finally did receive the diagnosis as an older adult (I suspect that I would not have).

The only solution to this conundrum, in my opinion, is to accompany news of the diagnosis with the immediate provision of as much and as intensive social skills and socialization training, education, counseling, coaching, and anything that addresses deficits in these areas, as is necessary.

see Two Diagnoses on page 34

Good Afternoon from page 22

Getting It Done, Together - Managing everyday life tasks and getting things done, day in and day out, can be stressful. Even when the daily life tasks can feel unfun, difficult, or boring, accomplishing them together as a team can make it easier and connecting.

Divide and Conquer: For some couples, it may be too challenging to execute specific tasks together, as partners may have different likes and dislikes, strengths and challenges, or paces. Instead, partners can choose to work separately, executing their different roles, but feeling like one combined team. Figure out how best to divide and conquer. Try to make intimate moments happen while you both are carrying-out your separate tasks - acknowledge your partner as you mop the floor with a “How’s it going?” or compliment your partner on getting things done, or share a connecting smile as you work, or have a light conversation while grocery shopping, if you are both willing and able.

Working as One: For some couples, it feels connecting, bonding, and fulfilling when you share the workload in unison to get



Grace Myhill, MSW

the job done. The act of working together and completing the tasks makes them feel connected, such as building a bookshelf or cleaning out the garage. If you want to feel even more emotional connection while doing chores, you can spice it up by adding a bit of dancing or singing while you work. You can clean while listening to music or talk about your days while raking leaves.

However you spend the day, choose to make every day a good day with your

partner. Be intentional and create moments of togetherness that are comfortable for each of you. Remember that a small gesture makes a big impact, so take time to do something connecting so your partner feels loved.

Additional Resources

- PFA Tips: Neurodiverse Couples: Making Meaningful Moments of Every Day – Having a Good Morning
- PFA Tips: Dating - He Said/She Said
- “Decoding Dating: A Guide to the Unwritten Social Rules of Dating for Men With Asperger Syndrome” by John Miller

© 2021 [Pathfinders for Autism](https://pathfindersforautism.org/)

This article is part 2 of a 3-part series. Coming soon will be part 3: Having a Good Night.

This article has been republished with permission. You may view the original article at <https://pathfindersforautism.org/articles/social/pfa-tips-neurodiverse-couples-afternoon>.

Grace Myhill, MSW, is a pioneer and

leader in the field of neurodiverse couples therapy. Since 2004, she has worked with over one thousand neurodiverse couples together or separately. She has developed numerous skill-building tools and lessons to enhance communication and emotional connection. Grace offers a variety of online groups for the many facets of this unique population: for neurodiverse couples together, for partners with an Asperger's/autism profile, for neurotypical partners who are currently in a neurodiverse relationship, and for neurotypical partners who are separated or divorced from an ex-partner with an Asperger's/autism profile. She currently holds the titles of Director of Couples and Partner's Services and Director of the [Peter M. Friedman Neurodiverse Couples Institute](https://www.gracemyhill.com) at AANE, where Grace trains professional clinicians to work effectively with neurodiverse couples through online courses she developed for AANE. She has written several articles and is a frequent guest on podcasts. For more information visit www.gracemyhill.com.

For therapists or partners in a neurodiverse couple who would like to learn more about AANE's online trainings and other resources, contact Grace Myhill at grace.myhill@aane.org.

Peer Navigator from page 19

Mind the Gap in the Community

The Health Resources and Services Administration has funded the AIR-B team to scale up MTG in family resource centers and other family-based organizations. As a result of the success of the program for autistic children and their families, MTG has been broadened to include resources that assist families of children with intellectual and developmental disabilities, and the program has been translated into additional languages based on community agency needs.

Peer navigators share that they appreciate the structure and organization of MTG. Faustina Salvador, a peer navigator from Special Kids Connect, explained, “Now when I work with families I have a structured plan, and discipline to do follow-ups.” Some agency leaders shared that, following training, they use MTG as part of their intake process with all families. Meeting regularly allows peer navigators and families to create long and short-term goals to meet families’ needs and proactively engage in services, rather than waiting for a crisis to arise. Peer navigators share that this helps families feel valued, helps them stay motivated, and encourages them to celebrate small accomplishments along the way. Families have shared with Kari Cayton, a peer navigator from Starbridge, that MTG has allowed them to feel “heard, understood, and supported while going through an unsure time in their lives.”

Having accessible and reliable resources available on-line allows peer navigators to direct their efforts towards building stronger rapport with caregivers. The activities and videos are practical and easy for families to use outside of session. These materials are available in several languages and are parent friendly.

Individualizing for Families

The pandemic resulted in substantial changes to service delivery, and agencies

and peer navigators worked hard to adjust MTG to fit new demands. Joyce Steel, a MTG agency lead at Starbridge, said, “While we value [MTG] and it aligns with our advocacy approach of teaching and empowering families, we are short staffed and staff are stressed. Family/caregiver needs have increased, advocacy requests that are more urgent and many families call in crisis.” Structural barriers around funding and staffing may require adaptations to the intensity of MTG. As Hannah Michaelsen, an agency leader from Care Parent Network, reported, “I also envision components of MTG being used with other families who may not need the full navigation model, and with some of our support groups for families of young children.”

An important part of any family navigator program involves working collaboratively with families to meet their current needs. Families come into navigator programs with different levels of understanding of their children’s diagnoses, varying life demands and levels of support from their families and communities. Schreiber shared this for families considering a family navigator program: “I recommend taking some time to consider what you hope to get out of the program for your family. Peer navigators are there to help you reach your family’s goals; so, consider how best the peer navigator can help you reach your goals. Don’t be afraid to raise concerns with the peer navigator or reconsider activities or goals...this is a collaborative program.”

For more information, please contact sfvejnoska@ucdavis.edu.

Complete Listing of Authors: Sarah Vejnoska, PhD, Postdoctoral Scholar, UC Davis MIND Institute; Samantha Hochheimer, MS, Research Coordinator/Data Scientist, University of Rochester Medical Center; Yue Yu, PhD, Postdoctoral Scholar, UC Davis MIND Institute; Jennifer Diaz Navarro, BA, Research Coordinator, UC Davis MIND Institute; Hala Alkhatib, BS, PhD Student, UC Davis MIND Institute; Joyce Steel, Director of Family Advocacy, Starbridge; Hannah Michaelsen,

MPA, Program Director, Care Parent Network; Suzannah Iadarola, PhD, Associate Professor of Pediatrics and Public Health, University of Rochester Medical Center; Melanie Pellecchia, PhD, BCBA, NCSP, Assistant Professor, University of Pennsylvania, Perelman School of Medicine; Amanda Gulsrud, PhD, Associate Clinical Professor, UCLA Department of Psychiatry and Biobehavioral Sciences; Elizabeth Hassrick, PhD, Assistant Professor, AJ Drexel Autism Institute; David Mandell, ScD, Professor, University of Pennsylvania Perelman School of Medicine; Connie Kasari, PhD, Professor, UCLA Graduate School of Education & Information Studies and Department of Psychiatry and Biobehavioral Sciences; Aubyn Stahmer, PhD, Professor, UC Davis MIND Institute

Special thanks to the family navigators and resource centers that contributed to this article and for their participation in Mind the Gap: Care Parent Network, Eastern Los Angeles Family Resource Center, Special Kids Connect, Warmline Family Resource Center, and Starbridge.

This project is supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) under cooperative agreement UT3MC39436, Autism Intervention Research Network on Behavioral Health (AIR-B). The information, content and conclusions are those of the author and should not be construed as the official position or policy of, nor should any endorsements be inferred by HRSA, HHS or the U.S. Government.

References

- Bilaver, L. A., Sobotka, S. A., & Mandell, D. S. (2021). Understanding racial and ethnic disparities in autism-related service use among Medicaid-enrolled children. *Journal of Autism and Developmental Disorders*, 51(9), 3341–3355. <https://doi.org/10.1007/s10803-020-04797-6>
- Carbone, P. S., Behl, D. D., Azor, V., & Murphy, N. A. (2010). The medical home for children with autism spectrum disorders: Parent

and pediatrician perspectives. *Journal of autism and developmental disorders*, 40(3), 317–324. <https://doi.org/10.1007/s10803-009-0874-5>

Chiri, G., & Warfield, M. E. (2012). Unmet need and problems accessing core health care services for children with autism spectrum disorder. *Maternal and child health journal*, 16(5), 1081–1091. <https://doi.org/10.1007/s10995-011-0833-6>

Iadarola, S., Pellecchia, M., Stahmer, A., Lee, H. S., Hauptman, L., Hassrick, E. M., Crabbe, S., Vejnoska, S., Morgan, E., Nuske, H., Luelmo, P., Friedman, C., Kasari, C., Gulsrud, A., Mandell, D., & Smith, T. (2020). Mind the gap: An intervention to support caregivers with a new autism spectrum disorder diagnosis is feasible and acceptable. *Pilot and Feasibility Studies*, 6(1), 124. <https://doi.org/10.1186/s40814-020-00662-6>

Jafarabadi, M. A., Gholipour, K., Shahrokhi, H., Malek, A., Ghiasi, A., Pourasghari, H., & Iezadi, S. (2021). Disparities in the quality of and access to services in children with autism spectrum disorders: a structural equation modeling. *Arch Public Health*, 79(1), 58. <https://doi.org/10.1186/s13690-021-00577-5>

Jones S, Bremer E, & Lloyd M. (2016). Autism spectrum disorder: Family quality of life while waiting for intervention services. *Qual Life Res*, 26(2), 331–42. <https://doi.org/10.1007/s11136-016-1382-7>

Stahmer, A.C., Vejnoska, S., Iadarola, S., Straiton, D., Segovia, F., Luelmo, P., Morgan, E.H., Lee, H.S., Javed, A., Bronstein, B., Hochheimer, S., Cho, E., Aranbarri, A., Mandell, D., McGhee Hassrick, E., Smith, T., & Kasari, C. (2019). Caregiver voices: Cross cultural input on improving access to autism services. *Journal of Racial and Ethnic Health Disparities*, 6, 752–773. <https://doi.org/10.1007/s40615-019-00575-y>

Wallerstein, N., Duran, B., Oetzel, J. G., & Minkler, M. (Eds.). (2017). Community-based participatory research for health: Advancing social and health equity. John Wiley & Sons.

Parenting Tips from page 17

in their own way and different in their own way. You will experience parenting challenges but learn to find the joy. Flip your attitude, celebrate the small things and don't give up hope. Overcoming the challenges and finding that joy is so freeing.

6. Meet your child where they are developmentally - Most developmental milestones are based on normal developing children. Don't perseverate on age limits and assume that your child will not meet developmental milestones just because they are older. Meet your child where they are developmentally; they will develop on their own timeline. It does not mean they are any better or less than other children; they just got there a little slower. Celebrate the achievements, and don't give up on them.

7. Focusing on the present and unconditional acceptance - Focusing on the present and unconditional acceptance are vital ingredients for raising a happy child. Perseverating about the future - school, grades, graduation, or future jobs - drains your energy for today. Each day, view your child through a compassionate lens, believing they can achieve anything they put their mind to. Our autistic children can surprise us, developing in ways that seemed impossible when they were younger.

8. The environment is loud and overwhelming - Learn about sensory overload. Approximately 80% of autistics exhibit sensory processing issues (Case-Smith, Weaver, & Fristad, 2015). Sensory sensitivity - sounds, sights, tastes, texture are perceived as aversive - is extremely common among autistics and a leading cause to many challenging behaviors (e.g., Cermak, Curtin, & Bandini, 2010; Hillman, 2021).



Heidi Hillman PhD, BCBA-D

9. Your belief in your child's ability influences their achievement - If you believe your child is highly capable and intelligent, you will demonstrate that belief through your words and actions. Your child will clearly hear the message, and they will more than likely rise to the expectation. Alternatively, if you focus on the challenging behaviors, believing your child is not capable, unmotivated, or helpless, then your child will hear that message and will perceive themselves as one big flaw. It's a self-fulfilling prophecy.

10. Focus on the positive - Theodore Roosevelt said, "Comparison is the thief of joy." Every person - you and I included - is a combination of positive traits and plenty of flaws. Choose to see your child's positive traits rather than focusing on their challenges. When you visit the doctor or therapist, rather than detailing the challenging behaviors and deficits, focus

on their strengths. When we trot out an itemized list of our children's flaws, we are comparing our autistic child to others, and destroying our children's self-esteem. Identify your child's strengths then decide how to modify their challenging behaviors using their strengths.

11. Keep pushing the boundaries - Push your child out of their comfort zone, just a little; don't make it easy for them. Rather than visiting the same park or taking the same route home from school because it is more comfortable for your child, play at different parks or alter your route home by just a few blocks. You are broadening your child's horizons, but also you are setting higher expectations.

You will experience challenging "tantrum-in-the grocery store" moments, you will worry about the future, you will become a tireless advocate for your child. I encourage you to take one moment at a time, one step at a time, one day at a time. Each day, find joy through the unique strengths of yourself and your child. Recognizing the joyful experiences helps you have a balanced perspective. Raising an autistic child is both challenging and joyful. Joy is defined in simple measures - a day at the park, an afternoon of Pokémon, a hug, your child talking about their interests, trying a novel food, or your child's first successful play date. I will be the first to say it is hard work raising an autistic child. I encourage you to not change the way your child views the world; embrace their neurodiversity. In learning to find the joy, you are accepting your child as autistic, leveraging their strengths and interests to help them live a fulfilling life; raising your autistic child in a way that allows them to thrive.

For more information, Heidi Hillman can be reached at hhillman@ewu.edu.

References

Case-Smith, J., Weaver, L. L., & Fristad, M. A. (2015). A systematic review of sensory processing interventions for children with autism spectrum disorders. *Autism: The International Journal of Research and Practice*, 19(2), 133-148. <https://doi.org/10.1177/1362361313517762>

Centers for Disease Control and Prevention (2020). *Autism spectrum disorders (ASDs): Data & statistics*. Retrieved from <https://www.cdc.gov/ncbddd/autism/data.html>

Centers for Disease Control and Prevention (2012). *Autism spectrum disorders (ASDs): What should you know?* Retrieved from <https://www.cdc.gov/ncbddd/autism/index.html>

Cermak, S. A., Curtin, C., & Bandini, L. G. (2010). Food selectivity and sensory sensitivity in children with autism spectrum disorder. *Journal of the American Dietetic Association*, 110 (2), 238-246. <https://doi.org/10.1016/j.jada.2009.10.032>

Hassall, R., Rose, J., & McDonald, J. (2005). Parenting stress in mothers of children with an intellectual disability: the effects of parental cognitions in relation to child characteristics and family support. *Journal of Intellectual Disability Research*, 49 (Pt 6), 405-418. <https://doi.org/10.1111/j.1365-2788.2005.00673.x>

Hillman, H. (2021). Designing environments to reduce challenging behaviors. *Autism Spectrum News*, 14 (2), 1. <https://autismspectrumnews.org/designing-environments-to-reduce-challenging-behaviors/>

Kubler-Ross, E. (1980). *Death the final stage of growth*. New York: Simon and Schuster.

Get Unstuck from page 21

play guitar - in reverse order - using brute repetition that built muscle memory which then led to understanding patterns - intervals and scales - might work for understanding time and meter. I started taking drum lessons, and it worked. I learned through using my body.

Develop a regular **creative practice** around your joy - journaling, video blogging, painting, cooking, whittling- something that feeds your natural energy. Something that keeps you limber and creative and dwelling in the place where your instincts live. It's vital to reclaim our real instincts.

Reclaiming my instincts required me to be vulnerable. I had to do real unmasking. I had to share the humiliating secret that I could not read music. I had to expose parts of myself that I'd walled off and stop hiding the parts of me that needed help.

I learned to unmask and say "it's ok if

I'm not any good, this is something I want to do" instead of only allowing the "presentable" out in the world. I founded my imaginary bar band, which is full of other middle-aged women who like to rock, it's called "The Lunch Mothers of the Apocalypse." Because I can now count, I can multitrack and build entire back-up band recordings. I've become a better guitarist and better musician than I've ever expected to be, and I am having the most fun in my whole life and that energy flows into the rest of my life. I retraced my steps and corrected my counterproductive thinking. I went from mediocre singer-songwriter to actually-bad imaginary bar band - but for me it's a triumph and a crucial example of how our thinking can become distorted over the years, how we can become alienated from ourselves and trapped in counter-productive masking. Being unable to understand why people did what they did, or how people got where they got-because

for me it was all masking - because there were so many things girls weren't "allowed" to do, I made a lot of concessions in order to be "allowed" to do something nearby what I wanted to do. I spent a considerable amount of time, energy and money being a solo singer-songwriter when really, I just wanted to be part of a group but didn't know how to count or be vulnerable around other musicians and I organized my life around hiding those things.

Stop doing things you don't want to do that you feel socially obligated to do if you can help it. I know we all have to work, but we don't have to mask.

Learn and avoid your sensory drains. You will never develop a tolerance through exposure. Protect yourself and simply avoid sensory drains.

Include a **wellness routine** in your life - we forget we have bodies: schedule water breaks, food breaks, and stretch and exercise breaks throughout the day. Get lots

of sleep. I can't believe how many years I struggled with perseveration, mood, and feeling just because I needed a sandwich and some exercise. I am not exaggerating.

I'm sharing this process of reclaiming my authentic energy in hopes that other late-diagnosed women might see something that they find useful and maybe feel a little better. I'm no expert, however, the result of all of this is that, unlike all of the years I spent in "survival mode," I've regained what I always wanted and needed in order to be completely myself. I enjoy life. I want the same for you.

*I want to acknowledge that there are plenty of dreamy, gentle boys from my generation that didn't meet the diagnostic criteria either and suffered in their own way.

Johanna R. Murphy, MFA, works as Director of Development for Evolve Coaching. For more information, call (412) 744-9017 or visit www.evolve-coaching.org.

Two Diagnoses from page 32

While the appropriate measures will depend considerably on the individual and their situation, they need to be taken the moment he or she expresses interest in ad-

ressing their condition or, for that matter, does not want to accept the diagnosis (as is likely to be the case). What must never be done, however, is assume that the diagnosed individual, due to age, intelligence, or any other reason, does not need any such

measures and will simply "learn" or "pick up" these things with time - this can be nothing less than a recipe for disaster.

Regardless of age, the one thing common to any new autism diagnosis is that it can have a profound effect on one's life

and on how one views and deals with the world at large and the people that inhabit it.

Karl Wittig, PE, is Advisory Board Chair for Aspies for Social Success (AFSS). Karl may be contacted at kwittig@earthlink.net.

Older Women from page 18

to reduce or eliminate the disability rather than support it. Manualized treatments don't always work, and behavioral treatments can actually be abusive. Because autism isn't just a set of symptoms laid over a neurotypical mind, neurotypically-informed studies can't simply be adjusted.

The female autistic mind works differently. Without individualized treatment, she runs a high risk of being unintentionally harmed by the very event that should help her. Indeed, research demonstrates that there are three major areas of health treatment for autistic people that cause harm: (1) difficulty accessing treatment/support; (2) lack of the helper understanding; and (3) a reduced sense of well-being (based on the first two areas) (Camm-Crosbie, Bradley, & Cassidy, 2018). If providers aren't trained well, there is even less access to treatment, greater harm, and less trust in the autistic female's experience. Treatment needs to be an individual specialty.

Further complication to late diagnosis in women may be that females have less social support overall than males; complication also arise from a lifetime of exploitation or misdiagnosis. This, on top of the new identity inherent in a late diagnosis, changes her sense of well-being and can make for a very painful adjustment.

So, what does work? First, the practitioner must be culturally competent in the autism world. This requires both humility and the ability to slow things down so both patient and provider can understand each other. The helper needs to accept their patient's lived experience as valid. So, too, do providers need skills in managing co-occurring disorders as studies show that at least 1 in 3 autistic people have a co-occurring disorder globally (Zeiden, et. al. 2020). Not only are co-occurring disorders



Mary P. Donahue, PhD

more prevalent in females, they correspond positively with age at diagnosis.

Next, understand that autism is a neurodivergence with its own brain structure. It doesn't need to be cured. Instead, treat the goals, focus on lived experience, teach coping mechanisms. A good way to remember to treat the situation rather than the autism is to keep in mind that if the client finds housing, becomes more emotionally aware, or attends better to her health, she is not less autistic (ASAN, 2022), she's more skilled.

Recognizing that the autistic female presenting for treatment has her own unique way of communicating, own pattern of thinking and perceiving, and own sensory needs is critical. Providers do things like lower lighting, ban candles and other non-essential smells, and provide a lower sensory room without lots of wall items or foot traffic outside. This will allow energy to be used for the appointment rather than for sensory assaults. Allow stimming, pacing, movement, and toss "eye contact" as

any sort of indicator. Allow breaks when necessary. No touching without permission AND prior warning. Have a "pain chart" that is experiential rather than numerical. Attention to the environment is highly important because autistic women don't "get used to" strange situations; they mask to make it through them. And we already know that masking thwarts diagnosis and treatment. It also thwarts trust.

Next, presume competence. Be open minded and creative. Just because someone has a different brain structure doesn't mean they aren't competent, with valid thoughts, feelings, and goals. Accept that manuals and behavioral interventions don't work; find out what does, directly from the client. Even if they are non-speaking, remember that ALL behavior is communication. A "difficult" client is trying to tell you something, a quiet one may be in crisis. Be prepared to use assistive devices, white boards, dancing, pointing, etc. Help her to make goals about things that are meaningful to her.

As clinicians become more accommodating in their acceptance of autism spectrum disorders, and therefore more competent in diagnosis and treatment, autistic people may feel able to present authentically, without masking, hopefully leading to a higher sense of agency, better mental health, and overall improved quality of life outcomes.

Mary P. Donahue, PhD, is Owner/Psychologist of Mindful Paths Psychological Services, LLC. For more information, email drdonahue@mindfulpaths.me.

References

Autism Self-Advocacy Network. <https://autisticadvocacy.org/wp-content/uploads/2021/12/ACWP-Ethics-of-Intervention.pdf>

Bargiela, S., Steward, R. & Mandy, W. The Experiences of Late-diagnosed Women with Autism Spectrum Conditions: An Investigation of the Female Autism Phenotype. *J Autism Dev Disord* 46, 3281–3294 (2016). <https://doi.org/10.1007/s10803-016-2872-8>

Camm-Crosbie, L., Bradley, L., Shaw, R., Baron-Cohen, S., & Cassidy, S. (2019). 'People like me don't get support': Autistic adults' experiences of support and treatment for mental health difficulties, self-injury and suicidality. *Autism*, 23(6), 1431–1441. <https://doi.org/10.1177/1362361318816053>

Leedham, A., Thompson, A. R., Smith, R., & Freeth, M. (2020). 'I was exhausted trying to figure it out': The experiences of females receiving an autism diagnosis in middle to late adulthood. *Autism*, 24(1), 135–146. <https://doi.org/10.1177/1362361319853442>

Muller, R. T., (2019). Why Women with Autism are so Often Misdiagnosed. *Psychology Today*, Retrieved February 2, 2023, via world wide web at: <https://www.psychologytoday.com/us/blog/talking-about-trauma/201905/why-women-autism-so-often-are-misdiagnosed>

Whitlock, A., Fulton, K., Lai, M., Pellicano, E., & Mandy, W. (2020). Recognition of Girls on the Autism Spectrum by Primary School Educators: An Experimental Study. *Autism Research*, 13.

Zeidan J, Fombonne E, Scorch J, Ibrahim A, Durkin MS, Saxena S, Yusuf A, Shih A, Elsabbagh M. Global prevalence of autism: A systematic review update. *Autism Res.* 2022 May;15(5):778-790. doi: 10.1002/aur.2696. Epub 2022 Mar 3. PMID: 35238171; PMCID: PMC9310578.



Greater Hudson Valley, NY, Support Groups

One Sunday a month from 10:30 am - 12:30 pm

YAI Tarrytown - 677 White Plains Road, Tarrytown, NY 10591

Free Support Group for the Family Members of Adults with an Asperger/Autism Spectrum Profile

This support group, formerly known as Families of Adults with Asperger's Syndrome/High Functioning Autism (FAAHFA) is now a part of the Asperger/Autism Network (AANE). This group is for parents, family members and friends of adult individuals who have an Asperger or similar autism spectrum profile. We will be hosting guest speakers at many of our meetings to address various topics of importance related to our loved ones.

Our mission is to help people with Asperger Syndrome and similar autism spectrum profiles build meaningful, connected lives.

For more information, visit the website www.aane.org or contact the facilitators:

Bonnie Kaplan - Parenttalk@gmail.com | Judith Omidvaran - Judyomid@aol.com

Socialization and Life Skills Group for Adults with an Asperger/Autism Spectrum Profile

This support group, Opening Doors, is now in partnership with the Asperger/Autism Network (AANE). This group is for adults who have an Asperger or similar autism spectrum profile. Learn, socialize and receive support from others who share common experiences.

Focused on: Socialization, Mindfulness, Creativity, Self-Advocacy, Health and Well Being, Career Counseling, Relationships and Fun!

For more information, contact the facilitators:

Anna L. Nasci, OTR/L, MS, NCC, LMHC | Masako Hashimoto, MS, NCC, LMHC - OpeningDoorsWestchester@gmail.com



AUTISM SPECTRUM NEWS

*Your Trusted Source of Science-Based Autism Education,
Information, Advocacy, and Community Resources*

www.AutismSpectrumNews.org



#YourTrustedSource since 2008

[Current Issue](#) • [Media Kit](#) • [Advertise](#) • [Submit an Article](#) • [Editorial Calendar](#)
[Join Our Mailing List](#) • [Articles by Topic](#) • [Issue Archives](#) • [Editorial Board](#) • [Event Calendar](#)

Autism Spectrum News By The Numbers

500,000 website pageviews and **365,000** unique visitors in 2022

50,000 followers on Facebook, Twitter, LinkedIn, and Instagram

1,300 articles and **65** quarterly issues accessible for free

About Autism Spectrum News

Autism Spectrum News (ASN), published by the 501(c)(3) nonprofit organization Mental Health News Education, began as a quarterly print publication in 2008. In response to readership feedback, ASN became an online-only publication in 2021. ASN 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. The publication's content guides individuals, parents, and service providers in the right direction from the very beginning while taking efforts to avoid the promotion of unsafe and unproven interventions and treatment methods.

In keeping with the publication's evidence-based mission, the esteemed [ASN Editorial Board](#) will only accept articles and advertising offering science-based information and/or treatments proven safe and effective for autistic individuals.

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.

For information about [advertising](#) and [article submissions](#) contact David Minot, Publisher, at dminot@mhnews.org.