

# AUTISM SPECTRUM NEWS

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INFORMATION, ADVOCACY, AND COMMUNITY RESOURCES

SPRING 2024

VOL. 16 NO. 4

## Navigating the Healthcare System

### Facilitating Health Care Visits: How Can We Prepare for a Therapeutic Visit?

By Mamie Richiutti, MS, BSN, RN  
Senior Director of Healthcare Services  
Melmark PA

Health care visits can be challenging for individuals with autism and the delivering providers. It is critical that we prepare both the individual and the provider to increase the integrity of the visit and ensure a successful outcome.

When I took on my role as Senior Director of Healthcare Services at Melmark, I came primarily from a hospital setting and took my ease of access to my health care providers for granted. I scheduled my appointment, arrived at the designated time, and checked in with the receptionist. Next, I was escorted back to see the provider, was seen, and left with a visit summary and instructions for follow-ups. However, I soon discovered the roadblocks that individuals with autism spectrum disorder (ASD) and their care providers face. Now, imagine you are a family member or care provider of an individual with ASD who requires a medical appointment. The en-



tire process looks a lot different for an individual with special needs. You schedule the appointment. You arrive and check in with your individual. Then, you are both brought back to the exam room, where

your individual becomes anxious and has a behavior. The provider insists that they cannot complete the visit due to non-compliance. You both are sent on your way without any treatment or answers.

Unfortunately, this scenario is all too common in the special needs' world. Family and care providers report difficulties finding medical providers who "accept" those diagnosed with autism, being banned from providers' offices due to behaviors, poor interactions with providers, and sub-par medical exams and treatments. Thankfully, the Americans with Disabilities Act (ADA) offers federal protection against disability discrimination. This Act calls for providers to provide accommodation for individuals with disabilities, including reasonable modifications of policies and procedures, effective communication, and facility accessibility. Ways providers can modify policies and procedures are by providing earlier appointments when the office is less crowded, allowing staff to complete paperwork for those who have difficulties, and allowing companions and service animals to accompany individuals to their appointments. Stronger communication methods may need to be explored for some situations. Interpretation services, simple large-print instructions, and digital

*see Therapeutic Visit on page 6*

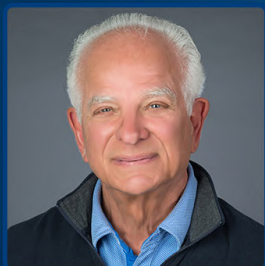
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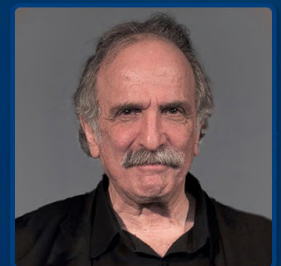
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**Supporting and Empowering Autistic Adults**  
 Deadline: August 28, 2024

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**Understanding and Developing Communication Skills**  
 Deadline: December 4, 2024

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**Autism Society of America**

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### Therapeutic Visit from page 1

access to health information are some ways this can be achieved. In terms of facility accessibility, there are several ways to meet this requirement. Making parking, offices, bathrooms, and exam rooms ADA assessable, as well as clearing floor space for maneuverability, are a few ways to achieve this (Health Care and the Americans with Disabilities Act, n.d.).

The Affordable Care Act does give some reprieve of health insurance restraints to those with autism. According to the US Department of Health and Human Services website, the Act bans the exclusion of individuals with autism from health insurance, as well as banning lifetime dollar amounts for most services. In addition, health insurance must cover preventative services and autism screenings (The Affordable Care Act and Autism and Related Conditions, n.d.).

Individuals with autism face a lifetime of medical treatment needs for conditions such as gastrointestinal issues, metabolic disorders, autoimmune disorders, and sleep disorders, among others, in addition to receiving autism services. It is imperative that barriers to medical services be eliminated to foster healthy experiences and, therefore, constant treatment. According to the Children's Hospital of Philadelphia, "reducing negative experiences in a medical setting during childhood makes it more likely that individuals with ASD receive appropriate preventive medical care throughout their lifetime and that adults with ASD will continue to make and keep regular medical appointments (Children's Hospital of Philadelphia, 2017)."

Studies have found that integrated set-



**Mamie Richiutti, MS, BSN, RN**

tings increase service access and enhance patient/family satisfaction. Bundling services together at one location can more easily accommodate multiple visits in one day, as well as offering a structured and familiar environment that can be comforting for many individuals with ASD. An integrated setting increases access to dental services, behavioral health, medical specialties such as neurology and gastroenterology, and therapeutic services such as speech and occupational therapy. During primary care visits, providers can use the shared electronic health record to see when patients are due for other services and more easily facilitate the scheduling of those appointments (Siasoco et al., 2017).

So, what can we do to ensure our individuals with special needs, particularly

those with autism, receive the care they need? We must advocate for our individuals to receive the same access as the general population. Below are some helpful tips for caregivers and health care providers to navigate health care visits for an individual with ASD.

#### Tips for Caregivers

- Meet with the provider's office prior to the visit to ensure they are aware of the individual's special needs. Extra time might need to be added to the appointment.
- Check with the provider to see when their office is least busy, and schedule appointments during those times to minimize distractions.
- Be aware of your rights. Those individuals with mental and physical disabilities have a right to the same health care access as anyone else.
- Complete paperwork and questionnaires in advance to minimize wait times.
- Prepare your individual for the visit by discussing what might happen. It might be beneficial to visit the office prior to the appointment to help prepare their individual.
- Ensure that appropriate support is available. Extra caregivers or office staff might need to assist during the visit.
- Bring distractions, preferred items, rewards/reinforcers, and any communication devices the individual uses

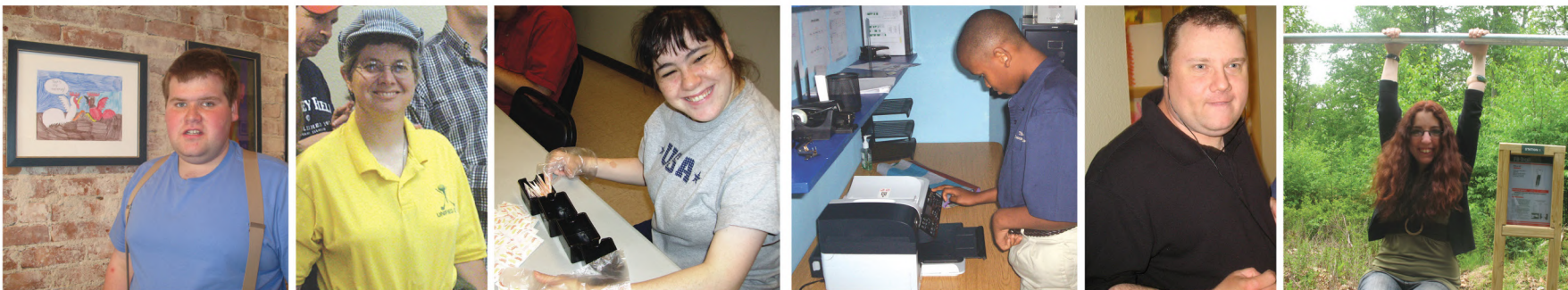
- Make sure a preferred family member or staff is present to offer comfort and support to the individual during the appointment.
- Work with a care navigator to coordinate services. Some insurance companies and medical offices employ care navigators who will work with individuals and caregivers to obtain prior authorizations for services, as well as find providers who offer pre-sedation or general anesthesia for testing and procedures.

#### Tips for Providers

- Stay up to date with education and training related to those with autism or other special needs. Many are not aware of the behaviors that those with autism might display, nor are they aware of common co-morbidities these individuals face.
- Hold special needs run-through drills to take staff through a visit with an individual with autism. This will give staff a chance to prep and problem-solve prior to the visit.
- Have a designated quiet area where individuals can wait for the exam room to become available.
- Allow extra time for appointments. Go slow and take some extra time if needed for breaks or to help patients acclimate to the environment or procedures.

see *Therapeutic Visit* on page 36

## THIS IS WHAT SUCCESS LOOKS LIKE



## THIS IS WHAT AN ADULT WITH AUTISM LOOKS LIKE!

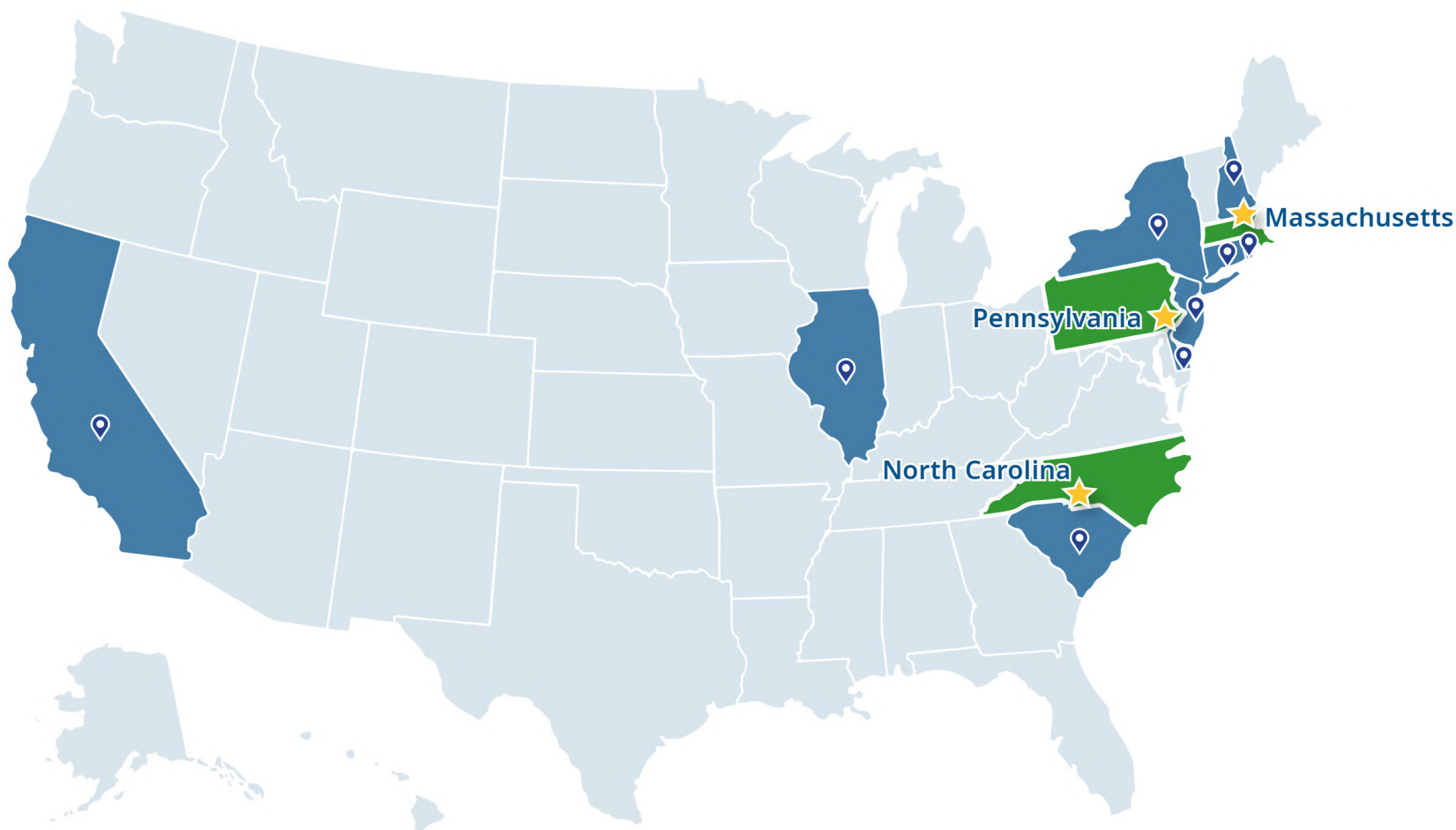
Adults with autism are diversely individual, and all are entitled as a matter of human rights to have opportunities to live their best lives.










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## Post-Pandemic Telehealth Tips for Providers Working with Autistic Children



By Lindsey Sneed, PhD, BCBA-D,  
and Li Ern Chen, MD, MS, FAAP  
Catalight

### Getting a Child's Attention

It can be difficult to get any child's attention remotely. It may be particularly challenging for a child with ASD who may not engage in joint attention. Here are some things to try:

- Be animated! Use big expressions and hand movements, even toys, stuffed animals, and finger puppets.
- Try changing your virtual background to something that could catch the child's attention.
- Ask the parent/caregiver to use a toy or favorite object to bring the child's attention to the screen.
- Try singing a song. Some of our clinicians have "welcome songs" they use at the beginning of an interaction.

### Eye Contact Is Not Necessary

One of the peculiarities of telehealth is that eye contact is contrived. Making eye contact or being able to tell if the child is making eye contact is very difficult virtually. For a child to look like they have eye contact with you, they have to look at the camera, meaning they are not looking at your face on their screen. If you need to know if the child will make eye contact, ask the person with the child to see if the child will make eye contact with them. Generally, when interacting with a child remotely, the best advice is not to worry about eye contact.

### Physical Environment

Creating an optimal physical environment for the telehealth visit is important. It can be very difficult to get any child to attend to the screen, answer questions, or follow instructions when there are distractions on their side of the screen. Asking the parent to minimize sensory stimulation and distractions is helpful. Having the child in a quiet room without their smartphone/tablet or other visual stimuli is ideal. This means not having any other screens visible in the room and not having the child near a window facing a distraction, like a busy street.

see *Telehealth Tips* on page 32

Since the pandemic, many of us have become more comfortable with telehealth. The virtual visit evolution has helped many, including children with autism spectrum disorder (ASD) and their families, who can take advantage of the benefits that telehealth affords. For children with ASD, telehealth represents positive and effective interactions with medical providers. Such interactions occur in the familiar and comforting environment of their own homes, reducing the anxiety that can sometimes accompany in-person medical appointments for children with autism spectrum disorder. Telehealth also allows for greater flexibility in scheduling appointments, lowering stress for parents by making it easier to access necessary healthcare services with less disruption of their daily routines.

At **Catalight**, one of the largest behavioral health networks in the United States with more than 14,000 practitioners serving 17,000 families each day, we've moved from doing occasional remote interactions to having daily virtual interactions with children with ASD, their families, medical providers, allied health providers, and teachers.

In conducting telehealth visits over the last four years, here is what we've learned about virtual interaction with a child who has been diagnosed with ASD that may be useful for providers:

### Child's Support Needs

The first step is determining how much support a child needs to be able to interact with you remotely. Many children with ASD also have a co-occurring intellectual disability or ADHD. If the child's disability is severe, it may not be possible to interact directly with the child, but with the help of a parent or caregiver, you can often observe the child's behavior. Asking the parent to interact with the child differently can be useful to see how a child is doing. For example, you could ask: "Let's see if he will respond to you when you call his name."



# Understanding Insurance Coverage for Autism and Co-Occurring Visual Impairment

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

According to Petretto et al. (2023), "...autism could currently be considered one of the most commonly reported co-existing developmental disorders in children with blindness or other severe visual impairment." The etiology, or the biological cause of the blindness, was directly correlated with the percentage of the children being also diagnosed with autism. The co-occurrence of autism can range from 33% in blindness caused by septo-optic dysplasia to as high as 70% of samples of children whose blindness was caused by optic nerve hypoplasia (Molinaro et al., 2020). The proper differential diagnosis is imperative with these children. It opens doors to several additional services and resources.

According to the CVI Center at Perkins School for the Blind, Cerebral/Cortical Visual Impairment (CVI) is the leading cause of blindness in children. Yet, it is alarmingly underdiagnosed or misdiagnosed because autism and CVI have several overlapping features (as cited in VanBergeijk and LaVoie, 2024). CVI is a brain-based visual impairment caused by damage or interruption to the brain's visual pathways or processing centers. Parents must find practitioners (pediatricians, ophthalmologists, and neurologists) who are well-versed in CVI and can conduct a differential diagnosis. A diagnosis is the starting point for a treatment plan and dictates the type of medical, educational, vocational, and behavioral interventions that should be a part of the treatment plan.

Some parents are hesitant to pursue a secondary diagnosis of autism. Nikoletta Livingston is an Occupational Therapist at Perkins who works with families to ensure they receive the appropriate diagnoses needed to access relevant services and specialty areas. According to Livingston, "Many families fear the stigma associated with an autism diagnosis, we work with them to challenge misconceptions so that they can access appropriate supports." In many states, for health insurance to cover certain behavioral therapies and outpatient clinical services like occupational therapy and speech and language therapy, the child must have an autism diagnosis. Without the autism diagnosis, families must pay for these treatments and services out of pocket. These treatments are often long-term and costly. Livingston also advises parents to:

- Ask your medical team if they offer case management within the hospital or someone to help coordinate care and promote team communication
- Create a one page "introduction" of your child, or share a basic information sheet with new team members and providers
- Sign release forms to allow school teams, medical teams, and outside pro-



A group of Perkins School for the Blind teenagers walk across a sunny campus together

viders to communicate with one another as appropriate

- If you have concerns, don't "wait and see" but seek answers to your questions; even if your child is young, starting early to gain access to resources and begin planning is important.

Insurance coverage is the key to accessing the health care system and relevant services. As the child reaches transition age, insurance coverage becomes increasingly more important. Under the Affordable Health Care Act, children may stay on their parent's medical insurance until age 26:

A group health plan and a health insurance issuer offering group or individual health insurance coverage that provides dependent coverage of children shall continue to make such coverage available for an adult child (who is not married) until the child turns 26 (ACA, SEC. 2714. 42 USC, 300gg-14).

This feature of the ACA (colloquially known as Obama Care) is widely known. What most parents of transition-aged youth with disabilities do not know is that their adult child with a disability may continue to be covered by their private medical insurance. The type of disability is immaterial. However, it is incumbent upon the parents to apply for Disabled Dependent Continuation Coverage to their insurance before they reach a certain age. This age varies from state to state, in the Commonwealth of Massachusetts BEFORE their 26<sup>th</sup> birthday.

## A New Model of Educating Students with Visual Impairments and Co-occurring Conditions

The Perkins School for the Blind has created the *Life Launch Program* to better prepare transition-aged students with VI and co-occurring conditions such as autism to enter the world of work and independent living. Accessing and navigating medical care is an important part of adult life and living independently. Students in the program will be taught self-advocacy skills,

specifically self-advocacy in health care settings, as part of the curriculum. This curriculum covers scheduling appointments, what to expect in various health care settings, insurance requirements, the importance of routine annual medical exams, the creation of a personalized medical folder with the student's medical history,

and preventative health measures (e.g., eating a healthy diet, daily exercise, taking medications, etc.).

To ensure the Life Launch curriculum includes the necessary components and that families have access to critical resources they need, Perkins collaborates with healthcare experts such as Amy Weinstock, the Director of Insurance Resource Center for Autism and Behavioral Health and Instructor, Department of Psychiatry University of Massachusetts Chan Medical School. The Center provides a whole host of services, including:

- Consulting with schools, agencies, and other organizations on insurance matters pertaining to autism and other disabilities
- Conducting community-based presentations
- Staffing a call center where families and professionals can seek technical assistance on insurance related issues.
- Publishing fact sheets - including a fact sheet on options after age 26 health insurance information. <https://massairc.org/factsheets/healthcare-coverage-for-adults-with-asd-frequently-asked-questions-for-parents/#page-content>

see *Insurance Coverage* on page 14

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# Telehealth Service Delivery to Persons with Neurodevelopmental Disorders

By Courtney Morgan, MBA, RN  
Services for the UnderServed (S:US),  
and Deven Unadkat, DO, MPA, FACEP  
StationMD, HealthTech Partners, Inc.

In December 2019, the Cerebral Palsy Associations of New York State (CP-NYS) partnered with StationMD, a for-profit physician service providing telemedicine to vulnerable populations, to participate in a five-year grant funded by the New York State Department of Health. The Statewide Care Facility Transformation Program grant offers a single strategy for an alternate model of care via telemedicine for more than 8000 lives.<sup>1</sup> The Telemedicine Triage Project (TTP), as it is known, is “an innovative model that provides telemedicine consultations for people with intellectual disabilities (PIDD) who reside in state-certified group residences across the state of New York in the United States, and present with an urgent but non-emergent medical concern when their usual provider is unavailable.”<sup>1</sup>

Services for the UnderServed (S:US), located in New York City, participates in this grant program along with other provider agencies. S:US provides services for individuals, which include a comprehensive array of supports to people with life circumstances marked by intellectual/developmental disabilities (I/DD), behavioral health and substance use challenges, his-

stories of incarceration, and trauma. S:US’ history has been about supporting people and communities that have been marginalized, communities of color, and communities impacted by poverty, homelessness, and food insecurity. This article chronicles our journey in this telemedicine program, including the impacts of health access disparities faced by people with I/DD.

The telehealth group StationMD provides specialized telemedicine clinicians to I/DD populations across 22 states. Its ser-

vices include 24/7 urgent care, as well as behavioral health/psychiatry treatment for people with I/DD. StationMD’s telehealth solution has been recognized by The Center for Medicare and Medicaid Innovation as an innovative telehealth solution for the I/DD population.<sup>4</sup> Given its expertise, StationMD was selected by CPNYS for this telehealth grant project.

The rapid adoption of telehealth was critical during the pandemic because hospital care was only available to the very ill. “One positive outcome of the COVID-19 pandemic was that the lockdowns and physical distancing forced a pivot to telemedicine and the increased use of other technology solutions to bring support to persons with ID/DD while minimizing physical contact.”<sup>5</sup> The timing for the rollout was concomitant to when community health access became limited. After decades of challenges and barriers to care, this organized intervention sourced between non-profit and for-profit entities created an entirely new access point.

Reflective of cultural responsiveness and emphasis on health equity, telehealth provision of care moderates the gap of access disparity. StationMD is not a replacement for primary care physicians but provides an additional layer of immediate clinical decision-making support that can also help bridge care during off-hours, weekends, and holidays. StationMD allows for the blend of a specialized remote service linkage of care for a person supported in their home environment, surrounded by familiar staff, with the option for families to join the session.

StationMD is ramping up behavioral health services as a response to increased demand, partnering with S:US to secure community behavioral health services for people served with I/DD. “Despite the prevalence of mental health conditions, research suggests that people with IDD may not be receiving adequate mental health care in the community.”<sup>2</sup> S:US has transitioned select individuals requiring medication stabilization to StationMD. A huge benefit of StationMD’s behavioral health services is that psychiatrists who specialize in PIDD are accessible in between scheduled appointments.

S:US program leadership staff articulat-

ed the impact, benefits, and disadvantages of telehealth services:

“I am grateful for telehealth visits as it is convenient and minimizes the long period of time that the people we serve have to wait at clinics. The disadvantage of a telehealth visit is that the medical provider has to determine a diagnosis, and oftentimes it is difficult for the medical provider to provide a thorough physical examination of the people we serve virtually.”

“I notice some staff are not tech savvy, and also, you have to worry about connecting to the internet when it’s time for the virtual appointment to be conducted.”

“I must say it is very efficient for minor conditions. Telehealth wait time is no more than three minutes.”

There can be some hesitation in navigating technology when starting to utilize a telehealth service. “When we created our process, we knew we had to keep things simple and help the patient and their caregiver connect to the doctor,” says Dr. Matthew Kaufman, CEO of StationMD. During every encounter, clients use a telephone to call a toll-free number, and a StationMD technical assistant guides the patient into a virtual visit with a specialized doctor. Kaufman continues, “After the first time the patient and their caregiver use our service, they realize how simple it is to use.”

According to Dr. Deven Unadkat, Chief Medical Officer at StationMD, clinicians are able to successfully resolve the patient’s medical issue 90% of the time during the telehealth encounter. Not all cases can be safely managed by telehealth. When conditions warrant an emergency room visit, the clinician will call the hospital emergency room and discuss the case with the receiving doctor. This streamlines the hospital visit process for clients, and pertinent clinical information is conveyed from doctor to doctor.

Approximately 98% of the S:US visits in 2023 resulted in effective care of PIDD in the safety of their own home. People served by S:US were able to spend more time doing the things they enjoy and less time traveling and waiting for medical care. “The American Hospital Association task force believed that virtual care strategies would allow vulnerable communities, particularly those that have difficulty recruiting or retaining an adequate health care workforce, the opportunity to maintain or supplement access to health care services.”<sup>3</sup> S:US saved over \$60,000 on direct care staff expenses over a two-year period as a direct result of utilizing StationMD services.<sup>7</sup> Currently, there is a national Direct Support Professional (DSP) workforce shortage.<sup>6</sup> S:US is leveraging the cost savings to provide further support for DSP recruitment and retention activities.

Due, in large part, to the pilot’s success, New York State has established permanent models for people with I/DD to receive telehealth services. For people in OPWDD-Certified group homes, the service is now an allowable cost to contribute to the rate of reimbursements by the state. For 1915c waiver recipients residing outside of certified group homes, it is expected that there will be a pathway to services under the waiver.

Telehealth has provided flexibility and a

## SERVICES FOR THE UNDERSERVED’S TELEHEALTH USAGE

IN RESIDENTIAL PROGRAMS 2022-2023

1,697

telemedicine visits took place across 46 S:US residential facilities for +/-230 persons served

36 (2.12%)

of 1,697 telemedicine visits were transferred to hospital emergency room for further evaluation

>200  
conditions

were diagnosed and treated by StationMD

Data from StationMD monthly utilization report.

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S:US

see *Telehealth Services* on page 27

# The Dental Disparity Dilemma

By Gina Williamson, RN, MSN  
Director of Children's Services  
Anderson Center for Autism

While the movement toward autism acceptance is certainly something to smile about, there remain many injustices for this population that must be addressed. Among them, disparities in dental care. Data gathered from a survey by the New York State Office for People with Developmental Disabilities (OP-WDD) disclosed that 15,000 individuals with intellectual disabilities (IDD) living in New York struggle to gain access to all-inclusive dental care (Koppell, 2022).

This problem leads to others; we all know oral health is directly tied to overall health. Periodontal disease, for example, can elevate blood pressure and increase stroke risk. Bacteria in the mouth can enter the bloodstream, traveling to organs like the lungs, where it may wreak havoc. And, of course, a simple issue like a cavity – typically resolved with an easy filling – can lead to tooth loss if not treated. According to Healthy People 2030, 13.4% of children ages 3-19 have untreated tooth decay, making tooth decay one of the main childhood diseases (Healthy People 2030, 2020). For most, dental visits twice a year come easily, which mitigates that risk. However, that is not at all the case for autistic and neurodivergent individuals.

A study by Erwin et al. (2022) focuses on oral health inequities faced by autistic children and the susceptibility to being at a higher risk of dental disease due to considerable levels of unmet needs concerning oral health and access to dental care. The study gathered evidence on the factors that affect access to care, oral health behaviors, and the delivery of dental care to children diagnosed with autism.

In a questionnaire given to dental providers, 72.3% of US dentists identified that financial compensation when treating this population was insufficient due to the extended amount of chair time to acquaint or desensitize this population. We must address these issues.

One reason for the inequity is the lack of training during dental school. It is time that we call upon all institutions of higher education to acknowledge the fact that 1 in 36 are now diagnosed with autism and ask that every curriculum include coursework that leads to a greater understanding of how to best support people with sensory processing challenges.

For Touro College of Dental Medicine at New York Medical College, that call came from Anderson Center for Autism recently and prompted a favorable response and near-immediate action. Our team at Anderson has collaborated with them on a second round of dental training programs to ensure that trainees can support the specific dental care needs of individuals on the spectrum. It has been so heartening for us to see everyone involved embracing challenges as opportunities; Touro College of Dental Medicine at New York Medical College professors are leading the way with their dedication to closing gaps in dental disparities. We hope that



other educational institutions are inspired by their work.

And research supports the need for such an effort. A mixed-method study by Krishnan et al. (2019) explored barriers to dental care that caregivers and children with special needs encounter. A pre-validated questionnaire was developed to gauge difficulties in caring for children with disabilities in the care of dentists, as well as in-depth interviews and focused discussions with caregivers and the difficulties faced in providing oral hygiene. This study identified the need for hands-on training for dental providers to be incorporated into the dental curriculum to bridge the gap in dental disparities for this population. The study additionally suggests that accommodation be made in the clinical setting to adapt to the sensory needs of children with special needs to ensure successful dental encounters.

Regardless of whether subject material is covered in dental school, it is also notable that there are now options for professional development once a practice is launched. For example, dentists, hygienists, and their employees can work with Anderson Center Consulting and Training (ACCT) to gain designation as Autism Supportive Environments. ACCT offers onsite and online training that empowers businesses, organizations, and groups with the tools and strategies needed to become inclusive. Participants can gain skills that will support more equitable care and, ultimately, better health outcomes in just a few hours.

However, expanding opportunities for dentists and related professionals to learn and grow is just a starting point. Like every other sector of the economy, finances must be considered as we explore the dental disparity dilemma.

Because many autistic and neurodivergent individuals have Medicaid as their primary insurance (which means a low reimbursement rate for providers), there tends to be a very small pool of dentists from which to choose. That said, if we are going to make dental care more available to autistic individuals, we must advocate for increased reimbursement rates so that more dentists will be willing to accept Medicaid – and, hopefully, those dentists will also pursue the necessary training and education to ensure appropriate and ac-

commodating service delivery.

Also, critically important from a fiscal standpoint is the need for a medical billing code for desensitization in the dental setting. Autistic and neurodivergent individuals often struggle to endure the sensory overload of a dental exam; ICD-10 coding would help break that barrier, allowing for a more comfortable experience for each patient and a more thorough dental exam with better results.

At Anderson Center for Autism, our mission is to “optimize the quality of life

for individuals with autism.” We see this as more than a mission; we believe we are part of a broader humanitarian movement. Addressing disparities in dental care for a population that is still so underserved will help us bring our mission to life for autistic and neurodivergent people everywhere. We must find ways to ensure that adequate dental care linked to overall health and wellness is available.

If we are truly going to mark a shift from ‘autism awareness’ into an era marked by ‘autism acceptance,’ we must be mindful of gaps and look for ways to bridge them. The dental disparity dilemma can be solved – and while we are making strides, we have some work to do.

Gina Williamson, RN, MSN, is the Director of Children's Services at Anderson Center for Autism. She is pursuing a Doctorate in Nursing Practice (DNP) at Capella University. Learn more at [anderson-centerforautism.org](http://anderson-centerforautism.org).

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see *Dental Disparity* on page 25

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# 75 Years: AHRC New York City to Celebrate Milestone Anniversary on May 13th, 2024

By AHRC New York City

It is with pride in an unsurpassed history and great hope for the future that AHRC New York City kicks off its 75<sup>th</sup> year with a **Gala on May 13th**. The organization began in 1948 with a \$3 ad in the New York Post placed by Ann Greenberg, a Bronx housewife whose young son with developmental disabilities had been denied access to school. She was looking for other parents to form a play group, and the response was overwhelming. Within a year, hundreds of New York City families of children with disabilities had banded together to create what would, within a decade, become a grassroots human rights movement of great magnitude that spanned across the city and the country.

Many other disability organizations had their start later in the 1950's, but AHRC NYC was the trailblazer. Its power was, and remains, its family roots.

### The Power of Families

Founded by parents and still governed by a Board comprised primarily of family members, the credo that propels the organization in all it does is based on the idea that people with developmental disabilities are entitled to access and opportunity so



Gathering of AHRC New York City founding members in 1949

they can live full and equitable lives. The organization's history is one of not only providing supports – **some of the “firsts” in the field** - but also of advocacy. From being a plaintiff in the Willowbrook lawsuit to calling for change in legislation and public policy, advocating for better education, living arrangements, prospects for work, and fuller lives in the community, AHRC NYC led the way. In its earlier years, AHRC

NYC was at the forefront of leading the newly arising provider community in its advocacy efforts and in developing provider associations. Reflecting on our history, Board President Ray Ferrigno, a parent of a young man with autism, sums it up well, *“There are many challenges to be met. But whatever the obstacle, our sense of resolve is unshakable. That is the major lesson we learned from our founders. We have made enormous strides in all these years, but there is still so much to be done.”*

AHRC NYC's 75<sup>th</sup> Anniversary is a celebration of far more than the organization. The event celebrates the history of services and supports for people with developmental disabilities in New York City, the achievements made by people with developmental disabilities and their families, the dedication of the entire provider community, as well as many different community partners who have embraced AHRC NYC's vision of a world where the power of difference is embraced, valued, and celebrated.

### Honoring Champions

The May 13<sup>th</sup> Gala will reflect on AHRC NYC's legacy and embrace a future of growth, championing the rights and opportunities of people with disabilities. The event's **Hall of Honor** will recognize individuals and groups for their exceptional dedication and contributions to the intellectual and developmental disabilities community, shaping the legacy of AHRC NYC. **The Hall of Honor** includes: **Maurreen E. O'Brien, President and Chief Executive Officer of New York State Industries for the Disabled** honored for her tireless efforts in creating meaningful employment opportunities for people

with disabilities; **Sheryl White-Scott, MD, FACP, FAAIDD, Senior Medical Advisor at AHRC New York City, and a Board Director of the Human Services Research Institute**, honored for her lifelong commitment to ensuring the well-being of patients with intellectual and developmental disabilities; **Beth Haroules, Esq., Senior Staff Attorney and Director of Disability Justice Litigation at the American Civil Liberties Union of the New York Affiliate of ACLU** is recognized for her lifelong dedication to defending the rights of people with disabilities; **Rebecca A. Seawright, Assembly Member for New York's 76th Assembly District, and Chair of the People with Disabilities Committee of the New York State Assembly** is recognized for her legislative work and dedicated advocacy for the rights of people with intellectual and developmental disabilities; **Mitchell Bloomberg, Chairman-Elect of the AHRC NYC Foundation Board, and Co-President of International Lights**, is honored for over 30 years of dedicated service on both the AHRC NYC Board and Foundation Board and for raising millions of dollars to support AHRC NYC programs; and AHRC NYC's **Our Broadway** takes center stage in the Hall of Honor. This inclusive theatrical experience, where performers with disabilities collaborate with Broadway stars, brings magical moments to life, and AHRC NYC recognizes three Broadway veterans and performers—**Dale Hensley, Gavin Creel, and Thayne Jasperson**.

Other honorees will include **Sharyn Van Reepingen, the AHRC NYC Anne Kraus Award** named in memory of a formidable AHRC NYC volunteer. Sharyn has demonstrated exceptional dedication to AHRC NYC's mission. And **Kerri Neifeld, Commissioner of the NYS Office for People with Developmental Disabilities**, is the Recipient of the **Leadership in Government Award** for her exemplary leadership and visionary commitment to enhancing services for people with developmental disabilities. **Errol Louis**, New York City journalist and host of Inside City Hall on Spectrum News NY1, who brings decades of distinguished experience in political journalism, will serve as the Master of Ceremonies. Mr. Louis knows New York better than any journalist today, and since AHRC NYC is quintessential New York, who better to shepherd attendees through the evening program?

Be a part of building a more inclusive and empowered community. Support the work of the organization. To learn more about the event and AHRC NYC's history, [click here](#).

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Raymond Ferrigno, President  
Marco Damiani, Chief Executive Officer



# Inclusivity and Equality in Treatment: Transforming Health Care, One Step at a Time

By Jorge R. Petit, MD  
Founder/CEO  
Quality Healthcare Solutions, LLC

Access to healthcare is a fundamental human right. Creating an equitable healthcare system requires that all aspects of an individual's health - physical, mental, and emotional well-being - be addressed holistically. Individuals with autism spectrum disorder (ASD) and intellectual and developmental disabilities (IDD) face significant healthcare disparities in access to medical and behavioral care, which can adversely impact their overall well-being, quality of life, and ability to participate fully in society. These disparities are complex, overlapping with issues of communication, cultural and linguistic challenges, socioeconomic barriers, and systemic biases in our existing healthcare system.

It is very clear that for children with ASD and IDD, early intervention is crucial in addressing developmental delays and improving long-term outcomes. Inadequate healthcare means lost opportunities for these early interventions, resulting in more significant and persistent developmental challenges. These can impact their ability to acquire crucial life skills, affect educational attainment, and reduce oppor-



tunities for independent living and employment in adulthood.

We also know that inadequate healthcare can lead to worsening behavioral issues in individuals with ASD/IDD. Without proper support and intervention, behaviors such as aggression, self-injury, and severe communication difficulties may become more pronounced.<sup>1</sup> These behaviors can increase isolation from social, educational, or vo-

educational opportunities and strain family/caregiver relationships. Additionally, negative healthcare experiences can lead to increased stress and trauma, creating a cycle of healthcare aversion.

What is needed is a multi-faceted approach to address these disparities, including specific initiatives, specialized training for healthcare providers, increased funding, community education, policy reforms

to ensure better coverage and support, and a shift towards a more comprehensive, accessible, and responsive system of care.

## Healthcare Disparities and Barriers

There is considerable data highlighting the disparities in healthcare access and quality of care for individuals with ASD/IDD. Even though autism can be diagnosed as early as two years old,<sup>2</sup> on average, children with autism tend to be diagnosed after age four, and studies have shown that Black and Latino/Hispanic children are diagnosed with autism later than White children, often missing crucial early intervention opportunities.<sup>3</sup> In marginalized communities, these disparities stem from many social, economic, cultural, and systemic factors.

Individuals with ASD/IDD are more likely to experience a variety of co-occurring medical conditions compared to the general population.<sup>4</sup> Some of the most common of these include sleep disorders, epilepsy, and gastrointestinal disorders – timely diagnosis and appropriate treatment of these conditions can be complex. Many individuals with ASD may have trouble communicating their symptoms, leading to delays in receiving proper care.

see *Transforming on page 24*



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# The Critical Role of a Caregiver in Navigating Systems of Care

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

**N**o one knows your child better than you. When it comes to understanding their unique needs – you are the expert. This is critical for parents and caregivers of children with emotional, behavioral, and cognitive differences. Whether you are identifying areas of concern or advocating for additional testing, services, or supports – you play a crucial role in your child's life.

For many families, navigating systems of care can be challenging. The systems are divided into the following categories:

- Medical
- Education
- Behavioral health
- Intellectual disabilities

Each system has a separate funding stream with distinct goals for your child. In addition, the systems are siloed, which means they typically do not communicate with each other or speak the same “language” (they use different words and acronyms).

While all of this can be overwhelming, especially if you are just beginning your



journey into the world of disabilities, there are steps you can take to make these systems work for you.

## Medical

Get to know your child's doctors and ask a lot of questions. Bring your list of questions (and any other documentation that will help you tell your child's story) to the appointment. This will set the tone for future appointments.

You should also acquaint yourself with the nurses and other staff when possible. Often, these individuals know the ins and outs of their practice or hospital and the best appointment times, and they can offer specialist recommendations. Once your child is a patient in a provider's system, you may have easier access and shorter wait times to see specialists.

Also, if your child has a disability diagnosis, they may qualify for state and federal medical funding through various

medical assistance programs. Check your state's human services website for more information.

## Behavioral Health

While you may believe medical and behavioral health are connected, these care systems are typically separate. As a parent or caregiver, it is your job to make the connection between your child's physicians and clinical team members about how their roles intertwine.

Often, in-home therapeutic services and school-based behavioral services collect data which, when shared by you, can help the medical doctor understand what behaviors are of concern, and influence other areas, such as medication prescribing or treatment recommendations.

Once enrolled in the behavioral health care system, more doors open to support your child, typically through local or state resources. If you are not in the system, you will not be aware of them. You can learn more about the behavioral health system and your state's benefits through their [Medicaid website](#).

When receiving behavioral health services, your child will have a treatment team consisting of a child and adolescent psychiatrist, a psychologist, a social worker, and perhaps a psychiatric nurse. The treatment

*see Caregiver on page 31*

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## Insurance Coverage from page 9

- For Massachusetts residents, explaining An Act Relative to Insurance Coverage for Autism (ARICA) <https://massairc.org/factsheets/arica-faq/#page-content>
- Maintaining a library of videos of past presentations, including how to keep your child on your insurance after age 26: <https://vimeo.com/871626930>
- Hosting bi-weekly lunch and learns for parents and professionals on a variety of insurance related topics
- Access to documents, including Legislation, FAQs, Agency Bulletins, etc.

The Life Launch Program is now accepting applications and will welcome the first class of students to campus in the Fall of 2024. For more information, visit: [www.perkins.org/transition-center/life-launch/](http://www.perkins.org/transition-center/life-launch/)

Amy joined the Transition Center at Perkins School for the Blind for a webinar on Health Insurance for transition aged youth with disabilities. You can view this discussion here: [www.perkins.org/resource-department/transition/](http://www.perkins.org/resource-department/transition/)

Perkins also offers individualized tran-



**A Perkins student smiles as he uses a microphone to record a podcast**

sition counseling for families and a range of impactful programming and resources designed to assist more academically oriented students with BVI to transition to post-secondary higher education programs, including colleges, universities, and Comprehensive Transition and Post-secondary

(CTP) programs. For more information on these programs and resources, visit <https://www.perkins.org/transition-center>.

*Ernst VanBergeijk, PhD, MSW, is the Founder and President of Ernst Equitable Education Solutions, a consulting firm that helps parents find appropriate educational settings and solutions for their children and helps organizations evaluate and design programming for special needs children, youth, and young adults. He has over 35 years of experience in the special education field, including working as the executive director/dean of two college-based transition programs for students with various disabilities. [ErnstEES.com](http://ErnstEES.com)*

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

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## Cultivating Sensory-Friendly Health Care Environments for Autistic Patients

By Richard Anemone, MPS, LMHC  
Senior Vice President  
Institute of Community Living's (ICL)  
I/DD Division

Autism spectrum disorder (ASD) is a multifaceted neurodevelopmental condition characterized by challenges in social interaction, communication, and **limited or repetitive behaviors**. Individuals with ASD might also experience sensory sensitivities, such as heightened responses to lights, sounds, textures, and other environmental stimuli. These sensitivities can make traditional health care settings overwhelming and distressing for autistic patients and their families, potentially leading to increased anxiety and difficulty accessing necessary and critical medical care. Creating sensory-friendly health care environments for autistic patients is crucial to ensure their comfort, safety, and well-being during medical visits.

To help illustrate what this experience can be like, I am introducing the character Ann, who is diagnosed with ASD and experiences anxiety when going to the dentist. Due to this anxiety, her parents often cancel her appointments due to "acting out" behavior and frequently avoid scheduling appointments due to embarrassment. Ann's parents also habitually research remedies online, which often leads to ex-



acerbation of her health conditions and the development of more serious health issues.

Sensory-friendly health care environments should minimize sensory overload and provide a calming and supportive atmosphere. Implementing sensory-friendly practices in health care settings offers numerous benefits for autistic patients, including:

- Reduced stress and anxiety during medical visits

- Improved access to essential health care services
- Enhanced patient satisfaction and overall experience
- Increased trust in health care providers
- Better health outcomes due to decreased barriers to care

By prioritizing the creation of senso-

ry-friendly health care environments, medical facilities can demonstrate their commitment to inclusivity and accessibility for individuals with autism spectrum disorder.

Health care facilities can **implement sensory modifications** to create a more accommodating environment for autistic patients. This may include using soft lighting, minimizing loud noises, providing comfortable seating options, and offering sensory-friendly waiting areas that incorporate calming elements such as acoustic tiles, weighted blankets, headphones, or fidget toys.

Ann's dental office made special appointment accommodations for her. This included early morning appointments to avoid wait times and large crowds in the waiting area. The office manager also played soothing music and kept the lights low.

Effective communication is also essential when interacting with autistic patients. Health care providers should receive training in communicating clearly and directly while being mindful of the individual's sensory needs. Visual supports, such as picture schedules or social stories, can also aid in conveying information and reducing anxiety during medical appointments.

Ann's social story about going to the dentist can help her understand that feeling anxious is okay, but hitting yourself or yelling is not okay. Ann's story can suggest

*see **Sensory-Friendly** on page 37*

## The Role of Mental Health Treatment for Autistic Individuals

By Michelle McGonagle, LICSW  
and Cailey Bussiere, MA  
The Guild for Human Services

Mental health treatment is an integral, yet often overlooked, component in the constellation of supports that surround individuals diagnosed with Autism Spectrum Disorder (ASD). Common mental health supports include case management, therapeutic groups to increase social-emotional learning, and behavioral-based intervention strategies. While these are important staples of treatment, there is a deeper need for access to individualized mental health treatment modalities. For children and adolescents with intellectual and developmental disabilities (I/DD), mental health conditions are "up to five times more prevalent than in the general population, and these problems get worse with age and the severity of the neurodevelopmental condition" (Bertelli, Forte, Bianco, 2023). Moreover, research shows that individuals with I/DD and ASD are at a higher risk for mental health issues and ongoing adverse experiences. These may include but are not limited to, physical, emotional, and sexual abuse and neglect, multiple hospitalizations, school and placement failures, and self-injurious behavior. This indicates an increased need for mental health support and access to the same types of services



as their peers without ASD and I/DD.

Components of Mental Health Treatment for Individuals with Autism

**Trauma-Informed Care** - In 1984, the National Association for the Dually Diagnosed (NADD) was established. This organization helped to overturn the long-standing failure of systems to recognize the prevalence of mental health issues, advance therapeutic treatments, and invest in research to benefit and improve the overall health of this

population. Advances in understanding Post Traumatic Stress Disorder (PTSD), trauma, and adverse childhood experiences (ACEs) created a better understanding of the full range of experiences that negatively impact the mental health and quality of life of individuals with ASD and I/DD. Furthermore, in 2003, The National Child Traumatic Stress Network (NCTSN) expanded the criterion for adverse events and offered seven distinct domains that are negatively impacted by complex developmental trauma: attachment, biology, affect

regulation, dissociation, behavior regulation, cognition, and self-concept (Cook, Blaustein, Spinazzola, van der Kolk).

Similarly, advances in trauma-informed therapy have identified core components of phase-oriented care. These include establishing safety, stabilization, affect regulation, skill building, addressing cognitive distortions, exposure to or integration of the trauma narrative, and the augmentation of resiliency factors. An additional key to providing support and trauma-informed care to individuals with I/DD and ASD, particularly in residential and day programs, is through the implementation of psychoeducation and trauma-informed consultation. This type of consultation, delivered to staff, caregivers, and family members, helps address the safety component in the environment and the attachment caregiving systems.

**Trauma-Informed Consultation** - The systems through which individuals with ASD and I/DD receive care have historically trended toward behavioral-based perspectives and approaches, which are not set up to explore the underlying, complex mental health experiences of the individuals served. Integrating mental health services into these systems through consultation is imperative as it creates a more holistic approach to treatment. Being a caregiver to individuals with ASD or I/DD

*see **Mental Health** on page 25*

# The Economic Undervaluing of the Direct Support Professional Workforce: Unveiling Societal Values and Discrimination Against People with Disabilities

By Marco Damiani  
Chief Executive Officer  
AHRC New York City

In the intricate tapestry of our society, Direct Support Professionals (DSPs) stand as unsung heroes, offering unwavering support to individuals with disabilities. However, despite their invaluable contributions, the DSP workforce remains severely undervalued economically, reflecting broader societal attitudes towards disability and discrimination. Let's talk about the economic undervaluing of DSPs and their interconnectedness with societal values and discrimination against people with disabilities.

## The Economic Undervaluing of the DSP Workforce

The economic undervaluing of DSPs is a multifaceted issue rooted in systemic neglect and societal misconceptions about disability. DSPs play a pivotal role in empowering individuals with disabilities to lead, as much as possible, independent and fulfilling lives. They provide crucial support ranging from personal care to job coaching, facilitating integration into the community and the workforce. Despite the indispensable nature of



their work, DSPs are under-compensated and lack adequate societal recognition for their contributions.

According to former Senator Tom Harkin, a pioneer in disability rights and a champion for the Americans with Disabilities Act (ADA), "The economic undervaluing of DSPs reflects a larger societal disregard for the rights and dignity of people with disabilities. It is imperative that we recognize and rectify this injustice."

## Societal Values and Discrimination Against People with Disabilities

The economic undervaluing of DSP work is intricately intertwined with societal values and discrimination against people with disabilities. Judy Heumann, the renowned disability rights activist, said, "The undervaluing of DSPs reflects deeply ingrained societal prejudices and misconceptions about disability. It is a manifesta-

tion of ableism – a systemic discrimination against individuals with disabilities."

Ableism perpetuates stereotypes and barriers that limit the opportunities and full participation of people with disabilities in society. It manifests in various forms, from inaccessible infrastructure to unequal employment opportunities. The undervaluing of DSP work is a stark manifestation of this discrimination, as it perpetuates the notion that the labor of individuals with disabilities and those who support them is less worthy of recognition and fair compensation.

## The Call for Change

Addressing the economic undervaluing of DSP work requires a concerted effort from policymakers, employers, and society at large. Judy Heumann aptly said, "We must challenge societal norms and advocate for policies that promote equity and inclusion for people with disabilities. Fair compensation for DSPs is not only a matter of economic justice but also a reflection of our societal values."

These staff are our most valuable asset. Policymakers must enact legislation that mandates fair wages for DSPs and the Front-Line Workforce, ensuring their contributions

see [Undervaluing on page 35](#)

# Supporting Autistic Adults: Am I College Ready?

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

Am I ready for college? Such a question drew the attention of high school senior students in college readiness sessions at [AHRC New York City's Middle/High School](#). College readiness encompasses academic, social, and emotional learning support for students with autism and intellectual disabilities to transition effectively from school to higher education. It is more than having appropriate levels of reading, writing, and math; the focus is placed on knowledge and skills that would help them transition and navigate college life.

## Transition Services

The Individuals with Disabilities Education Act Amended (IDEA) in 2004 mandates that transition planning for neurodiverse students should occur by the time students turn 15. Students should be assessed via vocational assessments during their transition phase to determine their interests and career/occupational path. When assisting students transitioning to college programs, students must increase non-academic skills, such as self-advocacy, self-determination, and executive functioning skills. Such skills are applied by ensuring students participate in service-learning



programs, integrating classroom learning through service to the community, internship activities, apprenticeships, and employment mentorship. In preparation for pathways to college, students and parents should attend college readiness sessions during their senior year in high school.

When the time comes for students with autism and intellectual disabilities to transition to college programs, they must acquire the skills to register for college courses, knowledge of college accommodations, manage their schedule inde-

pendently, and seek assistance when needed. However, research demonstrates that not all high school students with autism and intellectual disabilities are taught or have knowledge of the transition activities necessary to navigate college.<sup>1</sup> One study showed the reason that some students with autism and intellectual disabilities lacked such knowledge is that "no one informed or talked to them in a meaningful way about college readiness."<sup>2</sup> Students with autism and intellectual disabilities may experience challenges regarding college

readiness. However, students can succeed when schools provide appropriate support during their transition stage. Therefore, our school implemented college readiness sessions at AHRC New York City's Middle/High School for students who expressed interest and would like to pursue higher education upon graduation from high school.

## College Readiness

College readiness is one of the most crucial transition activities educators can provide to students with autism and intellectual disabilities. When students learn how to research, write, communicate appropriately, and work independently, they develop habits that will help them in all areas of their adult lives. There are some strategies that educators may already utilize during instruction to help students transition to college-level education, such as study skills and research techniques, written and oral communication skills, critical thinking, and collaboration. Furthermore, educators implement independent classroom learning, time management, organizational skills, and the importance of planners for college readiness. In addition to the strategies educators may utilize for college preparation, students should acquire knowledge on specific topics to help them navigate college life.

see [College Ready on page 28](#)



# Self-Advocacy in Healthcare: Empowering Autistic Adults to Take Control of Their Well-Being

By Katherine Cody, PsyD,  
and McKenzie Gelvin  
Spectrum Psychological Services

Navigating the American healthcare system is a challenging task for neurotypical (NT) and neurodiverse (ND) communities alike; however, there are substantially greater barriers to effective care and risk factors identified within the ND community. Research has shown that there are higher mortality rates among Autistic individuals (DaWalt et al., 2019), suggesting that current systems contain barriers to accessing effective care. According to self-report measures, 80% of autistic adults report experiencing a challenge when visiting a general practitioner (Doherty et al., 2022). Over half of autistic adults report experiencing communication challenges with physicians. Ongoing research continues to explore the nature of these barriers to determine possible explanations; however, a systemic review of previous research and stakeholder community sampling reveals several key findings for identifying a pathway toward improved self-advocacy in healthcare for autistic individuals and their caregivers (Benevides et al., 2020). Dr. Teal Benevides was generous enough to join me for an interview to review some



of these key findings and to highlight some relevant points to inform self-advocacy strategies discussed throughout this article (personal interview, February 12, 2024).

One of the key findings from stakeholder research reveals: **Mental health is health.** As such, beginning from a place of connecting within one's own community to focus on supporting access to resources and one's own overall mental health is

a foundational first step toward effective self-advocacy. The external resources that one can access through their community can be a substantial way to enhance mental health and, in turn, support overall health. A sense of community and connection to things other than oneself allows for one to feel a purpose outside of their sense of self. Obtaining peer support has been identified as the preferred method of

external support, meaning connecting with other neurodiverse individuals is crucial for mental health.

## Community-Based Resources to Consider

- Art and expression-based activities
- Yoga
- Animal experiences (i.e., horseback riding, connecting with animals in shelter)
- Nature-based activities
- Virtual and in-person peer-led support groups

When it comes to navigating standard and routine healthcare appointments, the main barriers to effective medical visits reported by autistic adults when surveyed include understanding if symptoms are severe enough to visit a doctor, struggles with making appointments over the phone, not feeling understood, challenges with communicating with the physician, and the atmosphere of the environment (Doherty et al., 2022). Various complementary approaches are utilized to combat these barriers proactively and prevent adverse health

*see Self-Advocacy on page 33*

## From Stigma to Acceptance: Insights from a Concerned Autistic Self-Advocate

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

My imagination often transports me into the thick of relatively grandiose situations. These episodes provide needed opportunities for release. In my mind, I sometimes have it out with my opponent during a presidential debate and winning, giving my acceptance speech after having won some prestigious award, or performing a few of my best songs in front of an audience of thousands. It's fun to do unless I imagine a less than joyous scenario.

As of this writing, the autistic self-advocate in me has been ruminating on a different kind of fantasy, one that is borne of stigma, of feeling marginalized, of frustration stemming from what I see happening to my community, and of wanting to set things right. I can envision being handed a megaphone of limitless range and being granted the power to command everybody's attention such that they would not only listen to but genuinely take to heart all that I have to say in response.

A grandiose imagining if there ever was one, though if it were to come to life, and if the message needed to fit within the space of one article, I would deliver an impassioned appeal to the greater society as follows:



Sam Farmer

### We Are Not Disordered

We do not need to be fixed or cured. What we need instead is acceptance and, more importantly, a sense of belonging. The prevailing narrative around autism, which focuses disproportionately on pathology and deficit, has, in doing so, rendered us ineligible for greater acceptance.

Contrary to what the prevailing narrative has been saying for quite some time, autism is not a medical condition, disease, or disorder. It is a naturally occurring neurotype (the way one's brain and nervous system are wired) among a multitude of neurotypes which have existed for as long

as humanity has existed. Just as biodiversity refers to the variety inherent in life on Earth, [neurodiversity](#) refers to the variety of neurotypes the human population embodies. We have been wrongly labeled as disordered, broken, and in need of repair because society has decided that the way autistic individuals function, by virtue of our minority neurotype, is undesirable. This outlook on autism fails to sufficiently acknowledge our unique attributes, abilities, and talents.

For many autistic individuals, our neurotype is core to self-identity. It shapes how we sense, process, and interact with the world. And yet, too many of us cannot be true to ourselves without consequence because we are not accepted for who we are.

The prevailing narrative continues to feed the stigma we are up against, a stigma that has compromised us in ways we do not deserve. [Autistic women are two to three times more likely to experience sexual violence](#) than non-autistic women. [Suicide risk](#) is several times higher for autistic individuals. Our [life expectancy](#) is significantly reduced. In the US, [at least 85% of college-educated autistic adults are unemployed](#), resulting in all kinds of untapped potential waiting to be realized at the workplace.

A society is often judged based on how it treats its most vulnerable. Ongoing discrimination against those segments of society that have always been vulnerable, including the autism community, is morally

reprehensible, divisive, and toxic to physical and mental health. Conversely, kindness, understanding, and acceptance bring us together and cultivate greater societal well-being.

### Society's Expectations Around Socialization, Communication, and Behavior Are Very Disabling to Us

This is because these expectations were not established with autism in mind. Many of us feel we live in a world not built for us. And so we are made to feel like outsiders, masking our genuine, authentic selves to "fit in." Masking, in this context, is in response to trauma. It has often resulted in burnout when done continually over a long period of time. Some autistics admit to having forgotten who they are.

Because of how our neurotype is at odds with existing systems, norms, and expectations, we become targets of ableism (discrimination against the disabled). Ableism, when internalized, is highly toxic to self-esteem. When our sense of self is damaged to the extent that internalized ableism commonly inflicts, attaining true happiness in life becomes impossible.

### Punishment Is Not the Way to Go about Helping Us

Aversive interventions, including electric

*see Insights on page 27*

## We Are All on the Same Side: Unite the Spectrum

By Robert Naseef, PhD  
and Stephen Shore, EdD

We are writing to explain why we do not need more labels to describe autism. We, the authors, became acquainted with each other in 1996 through a common mentor, Stanley Klein, the editor of *Exceptional Parent Magazine*, when we each published our first books: *Beyond the Wall: Personal Experiences with Autism and Asperger Syndrome* by Stephen M. Shore and *Special Children, Challenged Parents: The Struggles and Rewards of Raising a Child With a Disability* by Robert A. Naseef. Right away, we began helping each other understand what it is like to be Autistic and the challenges and rewards of family life. From his Autistic perspective, Stephen has helped Robert understand things about his son Tariq. Robert's 44-year-old son Tariq is unable to verbalize. Robert helps Stephen understand the family perspective when a child is diagnosed and the family lives on the spectrum.

We have presented our perspectives, which have been well-received nationally and internationally within the autism community over the past 20 years. For example, in 2019, we served as lead consultants to the Arc of Philadelphia and SAP's "Autism at Work" program, which involved collaboration with the Pennsylvania De-



Robert Naseef, PhD, his son Tariq, and Stephen Shore, EdD

partment of Education and the Bureau of Vocational Rehabilitation to develop the social skills curriculum "Preparing Neurodiverse Youth for the Workplace." In 2022, upon the request of the Qatar Foundation, we completed and delivered a "train the trainer" curriculum to enable Qatar to find meaningful employment for its neurodivergent population. Whereas the concept of neurodiversity has great potential for unifying the autism community, it has un-

fortunately become a source of division.

Neurodiversity is the concept of large variations in how human brains perceive, process, and respond to the world around them. The human race is incredibly neurodiverse. Neurodivergent individuals differ more than the typical norm. Neurodivergent conditions include autism, ADHD, dyslexia, synesthesia, dyscalculia, Down syndrome, and others.

Along with neurodiversity, there has

been a transition from a model of deficit, disorder, and disability to a more social construction focusing on strengths and making needed environmental and other adjustments to promote abilities to shine through. While espousing abilities-based ways of considering autism and other neurodivergent conditions, it is also important to hold space for the very real disabling challenges that can come with being Autistic or having other neurodivergent conditions in our society.

Relatedly, we have recently been frequently chatting about the push for a new diagnosis of "profound autism." Unfortunately, the autism community has been riddled with splits and controversies historically. None of the splits have helped Autistic people or their families, so we propose a common bond about the need to unite.

Stephen: All autistic people are bound together by differences in social communication, highly focused interests, and greater variations in sensory processing than the non-autistic population. For example, perhaps my communication difference displays as perseverating on a topic for too long, whereas Tariq has significant challenges in using spoken word. Diverse differences in communication bind us together. Tariq and I have highly focused interests and activities running deeper than

see *Unite the Spectrum* on page 36

## Autism Gets an Update: A National Autism Strategy for Canadians

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

*Note: While there are many areas of inequity, this article will focus on diagnosis and support services as seen by the Autistic writer living in Ontario, Canada.*

One in 66 Canadians is autistic. Collectively, we face numerous challenges to accessing services and supports, including long waiting lists and fragmented, inconsistent interprovincial services and funding. Each of Canada's 10 provinces and 3 territories chooses how it funds autism-related support services, and approaches vary across the country.

This is problematic in a nation in which roughly 23% of citizens are foreign-born. 8.3 million people represent a mix of languages, cultures, and religions. The lack of a dedicated Nationwide strategy to address inequities and complex ASD issues disadvantages all Autistic Canadians (Evans, 2013).

Autism itself, is not a disease. However, "Autistic people have a range of comorbidities resulting in a high use of health services. Doctors of nearly all specialties are likely to encounter autistic people in their practice" (Gallager et al., 2023). MDs most conversant with Autism Spectrum Disorder tend to be Pediatricians and Psychiatrists. Primary Care Providers



express greater discomfort in diagnosing and treating AS conditions (Davin et al., 2022). "Factors such as limited focus on ASD in medical school and professional trainings or workshops, as well as difficulties accessing resources or information about providing services to individuals with ASD, hinder their ability to provide care to individuals with [Autism]" (Ghaideri & Watson, 2019).

Equitable access to school and community supports is inconsistent, compromising early intervention for those living in

remote, rural communities—effectively two-thirds of Canadians. Northern regions lag behind national and provincial averages in quality of health and health care. Northern populations are more likely to experience poor health, have difficulty accessing health care, and die younger. These inequities are intensified in First Nations, Métis, and Inuit peoples, as well as the francophone (French-speaking) population (Health Equity in Northern Ontario - Health Quality Ontario (HQP), n.d.).

There are few affordable options for

adult assessment. According to Jamie Santana, an Autism therapist and Advocate, "You have to look at the full stage of life, you can't just look at under five, then youth and then forget about them when [they're] older" (Dhanraj, 2018).

Canada's National Autism Strategy (NAS)

20 years ago, the state of autism in Canada was already a public concern. Individuals and organizations were calling upon the federal government to exercise a leadership role to ensure that ASD treatment and support were consistent across all environments and jurisdictions (Provest, 2011).

The intent behind the NAS is to encourage a unified approach, ensure consistency in the services provided between provinces/territories, promote best practices, and address support gaps.

According to a press release from the Canadian government, "The [Autism] Network will work as an independent body to bring together autism organizations and partners, including individuals with lived...experience, to share their skills, knowledge, and resources to support key... priorities and provide a forum for ongoing engagement of Autistic communities on federal policies and programs" (Autism Explained: History of Autism, n.d.).

The NAS promises implementation of its

see *Canadian Strategy* on page 26

# What Is Health Equity and Why It Matters to Those with Disabilities

By Jennifer “Jay” Palumbo  
CEO of Wonder Woman Writer and  
Mom to Two Boys, One with Autism

According to the 2022 summary of the Maternal and Child Health Bureau’s National Survey of Children’s Health, more than 14 million children had special healthcare needs. These children, in particular, are more likely to experience chronic physical, developmental, behavioral or emotional conditions and require added care and services.

This is why [health equity for children with special needs, disabilities, or autism](#) needs to be carefully examined. These individuals face significant challenges in accessing quality healthcare, leading to disparities that can have profound long-term effects on their well-being and development.

Deloitte’s 2021 report, *Breaking the Cost Curve*, described how new business models, technological breakthroughs, personalized data, and regulations that could encourage change would dramatically slow down healthcare spending by 2040. However, health inequities remain a major barrier to this goal.

Inequities in the [US health system cost around \\$320 billion and could surpass \\$1 trillion](#) in yearly spending by 2040 if it remains unaddressed.



Systemic Challenges in Healthcare Access

The US Office of Disease Prevention and Health Promotion (ODPHP) defines a health disparity as “a health difference that is closely linked with social, economic, or environmental disadvantage.”

Children who experience unique healthcare needs experience these disparities in medical care and services. Some key points from the [National Survey of](#)

[Children’s Health](#) are:

- Children and youth in this category were nearly four times as likely to have unmet care needs as their peers.
- The most common reasons for unmet needs were related to cost and appointment availability.
- Fewer than 2 in 3 kids with special

needs had adequate health insurance to cover the services needed.

- Fewer than one in four youth with special needs, ages 12 to 17, received plans and services for adult health care.

Race, geographic location, and socioeconomic status compound these challenges, impacting the accessibility and quality of healthcare these children receive.

Sheila Thurman, [DDI Director](#) of the Office for People With Developmental Disabilities (OPWDD) Nursing Services, notes, “Many barriers exist to achieving health equity for people with disabilities. Having Medicaid-only insurance is a major limiting factor. Inadequate comprehensive and preventative health measures lead to poor outcomes and poor monitoring of chronic conditions.”

Within the health care system are multi-payer federal and state and Medicaid-specific initiatives focused on addressing social needs. These include models under the Center for Medicare and Medicaid Innovation, Medicaid delivery system, payment reform initiatives, and options under Medicaid.

Managed care plans and providers also identify and address social needs. For example, 19 states required Medicaid-managed care plans to screen for or provide

*see [Health Equity on page 29](#)*

## Autistic Health: Embracing a Holistic Approach

By Steven Merahn, MD  
Medical Director  
Partners Health Plan/Care Design NY

Human beings may seem similar because we all go through common developmental stages. However, in reality, human beings are remarkably diverse. Shaped by genetics and life experiences, we develop a wide range of personalities, temperaments, skills, capabilities, preferences, perspectives, and ways of being.

This means we are all neurodiverse in one way or another.

The foundation of human development rests on a person’s capacity to interact with their environment. The ability to sense, receive, and respond to information and experiences drives the development of new abilities, functional skills, and patterns of behavior. The scope and sequence of development are parallel to brain development and function. This combination of ‘nature and nurture’ results in how we individually express capabilities such as expression and receptive communication, social interaction and relationships, and control over behavior.

Some specific patterns of expression in those domains are associated with the diagnostic criteria for the form of neurodiversity we call “autism.” However, being autistic is not necessarily a disability, nor is it always disabling. The diagnostic criterion for au-



tism focuses on autism-related disabilities that can interfere with a child’s natural developmental progress; for some children, those disabilities may be profound.

Therapeutic interventions have the potential to reduce the burden of autism-related disabilities and support the autistic child’s capacity to fully develop individual capabilities, preferences, perspectives, and ways of being.

But we now know that an autistic child is far more than their diagnosis-related symptoms and behaviors. Autism is a

“whole person” biopsychosocial condition. There are common positive attributes of the autistic mind, such as creativity, attention to detail, a strong sense of right and wrong, memory, honesty, and deep focus. There are also shared patterns of autism-associated physical and mental health-related conditions.

Autistic children and adults have a significantly higher prevalence of asthma, allergies, epilepsy, gastrointestinal conditions, and mental health conditions compared to non-autistic controls (Carbone et

al., 2015). Almost 50% of children with autism are on at least one chronic medication for co-morbidities, and 30% have polypharmacy of three or more medications (Feroe et al., 2021).

Children with autism have more annual physician visits, more emergency room visits, and are more likely to be hospitalized (Cummings et al., 2015). Mean medical expenditures for children with autism and co-occurring conditions were four to six times higher than those of comparison groups (Shimabukuro et al., 2007).

With this truth, navigating the health systems can be a challenge for autistic children and adults and those who care for and about them. Care delivery is overshadowed by their “autistic symptoms and behavior.”

But, as the [World Health Organization](#) states, whole person health is more than just the absence of disease or infirmity, but a “state of complete physical, mental and social well-being” (*Constitution*, 2024).

How Can We Help Our Systems of Care Approach Autism From a “Whole Person” Orientation?

First, by orienting them to the fact that body functions serve their capacity for activities, participation, and management of their environment. Care planning should specifically focus on the value of physical health in an autistic’s capacity to be an

*see [Holistic Approach on page 34](#)*

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

## Part 1: Let's Change How We Define "Disability"

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

*Note: Autism Spectrum News has allowed me to herein adapt an old piece of mine into a three-part series. I jumped at the chance as the piece needed an update.*

Frequent readers of mine know the following statement: "Security is mostly a superstition. It does not exist in nature....Life is either a daring adventure, or nothing" (Helen Keller).

I love this quote because it reveals the terrible loss that often occurs when we stay in our comfort zones or give in to fear. It doesn't just encourage bravery; it tells us *we have no choice but* to be brave.

Yet Keller's phrasing doesn't intimidate either - it reassures. And Keller was blind and deaf at a time in which supports barely existed, so if she can say it, so can we... right?

Well, a recent, [excellent article](#) by fellow spectrumite and [Autism Spectrum News author Sam Farmer](#) brought many of us Helen Keller hero-worshippers to our knees. Keller, early in her life, favored eugenics. An emotionally fraught but easy decision to cancel, right?

Going back to Keller's quote alone for a



**Helen Keller with her hand on a braille book as she smells a rose**

moment...I have autism. And when folks like us hear what might (even remotely) feel like pressure to be "brave," many of us sometimes shudder because of past experiences when we were criticized or made fun of when we were scared. What we used to call "cowardice" has been thankfully re-examined under a myriad of more humane and accurate explanations – like

"fight or flight" – and this is massive progress on our roads to true inclusion.

But as an emotionally unhealthy byproduct of that change, we've grown to almost scorn real bravery. To many, bravery seems an obligation thrust on us only by past perpetrators, enforced by "jerks" or macho nonsense. Our last and perhaps future president called fallen military people "suckers" and "losers." Despite historically low crime rates, many people can't feel safe unless they own (often multiple) firearms. And people all across the country sacrifice their figurative souls, their literal souls, their mental health, and the mental health of people who love them in order to keep jobs that treat them miserably.

So, I'm prefacing this 50-year, 3-part plan/article with advice from my now-exposed hero (Keller) in an area where I'd like to see a change in *all* Americans, as without bravery, we can't implement any great ideas...no matter how great they may be. Spoiler alert: Keller changed her opinion completely later on. Can she still be my hero?

### 1A. The Deficit Lens

To start...All the widely read definitions of disability are deficit-based. Even from those who have championed our cause.

[From the US Centers for Disease Con-](#)

[trol \(CDC\)](#): A disability is any condition of the body or mind (impairment) that makes it more difficult for the person with the condition to do certain activities (activity limitation) and interact with the world around them (participation restrictions).

[From the Americans with Disabilities Act \(ADA\)](#): ...an individual with a disability is a person who:

- Has a physical or mental impairment that substantially limits one or more major life activities
- Has a record of such an impairment
- Is regarded as having such an impairment

Is the use of the word "impairment" by both of these entities inaccurate? No. But it isn't "accurate" either. It doesn't take a great brain to understand that this is a true "*beauty in the eyes of the beholder*" or "*two people looking at the same rock from different angles*" situation. If our choice of whether or not to use an asset-based definition or a deficit-based definition is arbitrary, then why do we choose the deficit model? Is it really just because we can argue disabilities as deficits so easily?

[see Defining Disability on page 32](#)

## Empowering Eye Exams: Strategies for Supporting Autistic Patients

By Elise Huntley, MA CCLS  
Certified Child Life Specialist  
Dayton Children's Hospital

Eye exam. Two words that can cause a lot of anxiety in families of autistic patients. Questions may arise about how your child will tolerate the exam and what to do if they need glasses. If your child has communication limitations or sensory sensitivities, you might wonder if they'll be able to complete an eye exam. Is it even worth making the appointment? Luckily, there are some tips and tricks to help you and your child make the eye exam appointment easier for both of you.

Eye exams are important for children with autism as they are less likely to be screened for visual impairment and more likely to have ophthalmologic disorders. In a research article in *Pediatrics*, it was found that children with autism are significantly less likely to be screened for vision difficulties during their well-child visits with the pediatrician than their peers without autism (Hoover et al., 2023). This is concerning as children with autism are more likely to need glasses and have a variety of ophthalmologic disorders. For children with autism the prevalence of ophthalmologic disorders is believed to be 13.5% in children with autism in contrast to children without autism or any other developmental disabilities (Chang et al.,



2021). These ophthalmologic disorders include amblyopia (lazy eye), strabismus (crossed eyes), nystagmus (rapid uncontrolled eye movement), optic neuropathy (damage to the optic nerve), and retinopathy of prematurity (scarring of the retina). In another study from 2019, ophthalmologic concerns such as refractive errors (needing glasses), strabismus, and amblyopia were found in 71% of children with autism (Chang et al., 2019). Having an eye exam and correcting vision can also impact behavior, as a correlation has been found between children with significant

refractive errors and behaviors (Aghai et al., 2016; Mohamed et al., 2019). The eye exam is an essential part of well checks and keeps your child healthy.

Although important, eye exams are not easy. Eye exams are typically long visits with lots of steps and demands on the child. Depending on your child's developmental level, it might be hard for them to participate in the subjective portions of testing, such as matching shapes and letters. If your child struggles with transitions, eye exams often have many tasks that children need to transition be-

tween (Coulter et al., 2015). For children with sensory processing differences, the sensory input during the exam might feel overwhelming. Bright lights shine in their eyes, lots of staff enter and leave the room, and often, doctors touch the head while completing their exam (Parmar et al., 2022). The whole eye exam can be exhausting and leave both the child and caregiver feeling frustrated.

### Preparing for the Eye Exam

Even before you arrive at the doctor's appointment, you can set your child up for success. When you schedule the appointment, try to find a doctor who has worked with people with autism and is familiar with ways to adapt an exam for patients with sensory differences or communication limitations. As you make follow-up appointments, you can request to see the same provider to ensure consistency for your child so that they can become comfortable and familiar with that provider. Another easy adaptation can be to ask for a particular time of day when your child will cooperate best or a quieter time of day when the waiting room won't be as busy. Before arriving for the appointment, ask the office what to expect for the visit and share potential support needs with the clinic. Some eye exam tests are subjective, while others are objective and don't require

[see Eye Exams on page 30](#)

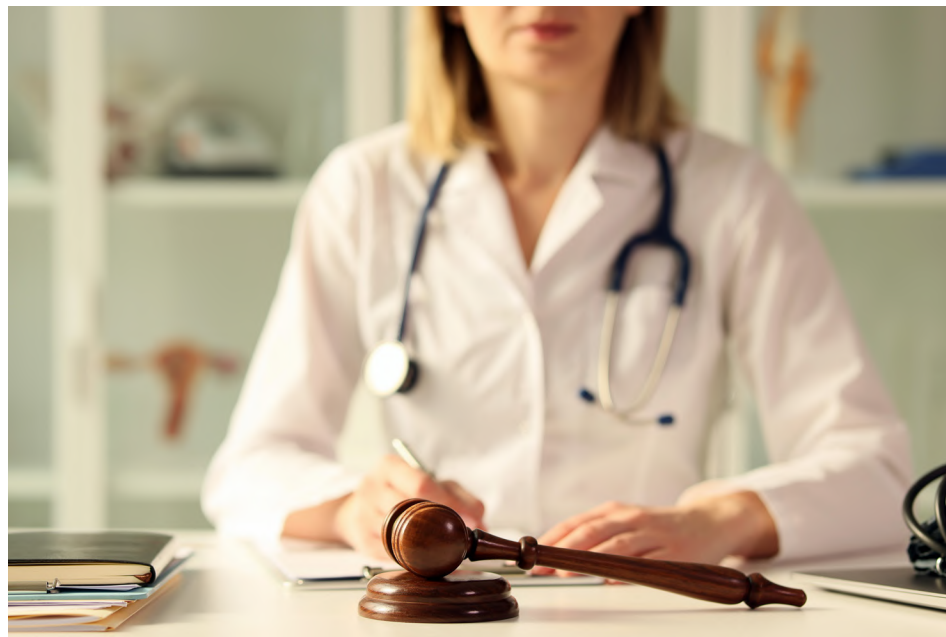
## Navigating Medical Decision-Making and Insurance for Autistic Children in Divorced Families

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

**M**anaging the care and needs of a child on the autism spectrum can be a full-time job. In addition to addressing the day-to-day care, educational, and behavioral needs of an autistic child, managing the therapeutic and medical visits can be quite involved, including such challenges as scheduling and getting to the visits, finding the right professionals, coordinating insurance approval and reimbursements, and easing the anxiety of a child at the medical visits.

So, how are these tasks handled when parents are divorced? Some possible options will be presented in this article.

If the parents are getting along well, then the decision-making and handling of issues becomes easier. If, during the divorce, one parent was given the authority to have the final say in making medical decisions, the medical needs of the child could be addressed more quickly and with less conflict. This type of agreement can occur when one parent has been more involved in the day-to-day caregiving role and is more familiar with the medical needs and professionals involved in supporting the



child. This is not to say the other parent is not involved, as agreements can state the other parent should be consulted regarding medical treatments, and their input should be considered in making decisions.

When both parents are or wish to be equally involved, decision-making may be shared 50/50. However, one or more individuals would need to be assigned to be potential tie-breakers in case the parents

cannot come to an agreement. This could be different people, depending on the type of expertise needed for a particular medical. The assigned person would likely need to be identified and have agreed to take on this role. Being required to wait on a third party to make a decision when parties cannot agree on what is in the best interest of the child may potentially cause a delay, which may be an issue in an urgent medical matter.

In high-conflict divorce situations, medical decision-making authority can be a cause of friction and prolonged and expensive legal battles. Ideally, divorcing or divorced parents should put the needs of the child first rather than fight over who gets to make the decision. Perhaps each parent can have different decision-making authority or discuss how they can come to an agreement. Sometimes, neutral third parties such as mediators or parenting coordinators can assist parents in coming up with solutions that would be acceptable to all involved.

Sometimes, transparency and information sharing can alleviate many concerns that divorced couples may have. It is recommended that both parents have access to important medical and caregiving information in case of emergencies, but also for day-to-day routines and care. Ideally, this can be in a hard copy or electronic format that each parent can access. There are apps where information can be shared and viewed by each parent, as well as other professionals or caregivers who might need the information to support the child or parents.

Insurance coverage and administration are areas that also need to be addressed when parents are divorced. Usually, one

*see Decision-Making on page 35*

## Challenges for Autistic Adults in Navigating the Labyrinth of Healthcare

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

**A**s I was fortunate enough to have had employment with good healthcare benefits, I did not have to face many of the challenges in navigating the healthcare system that autistics regularly encounter. Nevertheless, because of my involvement with the autism community over the past quarter century, not to mention my own recent experiences as a senior on the spectrum, I am confident in my understanding and appreciation of these issues to have informed opinions about them. Furthermore, I addressed some of them during my participation in AASET (Autistic Adults and Other Stakeholders Engaged Together).

Compared to the situation at the time of my diagnosis in late 2000, let alone during my childhood and later youth, improvements in diagnosing ASD, along with increased public awareness of such, means that an autistic person under a certain age (i.e., young enough for ASD diagnosis to have been available in their childhood) will likely have been diagnosed by the time they need to access the healthcare system; as such, any autism-related difficulties navigating it can be addressed, at least in principle. However, the exact opposite is true for older adults such as myself. Consequently, these two categories will need



to be considered differently. In the former case, procedures and practices can be formulated and applied whenever an identified autistic accesses the healthcare system; in the latter, an individual needs to be recognized as such before this can happen. Since most older adult autistics have not been identified, let alone diagnosed, this presents a conundrum for a large segment of the autism community – some form of massive ASD screening for older adults will be needed during healthcare intakes.

All of this is further complicated by

the fact that numerous comorbid conditions which are neither part of the ASD syndrome nor included in its diagnostic criteria are more common in the autism community than in the general population. These include psychiatric/psychological as well as purely medical ones. It would be extremely helpful, if not essential, for healthcare providers to know that a patient under their care is more susceptible to these conditions than is usually the case so that they can examine or have them tested for such.

Awareness of Autism  
and Comorbidities Is Essential

Probably the best-known instance of autism comorbidity involves gastrointestinal issues, which are not included among the traits for ASD, and explanations for their connection to such are highly speculative (to the best of my knowledge). I lived with these in my childhood and throughout my life. Still, I did not fully appreciate their significance until I asked the attendees if they had any such concerns at a support meeting that I facilitated. Even with previous knowledge of the issue, I was surprised when three-fourths of them raised their hands! Clearly, this is a very common problem. Again, healthcare providers need to be aware of this when treating an autistic patient and examine them thoroughly for such. Furthermore, this should be done by a physician with expertise in this area and, when warranted, by a board-certified gastroenterologist.

Other comorbidities involve neurodiversity and mental health. ADHD is so common in the autism community that, for many years, it was often given as a misdiagnosis for ASD, as was OCD (which is easily confused with the repetitive behaviors of autistics). Learning disabilities such as dyslexia and dyscalculia are also common. Psychiatric illnesses (e.g., bipolar, psychotic, and schizophrenic disorders)

*see Challenges on page 31*

## The Role of Mental Health Support in Autism Care: Breaking Free of the Patterns of This World

By Priya Winston, PhD, LMSW  
Transitions

As a mental health professional, I have had the incredible privilege of counseling individuals with Autism for over a decade. I have had the opportunity to witness and be a part of the beautiful journey that occurs when someone who received a diagnostic label of Autism Spectrum Disorder learns to become comfortable with every part of themselves and capitalize on their strengths to fulfill their purpose here on Earth. I've seen many realize that they think, learn, and communicate differently than others. They reckon with the idea that they may have to work harder than most to develop skills to fit into a world never created for them to achieve their goals.

Autism is often linked with mental health conditions like anxiety and depression. There has been a lot of research to support the correlation and comorbidity between these conditions. In my opinion, this is caused by the battles that come with Autism, like trying to fit in while feeling different from what society deems as normal. I believe the mental health struggles also come from the shame and stigma associated with Autism due to a lack of education and understanding of the



topic among the general population. For instance, people diagnosed are often categorized as high- or low-functioning. Those with strong academic skills (ex., reading, writing, math, and memorization) are often labeled high functioning, while those with other strengths like strong conversational or adaptive/independent living skills (ex., cooking, cleaning, building, hands-on tasks) are labeled as low functioning. People with a diagnosis tend to work extreme-

ly hard to hide or mask any indication that they have Autism as well. It is extremely difficult to try to hide who you truly are. This difficulty is often compounded by challenges with regulating and expressing emotions in a socially acceptable way.

The role of a mental health professional is to work with individuals to understand what a diagnosis of Autism Spectrum Disorder means for them. A spectrum means that the experience will be different for

everyone. This makes it critical for mental health professionals to listen and be open-minded to learn from their clients. For instance, seek their input about whether they prefer to be called a "person with Autism" or "Autistic person." It is the role of a mental health professional to encourage them to seek hope and faith that they can fulfill their purpose here on Earth despite a diagnosis. The role of a mental health professional is to teach someone that a diagnosis is simply a tool rather than a definition of who someone is. Clinicians, counselors, and therapists are to teach people that it is okay to receive support, help, and accommodations to accomplish goals. Going into a vulnerable position and seeking these tools is a strength.

I had the opportunity to develop a research-based course for a post-secondary education program that teaches young neurodiverse students all of these concepts. Many bright, talented, and wonderful young people broke into tears when we started talking about their experiences. It was the first time they ever spoke about Autism or understood what it meant for them. For many years, many of them have been taught that Autism makes them inferior to others. They were taught that this prevented them from having the life they

*see Breaking Free on page 37*

## Considerations to Accessing ABA Therapy Through Insurance

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

There are many services that can be beneficial for you to explore for your autistic child, including speech therapy, occupational therapy, and applied behavior analysis (ABA), and consulting with your child's primary care physician or school team for recommendations on services is an important step. ABA therapy is a frequently recommended service that incorporates positive approaches to teach functional skills, decrease non-functional skills, and help individuals become more independent and successful in home, school, and community settings. ABA programs generally focus on increasing language and communication skills, social and play skills, learner readiness skills, and self-care skills.

If you decide to pursue ABA services for your child, you can consider obtaining [services through your medical insurance](#). This can be a daunting endeavor, especially if you are not familiar with the process. There are several areas that you will want to familiarize yourself with as you look to secure ABA services for your loved one within the medical model. This includes navigating access to care issues, selecting a provider aligned with your



values and best practices in the field, and understanding the nuances of insurance authorization approval.

### Access to Care

While Medicaid eligibility requirements vary by state, commercial insurance requires a diagnosis of autism spectrum disorder (ASD) for ABA therapy to be covered. If your child does not have a formal diagnosis of ASD, that will be the starting point to access needed care. You will

want to start by discussing any concerns with your primary care doctor or pediatrician. They can sometimes provide initial screenings or refer you and your loved one to a specialist, such as a developmental pediatrician, child psychologist, or neurologist, who can conduct comprehensive testing for ASD. Often, caregivers must endure long waitlists to secure a diagnostic testing appointment, which is a barrier to accessing care. Caregivers should look to explore multiple avenues to secure a diagnostic evaluation appointment. Contacting

local autism clinics or centers that specialize in developmental disorders may also provide diagnostic testing. It is important to stay in communication with healthcare providers to inquire about waitlist updates and availability.

Waiting for diagnostic testing and the final report is just one of many access to care issues. While obtaining an ASD diagnosis is a necessary step, the diagnosis alone does not necessarily guarantee access to services. It is important to be educated on the specific coverage associated with your insurance plan. You will need to review your health insurance policy to ensure that you understand the benefits available for ASD related services, if your plan has them at all. Many self-funded insurance plans are not required to comply with state mandates to cover ABA services since they are regulated at the federal level. You may need to consider obtaining secondary insurance for your child to bridge any coverage gaps found within your primary insurance. You will also need to familiarize yourself with deductibles, copayments, coinsurance, maximum out-of-pocket limits, and coverage criteria for specific treatments. It is also important to stay up to date regarding changes in your insurance coverage because you will ultimately be financially liable for services provided that are not covered due to insurance changes or lapses.

*see Insurance on page 29*

# Filling the Gaps in Healthcare: The Vital Role of Information Sharing for Individuals with Autism and Intellectual and Developmental Disabilities

By Karen Lindgren, PhD, Bancroft, and Sally A. French, MSN, APN, PMHNP-BC Cooper University Hospital

**W**ading through the complex landscape of healthcare for individuals with autism and intellectual and developmental disabilities (I/DD) and their caregivers can be frustrating, often hindered by a variety of barriers unique to this population. While systematic and overwhelming, these challenges are solvable when we all make a concerted effort to fill in the information gaps.

By fostering strategic communication between healthcare providers, human service organizations, and families, we can unravel the complexities, fill the information vortex that often exists, and create improved healthcare outcomes and a more inclusive healthcare environment.

For the average person, healthcare includes making an appointment with a doctor, communicating any challenges, and hopefully finding solutions. For individuals with autism and intellectual disabilities, limited understanding and awareness among healthcare providers about their unique needs can result in miscommunication and inadequate care. By creating systems and spaces where families and human service organizations



can provide information and where doctors are willing to accept and review the information given to them, we can create spaces that include awareness, education, and the implementation of sensory-friendly practices within healthcare settings.

Some barriers faced by those with autism and I/DD include:

**Limited Appointment Time** - Individuals with autism and intellectual disabilities may require more time during healthcare appointments due to potential communi-

cation challenges and sensory sensitivities. In a conventional healthcare setting where appointment times are often limited, this poses a significant barrier to providing effective and personalized care. A shift towards longer appointments fosters a patient-centered approach, acknowledging and accommodating the unique communication needs of individuals with autism and intellectual disabilities.

**Sensory Overload in Waiting Areas** - Waiting areas in healthcare facilities, de-

signed without consideration for sensory sensitivities, can be overwhelming for individuals with autism and intellectual disabilities. The sensory overload experienced can exacerbate stress and anxiety, potentially leading to negative healthcare experiences and impacting the ability of the individual to effectively communicate concerns. To address this, a proactive approach involves redesigning waiting areas to be sensory-friendly. By creating calming and accommodating environments, healthcare facilities can significantly reduce stress levels and make the overall experience more accessible for individuals with sensory sensitivities.

**Communication Challenges** - Effective communication is at the heart of successful healthcare interactions. Individuals with autism may have unique communication styles, which can present challenges in traditional healthcare settings. To overcome this barrier, healthcare providers need to be aware of and adapt to these differences in communication styles, and for those with significant disabilities, even offer simultaneous communication with their caregivers. Implementing communication strategies that account for the diverse ways individuals with autism express themselves

see *Filling the Gaps* on page 35

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### Transforming from page 13

Physical discomfort caused by these underlying conditions can, at times, manifest as changes in behavior, such as increased irritability, aggression, self-injury, or repetitive behaviors, which may be misinterpreted as solely related to ASD/IDD rather than an underlying medical issue.

There is also a high prevalence of co-occurring mental health conditions, such as ADHD, anxiety, or learning disabilities, which can complicate the assessment and diagnostic process, leading to inappropriate interventions or a lack of support and services for the underlying ASD/IDD.<sup>5, 6</sup> Accessing appropriate mental health care can be very challenging because of factors like accessibility, cost, family and individual knowledge, language barriers, and stigma.<sup>7, 8</sup>

Effective diagnosis, treatment, and support for ASD/IDD face several barriers that can significantly influence the quality of care and the overall well-being of individuals with ASD/IDD. These barriers are often interconnected and can be categorized into the following areas:

**1. Financial Barriers:** All too often, families with lower socioeconomic means face greater financial challenges when having to access assessment, diagnoses, treatment, and support services that unfortunately lead to disparities in care and outcomes. Interventions, such as behavioral, speech, and occupational therapy, can be prohibitively expensive, especially if not covered by insurance, leading to costly out-of-pocket expenses. Insurance coverage for autism-related treatments can often be inadequate, and coverage can vary significantly between policies, leaving many essential therapies and supports not covered. Additionally, insurance policies may not cover all aspects of the diagnostic evaluation, particularly in-depth assessments needed for complex cases, and this can delay or prevent families from seeking care.

**2. Geographical Barriers:** Many rural or remote areas have limited access to specialized assessment, diagnostic, treatment, and support services. Moreover, there are fewer adequately trained healthcare providers to identify ASD/IDD, particularly in its less obvious forms or when it co-occurs with other conditions.<sup>9</sup> These geographic barriers also lead to travel/transportation barriers when accessing specialized services, which adds to financial and time burdens for many families/caregivers.

**3. Cultural Barriers:** Stigma and lack of awareness about ASD/IDD and its symptoms can delay parents or caregivers in recognizing and responding to early signs and seeking appropriate support and early intervention services. There are cultural beliefs and stigma surrounding ASD/IDD - particularly pronounced among racial/ethnic minorities and immigrant families - which can influence how symptoms are perceived and addressed and can impact engagement with the healthcare system. Frequently, non-English speaking families struggle to access services, communicate with physicians, and navigate complex administrative processes, limiting their understanding of treatment options and their ability to advocate for their loved one's needs.

**4. Systemic Barriers:** State and federal variability in policies and legislation can af-

fect the availability and quality of treatment and support services for those individuals with ASD/IDD. Furthermore, the complexity of the healthcare and educational systems can be overwhelming, especially for families new to the diagnosis or those with limited resources and health literacy.

The healthcare system often lacks the necessary accommodations for sensory sensitivities and communication needs, making medical environments overwhelming and inaccessible for many on the spectrum. Navigating Individualized Education Programs (IEPs) and accessing appropriate school-based services can be very challenging, often requiring significant advocacy by parents.

#### Best Practices and Strategies

Equitable and inclusive healthcare for individuals with ASD/IDD requires a focus on individualized care, person-centered approaches, specialized training, and interdisciplinary teamwork tailored to the individual and the family/caregiver's unique needs.

**1. Individualized Care:** Individuals with ASD/IDD present with unique sets of strengths, challenges, and healthcare needs. What is needed are care plans that are individualized, dynamic, and capable of adapting to the individual's changing needs over time, especially as they transition through different life stages. It is critical to involve the individual and their family/caregivers in developing the care plan, thus ensuring that it aligns with their preferences, values, and goals - fostering true collaboration and a greater sense of agency.

**2. Person-Centered Approaches:** Healthcare providers need to understand how to respect and promote the autonomy of individuals with ASD/IDD, recognizing their capacity to make informed decisions about their care. Often, providers will need to figure out how to adapt their communication strategies to meet the individual's needs, including visual aids, clear and concise language, or alternative communication methods for those with speech and language difficulties. Healthcare environments and procedures should be adjusted and adapted to account for sensory sensitivities common among individuals with ASD/IDD, such as lighting, sound, and touch preferences.

**3. Interdisciplinary Approach:** An interdisciplinary team - doctors, nurses, therapists (speech, occupational, behavioral), psychologists, social workers, and other specialists - is required to provide holistic care.

A team approach, incorporating insights from various specialties such as psychology, neurology, occupational therapy, and speech therapy, facilitates shared decision-making, ensuring that different perspectives and expertise are considered in developing and implementing care plans. Coordination and communication among team members are necessary to ensure that all aspects of the individual's health needs are coordinated, avoiding fragmented or ambiguous care.

**4. Continuous Training and Education:** Healthcare providers must engage in enhanced/specialized training to foster a deeper understanding of the complexities of ASD/IDD, including its varied presentations, co-occurring conditions, and the latest research in the field. Specialized

training allows for more accurate and timely diagnosis, critical for accessing early intervention services and ensuring that treatments and interventions are appropriate and effective. Specialized training also raises awareness of the specific challenges faced by individuals with ASD/IDD, including sensory sensitivities and social communication difficulties, leading to more person-centered and compassionate care.

- The **Autism CARES Act** (Collaboration, Accountability, Research, Education, and Support) supports training programs and initiatives to improve care for individuals with ASD, funding various training initiatives, research projects, and centers of excellence in autism care.

- **American Academy of Pediatrics (AAP) Guidelines** provide guidelines and training resources for pediatricians on screening, diagnosing, and managing ASD, promoting early identification and intervention.

The consequences of an inequitable healthcare system for individuals with ASD/IDD and their families are profound, impacting the mental, physical, and emotional well-being of the individual, but also the overall functioning and stability of their families and communities. Ensuring equitable healthcare for individuals with ASD/IDD is not only about health and well-being but also a critical element of social justice, economic efficiency, and societal progress.

These effects underscore the need for a holistic and adaptable healthcare approach that addresses individuals' unique and evolving needs throughout their lifespan. Addressing these will require greater awareness and education about ASD/IDD across the board, enhanced cultural competence and linguistic accessibility in healthcare services, more equitable distribution of resources, and advocacy for policy changes that increase access to comprehensive diagnostic and intervention services.

By working together, healthcare providers, policymakers, and communities can make significant strides in overcoming the challenges faced by autistic individuals and move towards a more effective, equitable, and supportive healthcare system.

#### Call to Action

##### Healthcare Providers

- Commit to ongoing education and training in ASD/IDD care.
- Embrace person-centered approaches and collaborate with interdisciplinary teams to ensure holistic care.
- Advocate for and implement practices that accommodate the unique needs of individuals with ASD/IDD and their families/caregivers.

##### Policymakers

- Recognize and address the healthcare disparities facing individuals with ASD/IDD.
- Enact policies that ensure accessible, affordable, and high-quality healthcare services.
- Support funding for autism research, training programs, and resources that

facilitate early intervention and long-term support, especially among racial/ethnic minority groups.

##### Communities

- Foster a supportive and inclusive environment for individuals with ASD/IDD and their families.
- Promote awareness and understanding of ASD/IDD to reduce stigma and facilitate better integration and participation in community life.
- Support local initiatives and organizations that provide services and advocacy for individuals with ASD/IDD.

##### Resources

[Centers for Disease Control and Prevention \(CDC\)](#)

[World Health Organization \(WHO\)](#)

[National Institute of Mental Health \(NIMH\)](#)

[Autism Speaks](#)

[Autism Society](#)

[Autistic Self Advocacy Network](#)

[US Department of Health and Human Services \(HHS\)](#)

[Autism Research Institute](#)

[Children's Hospital of Philadelphia](#)

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##### Footnotes

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**Mental Health from page 15**

is as challenging as it is rewarding. This system often includes parents, extended family members, special education teachers, occupational therapists, speech therapists, behavior clinicians, and day program or residential direct support providers. One overarching goal of trauma-informed care includes creating safety and developing positive capacities within the caregiving system. This includes supporting caregivers by providing psychoeducation to increase knowledge and skills around their ability to self-regulate, provide predictability, and create positive, safe relationships. Trauma-informed care further helps with both vicarious trauma of caregivers and prevents burnout while maintaining quality care (Blaustein, Kinniburgh, 2019).

**Individual Therapy** - Individual therapy, which takes place within a trusted relationship and in a safe environment, allows individuals to learn about themselves and the world around them. It is confidential and can be a unique contrast to the day-to-day experiences of individuals with ASD. The therapeutic relationship is based on unconditional positive regard, allowing the individual to gain agency over their treatment. It also has the potential to create reparative experiences that will ultimately foster resiliency and set the stage for future skill-building and growth. It is a place where almost all play, self-expression, and exploration are allowed and honored — a stark contrast to systems and environments that are highly controlled and monitored. In therapy, meaning can be made, joy can be discovered, and experiences can be externalized, examined, and recontextualized.

Given the cognitive impairments of individuals with ASD and I/DD, an attuned therapist needs to document and understand any changes in presentation and expressions of distress as indicators of mental health or trauma responses. Trauma-informed therapists are uniquely positioned to offer a framework for healing in the context of the therapy space. Through techniques that draw from various approaches, therapists can offer the space and time for reparative expression and exploration that is not allowed during day-to-day events. Some examples of effective treatment modalities for individuals with ASD and I/DD are psychoeducation and group therapy, play therapy, and expres-

**Michelle McGonagle, LICSW**

sive arts therapy.

**Psychoeducation** - Psychoeducation on self-regulation strategies greatly relieves (dis)stress and sets the stage for more individualized counseling. This may be modeled through co-regulation or explained with visuals and words.

**Group Therapy** - Over the past 30 years, Interactive Behavior Therapy (IBT), a model of group therapy grounded in the theoretical underpinnings of psychodrama, has shown efficacy in treating individuals with I/DD and/or protracted mental health issues and trauma. In one study, IBT group participants with I/DD experienced an equal or greater impact of therapeutic factors leading to positive change compared to neurotypical participants. Working to enhance social competence, acceptance, universality, and installation of hope, IBT aligns well with trauma-informed treatment frameworks (Razza, Tomasulo, 2005).

**Play Therapy** - Play therapy is a therapeutic modality where a trained mental health professional “uses the therapeutic powers of play to help clients prevent or resolve psychosocial difficulties and achieve optimal growth and development” (Association for Play Therapy, 2024). Play, often described as the language of children, can be especially beneficial when working with individuals with ASD and I/DD. Trauma-informed play therapy focuses on safety making, augmenting positive coping skills, facilitating emotional and behavioral regulation,

**Cailey Bussiere, MA**

and making meaning of the post-trauma self (Goodyear-Brown, 2010).

**Expressive Arts Therapy** - Expressive arts therapy refers to “the purposeful application of art, music, dance/movement, dramatic enactment, creative writing, and imaginative play [and] is largely a non-verbal way of self-expression of feelings and perceptions” (Malchiodi, 2020). These techniques are implemented by a mental health professional who has been trained in the use of expressive arts therapy. For individuals who are not primarily verbal communicators or who have trouble articulating their experiences, these modalities allow therapeutic work to move beyond the need for words. This approach is especially beneficial when working with individuals who have experienced trauma, as the expressive arts “are action-oriented and tap implicit, embodied experiences of trauma that can defy expression through verbal therapy or logic” (Malchiodi, 2020).

**Closing**

Individuals with ASD and I/DD are at risk for and present with higher rates of mental health concerns, including traumatic and adverse childhood experiences. While treatment continues to improve, mental health counseling is underutilized and underrepresented in trauma-informed approaches to care. The use of phase-oriented, trauma-informed treatment can help guide individual therapy and provide both reparative experiences and protective factors that contribute to the resiliency

and quality of life for a group of individuals underserved by the health system at large.

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**Canadian Strategy from page 18**

key goals by 2025 (A Blueprint and a Roadmap for National Autism Strategy, 2020):

- Affordability and access
- Information
- Employment
- Housing and
- Research

**Outcomes and Expectations**

A successful “NAS should be sustainable, efficient and provide real outcomes for Autistic Canadians and their families. To do this...the government [is to] develop a body of evidence on what is working, to aim for continuous improvement, and to have annual, public...report backs on progress” (A Blueprint and a Roadmap for National Autism Strategy, 2020) in order to:

- Define autism.
- Involve autistic people at every step through advocacy, self-advocacy, and outreach.
- Support autistic adults with rent, groceries, mental and physical health services, and transportation to assist ASD adults who live on their own with no government support.
- Train non-autistics to help and support autistic people, creating a more knowledgeable and accepting society.
- Care for autistic seniors and train health-care professionals to work with them.
- Aid autistic adults in paying their bills and accessing housing, alleviating the burden of poverty, and increasing their quality of life.
- Improve access to mobility aids, assistive devices, and technology, as well as provide a free and accessible transportation system for people with sensory sensitivities.
- Give access to all types and levels of education, whether through scholarships or other means. The strategy also involves comprehensive training of education staff who work with autistic students.
- Research and collect health data from autistic people across Canada to pro-

**Annie Kent, MA**

vide policymakers with accurate statistics on the autistic population and what their lives and needs look like. Such data is expected to prove useful in developing programs and services that benefit autistic Canadians.

- Research the intersectionality of race, class, and gender in ASD. Like any other group, Autistic people experience differing privileges and prejudicial treatment depending on who they are (beyond being autistic). Autism services for Indigenous peoples is an area of enormous importance as there are more unmet needs among Aboriginal individuals and families.

**Will It Help?**

There's less criticism of the NAS today than even a few years ago. Some Autism Advocates initially doubted the government's promise to honor the “Nothing about us, without us” principle because a “needs study” was too small, “and only 2.4 percent of the participants...were even autistic” (a4aontario, 2021). The Autism community remains concerned that autism organizations will monopolize Strategy funding while seeking to represent their own business interests.

I want to believe the strategy is being developed in good faith, that it will include Autistic Voices, and improve many aspects of life for autistic Canadians. But while actively working as an Advocate, I knew of 30+ provincial Mental Health reform reports written between 1983 and 2016, which seemed ultimately to be shelved.

NAS funding is federal, and provincial failures don't mean the Federal Strategy will fail. However, any plan can fail due

to unexpected circumstances. The NAS promises to increase support services as well as provide additional funding for those services. This reminds me of the nearly 50-year-long psychiatric hospital deinstitutionalization process that began in the 1960s. Deinstitutionalization was supposed to be a humane process, allowing patients greater dignity by receiving care in their home communities. But, few community mental-health centers were built, creating an extreme shortage of mental health care and increasing homelessness. Governments are good at sloganeering, but their plans may amount to empty vows.

**Final Thoughts**

Before my ASD diagnosis, one psychologist told me: “You were assessed by the best Neuropsychologist in the city. If she didn't diagnose Autism, you're not autistic.”

One of my chief concerns about the National Strategy is whose voices will carry farther. Autistic voices? Or those of the clinicians who spend a few hours asking questions, then assume they know us better than we know ourselves? Nothing about us without us must be the guiding principle.

*Annie Kent, MA, spent two decades working in public sector disability, mental health, and infectious diseases advocacy and education. Diagnosed with three closely related categories of neurodiversity, a lack of awareness and understanding led to autistic burn-out and retirement from the field. She remains an active advocate, always learning and engaging remotely with several Autism and ADHD organizations and forums, including the Canadian ADHD Resource Alliance (CADDRA). For more information, visit her website, [www.aspiefemmepress.ca](http://www.aspiefemmepress.ca), or email Annie at [ajollymo@lakeheadu.ca](mailto:ajollymo@lakeheadu.ca).*

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### Telehealth Services from page 10

critical pipeline to the delivery of care for the I/DD population in a complex health-care environment. Trusted partnerships, as evidenced by S:US' collaboration with a telehealth service provider such as StationMD, are proven sustainable models and solutions to reduce pressure on care providers and the healthcare delivery system as a whole. The impact of this strategic partnership reinforces S:US' philosophy of providing tailored, person-centered services in integrated settings to transform the lives of the people we serve and improve our communities.

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For more information about S:US' services for people with intellectual/developmental disabilities, visit [sus.org/our-services/intellectual-developmental-disabilities](https://sus.org/our-services/intellectual-developmental-disabilities). For more information about StationMD, visit [stationmd.com](https://stationmd.com).

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### Insights from page 17

shock, continue to be leveled on many of us to reverse those behaviors of ours that society has deemed unacceptable. Such methods try to force us into behaving in ways that are typical of the non-autistic majority, essentially erasing our autism. These practices are not helpful. Rather, they are torturous, traumatizing, and dehumanizing. Arguably, they constitute human rights violations.

Skill-building is an important and worthwhile endeavor, **but only if done in ways that sufficiently respect our neurodivergence**. We would prefer that the counselors, teachers, and clinicians with whom we work meet us where we are, not based on where they feel we should be, and that they hold realistic expectations of us. Otherwise, adverse outcomes arise. It all comes down to being treated with kindness and decency.

#### Stop Perpetuating Harmful Stereotypes About Us

The autism community is not monolithic. Rather, we exist on a highly diversified spectrum. As such, any stereotype perpetuated about us is an unjust oversimplification.

The stereotypes we are up against stem from misunderstandings about us. Differences between autistic and non-autistic individuals with respect to sensory processing, behavior, thinking, learning, communication, and socialization account for many of these misunderstandings.

To name but a few:

- “But you don’t look autistic.” Autism does not have an associated appearance, so many of us construe this statement as hurtful. In fact, some autistic individuals are models, [Julian Scott](#) and [Nina Marker](#), for example.
- “There are no autistic adults, only au-

tistic children.” No, it doesn’t work that way. Autism is for life because it is a neurotype, a way of being. It is often inherited and genetically passed on.

- “Autistic individuals are only good at STEM-related pursuits.” Don’t say this to the [autistic actors starring on Broadway](#) or to an autistic [Rock ‘n Roll singer, teacher, or lawyer](#).
- “Autistics cannot feel empathy.” Not true. In fact, many of us feel what others feel very deeply. Because [empathy does not manifest itself in autistics the way it does in non-autistic individuals](#), it is often assumed, wrongly, that we are incapable of it.
- Contrary to what most people believe, when some of us do not make eye contact, it does not mean that we are not paying attention or are uninterested in what others are saying. It is because we are trying to self-regulate to avoid sensory overload so that we can listen better than we otherwise would, with our ears and hearts.
- “Nonverbal autistics have limited thinking and learning abilities.” not everything is as it seems on the surface. [Elizabeth Bonker](#), valedictorian of the Rollins College Class of 2022, and [Philip Reyes](#) are two cases in point. Both are non-speaking and are more than capable of thinking, learning, and using words to communicate. In this instance, “nonverbal” is the wrong descriptor, implying an inability to use words – a repeatedly misused term in this context. “Non-speaking” is more appropriate.

Many of Us Do Not Want to Be Viewed as “Inspiring” Whenever We Rise Above Our Challenges

We simply want to be viewed as everyday human beings, regardless of our

achievements. We would rather hear “great job” than something akin to “You inspired me by doing what you did despite your autism.” The latter, in our view, suggests disrespect.

We do not exist to inspire others. We exist in our own right.

#### Please Listen to Our Lived Experiences

If we share our experiences, we are not putting on an act or pursuing a hidden agenda. We do so truthfully because we want to be better understood and accepted for who we are.

All too often, non-autistic individuals are making decisions that directly affect us but without our input. Trauma frequently results when we are silenced in this fashion. This is why our lived experiences need to be heard. Nothing about us without us!

#### Where Should Society Go From Here?

Society benefits when autistic and other neurodivergent individuals are granted the accommodations on which we depend to be at our best. The more this happens, the more we move from feeling disabled and otherized to feeling empowered, accepted, and valued, and the better equipped we become at doing right by the people with whom we associate. In this regard, accommodation is a win-win.

Some accommodations address our heightened sensory sensitivities to light and noise as well as our tactile sensitivities (clothing textures, for example) etc. Others relate to our self-care needs (remote work often helps in this regard), how we learn and work best (in team settings vs. individually, for instance), and how we best communicate (in writing vs. speaking, face-to-face vs. at a distance), to name a few.

Autistics have lots to contribute when allowed to do so and when accommodated accordingly. We tend to be exceptionally detail-oriented, creative, thoughtful, analytical, adept at pattern recognition, able to focus intensely for long periods of time, and loyal to those who matter to us.

Companies that hire us benefit from our unique perspectives and problem-solving abilities. Our strong sense of right and wrong accounts for [our capacity for whistleblowing when we witness workplace misconduct](#). A collaboration involving neurotypical and neurodivergent co-workers results in greater [interpersonal intelligence](#), considering the neurological, learning, and thinking differences associated with this dynamic.

The best way forward? In my view of a rightly ordered world, it’s all about kindness and acceptance of others. Accommodation follows from these, whether at the workplace or society. Looking back on my life as an autistic and learning-disabled individual, the accommodations I received over the years proved invaluable. They were granted by good people who accepted me for who I was, looked past my social quirks and idiosyncrasies and saw the good in me, wanted more for me, and valued being associated with me. In return, I have worked hard, exercised kindness, been a good friend, accommodated others, and remained loyal. It’s a win-win. That’s the way forward!

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

### College Ready from page 16

AHRC New York City's Middle/High School implemented college readiness sessions in December 2023. The college readiness sessions consist of 45-minute weekly sessions with high school senior students. Topics of discussion are geared toward self-awareness, college planning, decision-making skills, knowing their disability, and reviewing their Individualized Education Plan (IEP) or Section 504 Accommodation Plan (504 Plan) for students who have a disability but do not receive special education services. Understanding the law when it shifts from special education to higher education is important to understand, as is how the shift in the law impacts their lives as adults, college research, types of colleges or universities, college accessibility services and accommodations, types of college degrees, admission process, and financial aid. In AHRC New York City's Middle/High School's first college readiness session, students were given a folder with a copy of their IEP, college planning tools, & college readiness information. One student asked, "Why do I need a copy of my IEP?"

Students pursuing college pathways should be familiar with their IEP or 504 Plan and actively participate in annual reviews. Students' active participation in their annual IEP meetings or implementation of 504 plans allows them to promote self-determination and self-advocacy, which are non-academic skills necessary to transition to college life. For example, students reviewed the testing accommodations provided to students in special education. Learning about testing accommodations helps students with autism and intellectual disabilities understand their accommodations according to their needs, increase their self-awareness, and plan how to request reasonable accommodations. Students asked what their rights were to disclose their disability when applying for college accessibility/disability services to request accommodations.

Under students' rights, college students can self-disclose their disability if they choose to. While some students may share this aspect of their identity to provide a comprehensive picture of themselves and the college services they are applying for, others may choose to keep it private. The Family Educational Rights and Privacy Act (FERPA) prevents higher education settings from disclosing a student's disability without the student's consent.<sup>3</sup> However, when students choose to self-disclose their disability, we encourage them to focus on how it has shaped their identity, influenced their academic journey and community experiences, and contributed to their personal growth. Therefore, the accessibility/disability offices may comprehensively understand their reasonable accommodation request. When requesting reasonable accommodations, students have the right to receive accommodations approved by the Office of Accessibility/Disability Services, and they have the right to appeal the approved decision.<sup>4</sup> From a legal standpoint, a student asked, "How am I legally protected when I transition to a college program?"

#### Understanding the Law

Students with autism and intellectual disabilities in special education settings are covered by critical federal laws such as the IDEA, subpart D of Section 504 of



**Trudy Ann Pines, EdD**

the Rehabilitation Act, and the Americans with Disabilities Act Amendments Act of 2008 (ADAAA), which redefined the term disability in Section 504 and ADA.<sup>5</sup> IDEA is an educational law requiring schools to provide educational services to students with supportive accommodations and additional services to help them succeed academically, socially, and emotionally.<sup>6</sup> However, when students with autism and intellectual disabilities transition from high school to a college program, students are covered by two federal civil rights laws, subpart E of Section 504 of the Rehabilitation Act and the ADA. Under the civil rights laws, college students may register with the Office of Accessibility/Disability Services and request reasonable accommodations. Furthermore, colleges are not required to provide specialized classes.<sup>7</sup> While gaining knowledge on how the law differs between high school special education and higher education settings, students should be encouraged to conduct college research to help them determine what type of college they would like to attend based on the services colleges provide. Students' interest in our college readiness sessions focused on community colleges.

#### College Life in Community Colleges

Students with autism and intellectual disabilities are increasingly involved in pursuing higher education.<sup>8</sup> A growing body of research demonstrates that students with autism and intellectual disabilities begin college life at community colleges.<sup>9</sup> Community colleges are expanding their services to help students with autism and intellectual disabilities achieve their career goals. Students may begin college life through college transition experience programs. College transition experience programs allow students with autism and intellectual disabilities to introduce themselves to the experience of college life, civic engagement, academic advisement, and participate in college courses with support services.<sup>10</sup> Community colleges are typically non-residential higher education settings. Therefore, students commute from home via public transportation or ride-share services or are transported by family members. Career advisers or mentors can assist students explore their skills, values, and future goals and support them with internships and paths to employment.<sup>11</sup> AHRC New York City's Middle/High School students who have visited community colleges as part of their transition activities have generally expressed that attending a community college would

be a better transition as it would be easier to learn and navigate college life. How can students move forward to complete the correct steps to transition to a college program?

As students with disabilities embark on their journey to further their education via college transition and matriculated programs, schools and educators need to recognize, identify, and implement a college planning timeline for students and families. A college planning timeline ensures a plan that students and families may follow with the support of the school clinical team and transition coordinators to ensure a successful transition to college life. Below is a sample of a college timeline that students and families may follow during school transition to college. It is important that parents/caregivers be active participants in their child's IEP meetings, college research, and college admissions process. Parents should become comfortable and knowledgeable about their child's disability and how the law differs from high school to college.

#### College Planning Timeline/Junior Year

##### September-October

- College planning via college readiness sessions
- Discuss personal statement prompts and essays for the college students are applying
- Complete SAT or HSE practice tests
- Discuss transition services, career planning, and social services the student may require (i.e., NYS Office of People with Developmental Disabilities eligibility & Care Management)

##### November-December

- College Research & Interest Surveys

##### December-February

- Regents Examinations for students pursuing local/Regents high school diplomas
- Potential College Visits
- Choosing a college/university

##### March-June

- Regents Examinations for those pursuing local/Regents high school diplomas
- Discuss the college list and application deadlines.

##### July-August

- Preparing for local/Regent's diploma.
- Regents Examinations for students pursuing local/Regents high school diplomas

#### College Planning Timeline/Senior Year

##### September-November

- College planning via college readiness sessions
- Discuss admissions applications and

personal statements

- Review application deadlines and recommendations
- Discuss completed applications to be submitted to colleges
- Discuss transition planning, career planning, and student exit summary with parents, school district, and Care Coordinator

##### January-April

- Regents Examinations for students pursuing local/Regents high school diplomas

##### April-June

- Regents Examinations for students pursuing local/Regents high school diploma
- Discuss the final choice for college/university.

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**Insurance from page 22****Finding an ABA Provider**

Once your child has an ASD diagnosis and you have confirmed your insurance benefits cover ABA therapy, the next step is finding an ABA provider. You will first want to confirm that your insurance is accepted by the provider and that you are aware of any responsibility for out-of-pocket costs. If a provider accepts your insurance, completing intake paperwork and starting the process to initiate therapy is something you should work quickly to do, as many providers, unfortunately, have waitlists for assessments that extend several weeks or even months out. You can complete the intake process with as many providers as you would like but will only be able to move forward with the assessment process with one provider.

Just because a provider accepts your insurance and adds your child to their waitlist does not mean their approach and philosophy to care is appropriate for your child and aligns with your values and goals. ABA providers are not created equal, and there is not a one-size fits all approach when it comes to treatment. Programming and teaching approaches should be individualized to your child and include the use of evidence-based treatment that is overseen by a Board Certified Behavior Analyst (BCBA). Quality care providers focus on child-centered approaches and trauma-informed care, and compassion and relationship building are the foundation of their model. Quality care providers also incorporate your input at each step of the process to ensure your perspective and priorities remain at the forefront of treatment, collaborate with other service providers to ensure care is coordinated and consistent across all aspects of your child's environment, and make data-driven decisions to treatment to ensure programs are consistently reviewed and updated.

**Brandon Sierchio, MA, BCBA****Authorization Approval**

ABA therapy covered through insurance is considered a medically necessary treatment. For your child to receive medically necessary ABA services, several criteria need to be met. For example, there must be documentation of severe challenging behavior and/or communication and social interaction issues related to characteristics of ASD. Furthermore, the challenges documented would need to present a health or safety risk to self or others or present a significant functional interference within the home and/or community. It also would need to be demonstrated that behaviors are developmentally inappropriate and pose a significant obstacle to the individual's performance of developmentally appropriate daily functioning.

Once medical necessity is determined through an assessment, it will be the provider's responsibility to develop goals and interventions that address symptoms of ASD, including but not limited to: deficits

**Kristen Daneker, MS, BCBA**

in social-emotional reciprocity, difficulties with transitions, insistence on sameness, deficits in verbal and non-verbal communication skills, fixated interests, deficits in flexibility and routine, and restricted and/or repetitive patterns of behavior, interests, or activities. While specific skills can be targeted in ABA therapy, goals need to be aligned with the symptoms of ASD. Your child may struggle with tying his shoes, but not being able to tie your shoes does not meet medical necessity criteria. Instead, a goal to reduce your child's insistence of sameness and flexibility with novel stimuli should be developed in which he learns to wear a variety of types of shoes with different fasteners, laces, zippers, toe coverings, etc.

Successful authorization approval requires a clinical recommendation of service hours aligned with general standards of care within typical dosage guidelines (i.e., number of weekly hours for direct therapy, program supervision, and parent training), daily maximum hours usage

**Howard Savin, PhD**

(i.e., number of daily hours covered for each service), and covered locations (i.e., home, clinic, or school, though many insurance plans do not cover services rendered at school locations). Authorizations also require key components such as assessment data, progress on goals, titration and discharge criteria, and an estimated service duration.

As you can see, there is much to be done and learned on the front end to secure ABA therapy through insurance. Educating yourself and understanding that many barriers can arise throughout the process is important to successfully navigate the healthcare service model. Above all else, do not let the process deter you from seeking out these services if you believe they are the best fit for your child.

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**Health Equity from page 19**

referrals for social needs in 2017, and a recent survey of Medicaid-managed care plans found that almost all responding plans reported activities to address social determinants of health.

**Barriers to Communication and Quality of Care**

Effective communication is vital in healthcare, yet children with complex needs or who are non-verbal often struggle in this area. Inadequate communication can lead to misdiagnosis and suboptimal care.

Additionally, the quality of care is frequently compromised, with children with special needs or autism not always receiving coordinated, continuous, timely, and inclusive care.

Thurman explains, "We will have health equity when every person has equal access and opportunity to achieve their highest levels of health. Children and adults with complex mental, physical, and behavioral needs due to autism or other disability often cannot verbalize how they are feeling. Being unable to communicate their signs and symptoms of wellness or illness can lead to misdiagnosis."

**Social determinants of health (SDH) also play a crucial role in shaping the healthcare experiences of children with disabilities.** Family income, job security, insurance ac-

**Jennifer "Jay" Palumbo**

cess, and living conditions can create additional stress and impact these children's overall health and well-being. Addressing these social determinants is essential in mitigating the health disparities faced by children with disabilities.

**The Importance of Policy and Legislation**

Policy and legislation can help in advancing health equity for children with disabilities. Initiatives such as providing Medicaid reimbursement increases for diagnostic and treatment centers can help address the

healthcare crisis facing families and individuals with disabilities. Supportive policies and legislation are crucial in ensuring access to necessary healthcare services.

Thurman emphasizes, "Policy and legislation play a huge role in advancing health equity for those with disabilities. Currently, in New York, we are calling on Governor Hochul and our elected officials to address the crisis facing families, staff, and individuals with disabilities. This is the only way to keep health care available for New Yorkers with disabilities. Providing Medicaid reimbursement increases for freestanding Article 28 Diagnostic and Treatment Centers is both the right and the fiscally responsible thing to do."

**Data-Driven Approaches and Economic Impact**

Leveraging data and technology can help develop targeted interventions and policies to address the disparities faced by children with disabilities. Furthermore, addressing health disparities can unlock economic value and improve the quality of life for millions of individuals. Investing in health equity is both a moral imperative and a smart financial decision.

Achieving health equity requires a multifaceted approach that addresses systemic barriers, improves communication in healthcare settings, enacts supportive pol-

icies and legislation, and leverages data for targeted interventions.

As Thurman rightly points out, "Health equity is important for individuals with disabilities because it is only fair that our most vulnerable receive equal access to the same high level of quality care as everyone else."

By committing to these efforts, we can ensure that our most vulnerable populations are not left behind and have the opportunity to attain their highest level of health.

*This article was originally published on Forbes on February 26th, 2024, and has been republished with permission. [View the original source.](#)*

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### Eye Exams from page 20

participation from the child. Figuring out these types of exams and what sensory experiences to expect can help you prepare your child before the visit (Parmar et al., 2022). Sharing your child's support needs can help the clinic prepare to make your visit easier, as they may budget additional time for your child or assign appropriate support staff.

Once you figure out what to expect for the eye exam, you can prepare your child and set them up for success. Preparation books and social stories are a great way to prepare children for new experiences and can help lower anxiety before the exam (Coulter et al., 2015). Some generic books about eye exams that might be helpful include *Howard and the Amazing Eye Exam* by Michelle Weed and Dr. Catherine McDaniel, *Emma Goes to the Eye Doctor* by Dr. Claudine Courey and Dr. Gabriella Courey, *I Need Glasses: My Visit to the Optometrist* by Virginia Dooley and Stephanie Roth, and *I Can See Just Fine* by Eric Barclay. There are also videos on YouTube about what it's like having an eye exam and walking a child through what they should expect for their visit. If your child struggles being in new and unfamiliar settings, you can request a tour of the clinic and introduce your child to the setting before the appointment. Typically, part of the test includes matching shapes and letters, so it can be helpful to practice matching with your child prior to the appointment. When you prepare your child for their visit, you are giving them the tools to be successful in their appointment.

#### Supporting Your Child During the Exam

There are several ways to ease into the appointment, such as bringing items with you. Comfort items like a blanket or favorite stuffed toy can help the child feel more comfortable in an unfamiliar setting. Toys like pop its and fidget spinners can provide distraction during the exam. Demonstration is another helpful tool during visits. Demonstrating the flashlights and other parts of the exam on a baby doll or caregiver is a technique called shaping, which has been found to increase cooperation with eye exams (Coulter et al., 2015). Adaptive sensory environments are another resource that can be helpful in decreasing the anxiety of patients and increasing cooperation in the medical setting (Shapiro et al., 2019; Cermak et al., 2015; Fallea et al., 2022). Simple adaptations like turning down the lights, moving to a quieter room, and limiting staff can ease the time spent in the medical setting. Alternative seating and weighted blankets are another sensory adaptation to increase cooperation. Research has found that in the school setting, alternative seating, such as therapy balls and inflated wobble cushions, increased a child's engagement and attention (Shilling & Schwartz, 2004; Pfeiffer et al., 2008). In our clinic, we have had a lot of success in using a vibrating cushion to help active and sensory-seeking patients sit still. By



**Elise Huntley, MA, CCLS**

providing sensory input while they're sitting, we've found that patients sit still better, which allows the provider to complete the eye exam. We also have weighted lap pads available in the clinic, as research has found a correlation between using weighted blankets and anxiety. We've found that it's a non-invasive way to help the patient sit still during an exam (Eron et al., 2020). Bringing these preferred sensory items and favorite toys to a visit can be an easy way to keep your child comfortable in an unfamiliar setting.

For an initial eye exam, the patient will typically need their eyes dilated as this helps the provider examine the eye and potential prescription needs. It can be helpful to discuss this with the clinic before the visit, as some clinics dilate eyes with drops while others use a spray. If your child might struggle with the stinging sensation of dilation, a helpful tip is to provide alternative sensory input like vibration or deep pressure. Drops can also be administered with the child's eyes closed. Have the child lay their head back and close their eyes, then administer the drops on the eyelash or the inside corner of the eye. When the child opens their eyes while lying down, the eye drops will naturally go into the child's eyes. Another idea can be practicing drops at home with regular saline prior to the dilation drops during the clinic visit. At our clinic, we offer the opportunity to split visits. For patients who may struggle with the full visit that is typically 2 hours, we can split it into two appointments. On the first appointment, the child does all parts of the exam that happen before dilation. Then, the family either administers dilation drops at home or they can return on a different day for clinic staff to dilate the child's eyes and complete the post-dilation part of the exam. With the right adaptations and support, children with autism can be successful with an eye exam.

#### Setting Your Child up for Success

As the caregiver, you are the expert on your child. It is helpful for staff when you share information about your child and

how they can best support your child's needs. Research has found that patients with individualized care plans have fewer challenges with anxiety and coping (Liddle & Sonnetag, 2020). Sharing information about your child's expressive and receptive language skills can help staff communicate with your child. It takes teamwork to care for children, so sharing your child's interests, triggers, and sensory needs can help staff engage with and support your child. As the caregiver, you know what helps your child, and you can empower the staff caring for your child by sharing those helpful strategies with them.

An eye exam can feel overwhelming to families. Fear and stress may lead some families to postpone appointments. Eye exams are so important for children with autism due to the increased risk of eye diseases and the lack of screening tools at the pediatrician for well-child visits. With preparation and adaptations to care, children with autism can successfully complete eye exams in ophthalmology clinics.

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**Caregiver from page 14**

team will consider a variety of treatments and interventions as they evaluate your child. Ensure you participate in treatment team meetings and are forthcoming about your child's challenges. It is well-documented that family engagement is essential to a child's successful outcomes.

**Education**

The education system is incredibly important to the well-being and success of all our children. The [Individuals with Disabilities Education Act](#) specifies that children with disabilities are entitled to a [Free and Appropriate Public Education](#) (FAPE), which may or may not look like the standard education program in your area.

FAPE requires schools to provide special education programming to meet the unique needs of each child. While you are not required to disclose medical information to your child's school, it can be helpful when advocating for services or accommodations to be made and documented in your

**Amy Kelly, MBA, MNM**

child's [individualized education program](#).

As a parent or caregiver, you are an equal partner with your child's school team and should be an active participant. For more

information on educational rights, vocabulary, and other specifics, visit [www.wright-law.com](http://www.wright-law.com).

**Intellectual Disabilities**

If your loved one has an IQ test score of 70 or below and demonstrates difficulties in learning, problem-solving, memory, and speaking, they likely will qualify for your state's [intellectual disability](#) system.

Many clinicians can diagnose intellectual disabilities, including, but not limited to, developmental pediatricians, psychologists (school and clinical), psychiatrists, neurologists, and trained pediatricians and nurse practitioners. The general rule of thumb is children under the age of 5 who show symptoms of an intellectual disability are diagnosed with "global developmental delay" until they can be tested with fidelity by a trained professional. Having an intellectual disability diagnosis allows your child access to special education services, [home and community-based Medicaid waiver services](#), and [Social Security Administration benefits](#), all of

which can be crucial to their future and are not necessarily available unless you have an official diagnosis.

Remember, as a parent or caregiver, you are a primary player in each care system, and only you can provide the true expertise on your child.

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**Challenges from page 21**

sometimes occur in autistics as well. Once again, autistic patients should be evaluated for these whenever there is any indication of such and if warranted, referred to an appropriate specialist.

While some of the above comorbid conditions are purely organic, many psychiatric/psychological conditions are the result of living with the challenges of autism. For example, deficits in basic life skills can cause substantial anxiety in daily living. Also, difficulties with social skills can result in significant depression, not to mention the social anxiety so common among autistics. In the most extreme cases, prolonged social isolation and bullying can result in post-traumatic stress disorder (PTSD) and even suicidal ideation. All these conditions are common among autistics. Healthcare providers need to fully understand and appreciate that autistics very often face, or have faced, such situations and that these can be the results. They then need to determine if any of them exist and, if so, what actions need to be taken and what specialists or treatments they should be referred to.

Most autistics have some form of sensory sensitivity (often more than one), and many of these can be triggered by any number of medical or clinical procedures. Chemical sensitivities, including adverse reactions to certain medications, are also not uncommon. Yet again, providers need to be aware of these issues and be on the lookout for them when treating autistic patients.

Finally, autistics as a group are not (to put it mildly!) known for our good health habits. For example, our eating habits often leave much to be desired. This can be due to selective eating issues (as is the case with me) or simply bad food choices. In any case, our resistance to change, particularly concerning personal habits, can make it extremely difficult to modify these patterns in favor of healthier ones. Also, autistics sometimes have an aversion to physical activity, especially if they are poor at sports (as so many of us are) and have been ridiculed or worse for it. Again, our resistance to change can make adopt-

**Karl Wittig, PE**

ing good exercise habits very difficult indeed. As always, healthcare providers need to be made aware of these issues and must understand that an autistic patient is likely to have poor health habits. They can then be treated in an appropriate manner, either by lifestyle improvements (if and where possible) or by addressing conditions resulting from poor habits (e.g., obesity, diabetes, etc.).

**Older Adults Face a Byzantine Nightmare**

The vast majority of autistics who entered adulthood prior to improved diagnostic criteria for ASD and public awareness of such may not even be aware that the autism spectrum exists, let alone that they might be on it. Consequently, the healthcare system that they need to access whenever a medical situation arises has no knowledge that such a patient might be living with autism, let alone take this into account when planning treatment. Given the well-known challenges and deficits of autism, particularly among older adults, the possibilities for things to go wrong are too numerous to even consider.

This is all exacerbated by the fact that, as we get older, we have a greater need

for healthcare than we did when we were younger and generally in much better health. Furthermore, medical and health issues affecting older adults, especially senior citizens, tend to be more unusual than those typically faced by younger patients. These, in turn, require more specialized care than common problems, which any competent provider can readily treat. Identifying appropriate medical specialists is more complicated than finding primary care practitioners because medicine has become so specialized that a suitable provider needs expertise in a particular condition and not just in their general medical specialty. The upshot is that navigating the healthcare system for an older adult becomes much more complicated than it is for a younger person.

Finally, the complexity of health insurance and, consequently, of the healthcare system itself has literally exploded, especially during the past decade. What used to be an annoyingly difficult bureaucracy at times has turned into a byzantine nightmare of horrendous proportions. It has become extremely difficult to find a specialist who can treat your particular condition – insurance company websites list doctors according to general specialty (cardiology, gastroenterology, etc.) rather than subspecialty (which you need to know to find an appropriate provider). On top of this, it is often very difficult to determine whether a provider is even in your network, which can literally change from one day to the next. I had one experience in which the doctor's receptionist put the burden on me to find out whether he was in the network for my specific plan since his office could not make that determination!

The above three factors have created the "perfect storm" of an unnavigable healthcare network. This is especially true for most individuals in either an HMO or some other plan that requires all your providers to be in a given network. Not only are there numerous insurance companies, but each of the major carriers has literally dozens if not hundreds of different plans, each having its own provisions and provider networks. This is especially the case for affordable healthcare marketplace "Obamacare" plans

(which I had for several years) and so-called Medicare Advantage plans (which my friend currently has).

When I was treated for a severe sinus condition several years ago, it was not enough to find an ear, nose, and throat (ENT) doctor (all of which were grouped in the same category on the provider network list) – I needed to identify one who specialized in sinuses and, as it turned out, sinus surgery. Luckily, I was able to locate an excellent doctor who found substantial polyps and performed surgery to remove them. Thankfully, it went very well, and I had a good outcome, but finding this doctor required nothing less than herculean labor on my part, along with the help of my primary care doctor and his entire staff (I am not exaggerating!).

While all of this can be daunting for anybody trying to navigate this system, it is especially horrific for autistics. We famously need some form of systemic order as well as specific and detailed information to deal with most situations; the current healthcare system, in many instances, provides neither of these. I shudder to think that, if it was such an ordeal for me to deal with all of this, despite my having access to very good healthcare and some ability to figure out the system (with considerable effort), what an impossible situation this presents to the many autistics who are not nearly as fortunate.

**Looking to the Future**

As much as the situation has (or at least can be) improved for younger and diagnosed autistics, there is still much that needs to be done. The path is somewhat clear and what is needed within the realm of possibility. For older and undiagnosed autistics, however, the situation is far more dismal. As with many other issues, the need to diagnose (or at least identify) adult autistics becomes paramount. It would also help to address the many shortcomings of our healthcare and insurance systems!

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### Defining Disability from page 20

I'd argue that when folks with AND without disabilities are confronted with the unknown, as a default, we just automatically go to the negative. I say all the time that if you bring city kids into the country, they want to kill everything that moves. And if you bring country kids to the city, they wonder why all these weird people aren't locked up. A fear of the unknown is one of the few human characteristics that binds everyone. This vague fact shapes and creates opinions that extend to specifics about people of different skin color, about when you see a text from your boss, about when your child is out late and hasn't called in... Our overall progress herein is surprisingly only 10% of things we need to learn. 90% of the effort will be in "unlearning" the attitudes we're conditioned to have, no matter how progressive we may think we are. Unlearning is an underestimated factor in every social movement. When we say a negative comment to a child, we instinctively think that one apology rectifies the damage. It doesn't. Laziness in us enforces a one-to-one math. But the math is more like five to one or ten to one. You need five or ten positive affirmations or apologies to rectify the damage of one hurtful comment.

Going back to the deficit model, another contributing factor is that a theoretical "asset model" has limitations, and everyone subliminally knows this. Multiple attempts at wordplay, for instance, have sought to linguistically alter "disability" through a positive lens. "Differently abled," "Don't 'dis' my ability," "handi-capable," etc. Their failure to catch on as substitute terms reflects more than the arguable condescension lying underneath. Maybe anything with a prefix of "dis" (as put forth by the second example) is simply bound to have a psychologically negative effect? Maybe – dare we say it? – the positive lens isn't the answer, even if it's better than the negative lens?

What if we stopped caring about the lens, looked at the whole camera, and then, what if we *turned* the camera 180 degrees around? What if we started to define disability by looking out rather than in? What if we defined disability as the rest of the world's inability to include us, to accommodate us, and then we put the negative stigma on them (i.e., you, the non-disabled person)? Very often, we bitterly have to concede that the problems of disabled people are entirely external anyway or that our only problem is other people's attitudes, right? Well, then, let's back up that statement and put the lens there, and see how negative the defaults are when zeroed in on a majority.

Immediately, at least one reader will challenge this. To them, disability can never not be a negative. The argument about, say, the medical needs of a significantly challenged person and how "it isn't external sources" that prevent them from walking, speaking, or achieving a college degree...

Well, since when is independence, or *not* needing assistance, the measuring



Michael John Carley

stick for the value of a human life? First off, don't we *all* need assistance at some point? And even if we didn't, aren't we ready as a society to acknowledge that human progress *has not* been solely dependent on competition, that it has actually been equally (if not more) dependent on cooperation? And sharing? Or are we still believing in the "survival of the fittest" lie because it serves to justify our economic system? Someone *has to be* the "dumbest student in class" or the "worst player on the team." Relativity aside (i.e., how good is the class or team), why do we *need* to make the people who fit these descriptions...feel bad?

Think of the wheelchair user and the accumulated effect that they endure over a lifetime of passing by inaccessible buildings. Since accessibility is at least 50% an economic challenge, how then to interpret the refusal to spend what is only money on making all our buildings accessible? Are we saying to the wheelchair user, "We don't care what your needs are" several times a day for your entire life?

Physical disabilities are not mental health conditions, save for the fact that we make them mental health conditions. And you don't have to be a Bernie Sanders fan to know that the money for such change, despite the whining, more than exists in this country.

In the big picture, this might be less about "disabilities" and more about "minorities" and "majorities."

"Minorities" and "majorities" are two words thought of as sociological terms, but they're math terms first. And if you are a part of any majority (racial, gender, economic class, immigration status...), you will instinctively believe that your way of doing things is the best way. That's just how majorities think, whether their way of doing things is brilliant or crap. And if you're part of any minority, you instinctively will *doubt* your way of doing things – again, whether your way of doing things is brilliant or crap because that's just how minorities and majorities think. Until we are all educated and made aware of how irrational this instinct is, we just obey the anthropology. Would a hypothetical majority-deaf world not instinctively look upon the hearing minority as inundated with

anxiety-producing stimuli that renders them nervous wrecks? And, therefore, capable of less?

In softening the ideas from the militants of long ago, maybe we shouldn't look at our inability to include. Maybe "disability" can be defined as an insecure society's subliminal yet passionate demand to "exclude?"

#### 1B. Categorization: Compartmentalize Better

Of all the six traditional elements of Diversity, Equity, and Inclusion (DEI) – race, gender, sexual orientation, religion, and veteran status – disabilities are easily argued as the most intimidating for outsiders. To obtain the confidence necessary in, say, your company's onboarding process, one might feel they need to become an expert on "disabilities" – and that might be 1,000 diagnoses you have to learn.

A great example of this lies within corporate ERGs (Employee Resource Groups; basically, these are support groups). An ERG of five people of Latin descent will all be different people, perhaps with intersectional uniqueness, if not also distinctly different personalities. But their shared Latin heritage will justify the gathering. They will feel more comfortable saying certain things to each other than they would amongst the non-Latin people that dominate their company.

But to have a support group for disabled folks? Let's say you get one wheelchair user, one hearing-impaired person, someone undergoing chemotherapy, an autistic, and someone with Post-Traumatic Stress Disorder suffered during a childhood of poverty...there's not a lot of shared experience there.

When I was the Executive Director at ASTEP (now called "Integrate"), working with Fortune 1000 companies in New York City, we went with the following two-way model of disability:

#### 1. Visible Disabilities

- Physical – mobility limitations...
- Sensory – hearing, vision...

#### 2. Non-Apparent Disabilities

- Mental health – depression, anxiety, bipolar disorder...
- Physical health – diabetes, epilepsy, cancer...
- Learning – dyslexia, ADD...
- Developmental – ADHD, autism...

But I have since morphed into a fondness for the following three-way outlook:

#### 1. Accessibility

- Access/opportunity – plus the trauma of access denied

#### 2. Neurodiversity

- Some Disclosure options
- Identity vs. pathology
- Behavioral differences
- "Cherry picking" vs. truly inclusive

#### 3. Health

- Privacy (Cancer, HIV...)

I like this version better for many reasons, one of which is the aforementioned example of the wheelchair user being told through building designs that we don't care about them (and that "physical" and "non-apparent" overlap). But this new setup also resolves many contradictions, such as the topic of disclosure. Neurodiverse folks often have the ability to hide their diagnosis, and so disclosure becomes an option that is theirs to choose. And in almost all cases herein, it is much better for the individual's mental health if they are disclosed. When disclosed in their communities, they feel valued. To feel similarly valued, but not to have disclosed will always contain much internal doubt about whether or not people really do accept you, or do they only accept you because they think you're like them?

And yet, in the health space, disclosing your condition to the world is most often *not* a good idea, as significant medical diagnoses can often be used to marginalize or stigmatize you in ways that can especially stifle, say, your career trajectory at work. "We've got this promotion to give, and Jane is easily the best candidate, and she's earned it. But Jane's cancer is now stage four, and turnover costs us money, so maybe..."

Stay tuned for "What I'd Like to See Change in the Disability World Over the Next 50 Years - Part 2: Know and Teach the REAL History."

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### Telehealth Tips from page 8

In summary, telehealth can improve access for children with ASD and their families. Accommodating a child with ASD in the virtual environment can also

improve your understanding of the child and his or her needs. As telehealth continues to evolve and become more widely accepted, it holds the potential to greatly improve the wellbeing and overall quality of life for children with ASD and

their families by providing convenient, high-quality access to essential medical care and support. As a very early adopter of telehealth, we've seen it as a silver lining to the pandemic since observing firsthand how effective it can be for chil-

dren and their families.

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*Self-Advocacy from page 17*

outcomes; however, it is important to note that it begins by feeling empowered to make choices regarding healthcare providers. If a provider does not show an understanding of your neurodiversity, communication preferences, and sensory processing needs, it is acceptable (and perhaps even advisable) to meet with another provider and explore your options. The goal of the tools identified below is to make healthcare accessible, effective, and lower possible risks of things being missed or misunderstood.

## Proactive Tools for Your Toolbox

- Prepare a written list of questions and/or concerns for the physician
- Create an “all about me” document for moments when language is less accessible
- Print and fill out a body map to reflect where you might experience pain or other body sensations
- Bring a support person (i.e., family member, trusted friend/neighbor, caregiver) who is aware of your personal goals and needs to aid with any communication gaps
- Identify your preferred communication method and explore how your provider can support implementation (i.e., communication via patient portal or email versus phone)
- Request to wait in the car or in a room where you can regulate light/sound while waiting for the provider
- Inquire if your provider has received training in the SHARE approach to client-provider decision-making [AHRQ SHARE Training](#) to explore collaborative approaches to navigating your care

Autistic individuals are more likely to visit an emergency department (ED) compared to those without autism (Nicolaidis et al., 2013). There are several reasons why Autistic adults may be at risk of a lesser experience when visiting the emergency room compared to their non-autistic counterparts. According to Vohra et al. (2017), co-occurring presentations, including intellectual disabilities, depression, anxiety, ADHD, substance dependence disorder, and symptoms associated with autism make for a more difficult experience when visiting emergency department services. In addition to co-occurring psychiatric presentations, Autistic adults are at a greater risk for physical comorbidities like diabetes, cardiovascular conditions, and high cholesterol, leading to increased and less-than-ideal emergency department visits. Many autistic individuals experience behaviors like aggression, destruction, self-inflicted injuries, and other self-injurious behaviors, which may often require immediate and urgent care (Vohra et al., 2017). As a result of these self-injurious behavior patterns, there is an increased possibility of emergency department visits (Matson and Rivet, 2008). Furthermore, Autistic adults are at greater risk of receiving psychiatric assessments in emergency

**Katherine Cody, PsyD**

departments due to the nature of the emergency department itself eliciting sensory overload emotional, and behavioral dysregulation. This by no means that the ED should be avoided; however, it is an indicator that when emergency care is warranted, entering into the ED with preparation will facilitate improved access to care and effective self-advocacy.

## Tools for Emergency/Crisis Settings

- Prepare an “all about me” document for emergency/crisis settings that shares both autism-related needs AND relevant history (i.e., history of prior hospitalizations, history of recurring conditions)
- Request for a supportive friend, family member, or caregiver to remain with you to support communication needs
- Keep an updated medication list available to be produced when needed to lower the demand to recall crucial information in the moment

Medication management is an area of identified risk for ND populations, and Dr. Benevides identifies the risk for polypharmacy is increased for those with variable communication patterns in medical settings. Having specific strategies to manage medication and communicate with providers is a key component of self-advocacy when managing multiple providers who prescribe medication. In the United Kingdom, an initiative to prevent and reduce overmedication, and the more we understand the efforts being put into this, the better we can advocate here ([UK STOMP Initiative](#)).

## Strategies for Medication Management

- Maintain an updated list of all current medications, what they are prescribed for, and current responses, as well as a list of historical medications, side effects, and reasons for discontinuation
- Write questions in advance of appointments if possible
- Ask trusted family, friends, and caregivers to provide observations of your response to medications to allow for improved awareness of the impact

**McKenzie Gelvin**

(strategy for navigating interoceptive processing differences)

Accessing mental health support is a key component of overall health and another that is rife with barriers to effective care. Medical systems (i.e., psychiatric facilities and crisis teams) have not always received training in support for ND populations, which means the autistic experience in these settings is not always effective. Despite this, this should not prohibit you from searching for care when needed.

## Self-Advocacy in Mental Health Tools

- Search for neurodiversity-affirming providers (PsyPact is a way of finding psychologists licensed in other states who are approved for telehealth across state lines)
- Suicidality resources and visual aids to reflect on reasons for living can be found here: [Autism Crisis Support Resources](#)
- The 988 crisis hotline has received some consultation on how to support ND adults (it is still a work in progress, but it is a resource that exists and should be used when needed)
- Milestones Autism Resources has generated many digital tool kits to support navigating systems, but this [Mental Health Toolkit](#) is a starting point

It is important to understand that this is not an exhaustive list of self-advocacy strategies, and in fact, there is still ongoing research to be done. Additionally, while most complementary and alternative approaches to medicine (CAMs) have not yet been researched in Autistic individuals, it is important to feel empowered to explore supports related to sleep, nutrition, yoga, exercise, supplements, and working with providers who have expertise in understanding best practices in these areas to support the exploration of approaches to individualized implementation when needed. Finding providers who are willing to collaborate with you to explore these strategies is another component of self-advocacy when navigating healthcare systems. Finding your voice in the face of systems that have not been designed to support ND

individuals is a challenge, but there is work being done in the clinical, research, and stakeholder communities to assist with improving your access to systems and healthcare while also identifying these self-advocacy strategies.

Lastly, warm thanks are offered to Dr. Benevides for generously contributing her time to offer her professional expertise in guiding many of the self-advocacy points identified in this article.

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### Holistic Approach from page 19

active member of the family and community, which are as follows:

#### Body Functions

- Mental functions
- Sensory functions
- Voice and speech functions
- Functions of the major organ systems (heart, lungs, digestive, immune, metabolic)
- Reproductive functions and sexual health
- Neuromusculoskeletal and movement-related functions
- Functions of the skin and related structures

#### Activities and Participation

- Learning and applying knowledge
- General tasks and demands
- Mobility
- Self-care
- Domestic life
- Interpersonal interactions and relationships
- Education and employment
- Community, social, and civic life

#### Environment

- Products and technology
- Natural environment and human-made changes to the environment
- Support and relationships
- Attitudes
- Services, systems, and policies

Everyone has a “health-resource community,” which are those individuals, organizations, entities, and environments (including the patient and their family) that have any involvement or influence – actual, virtual, or potential – on the variables that influence their health and well-being. For autistic children and adults, this community often has significant and overlapping care requirements among the medical, behavioral, social, educational, home, and community service sectors. When these services are not integrated, it can result in fragmentation and inefficiencies known to reduce the possibility of optimal life-course outcomes.

Integrated care means that all members of someone’s health resource community are oriented toward the “whole person.” This involves looking beyond disabilities, disruptive behaviors, or challenges with activities of daily living to identify individualized opportunities for growth and achievement across a wide range of person-centered developmental and behavior-



Steven Merahn, MD

al domains.

Until our health care systems recognize the need for a model of “autism-tailored care,” it will fall on patients themselves, their family members, caregivers, or advocates to ensure the system meets their needs for body functions, capacity for activity and participation, and managing their environment.

#### Routine Visits

For routine visits, talk about the appointment beforehand and tell your loved one what to expect. You could show a calendar or use a social story. Before the appointment, prepare for – and practice – some of the things that are going to happen, such as:

- Sitting in the waiting room
- Laying down
- Removing clothing/being touched
- Following instructions (“deep breath;” “open your mouth”)

Ask the office if you can make a brief visit in advance so the environment (spaces, sounds, lighting, people) is familiar. Let the office know the patient has autism, and if the autistic person has common expected behaviors, let the office know what to expect. If there are sensory issues, use the tools (headphones, sunglasses, etc.) that are familiar and comfortable. Ask for the first appointment of the day to reduce the wait time.

Make sure a family member, caregiver, or advocate who is familiar with the autistic person is present and bring rewards or distractions. If you have a behavior therapist, consult them for support or recommendations to ensure a successful visit.

#### Emergency Room

Emergency medical care can be especially stressful for autistics and those who care for them. Emergency rooms are often unprepared to accommodate autistic patients, resulting in misconceptions and problem behavior. While this can’t always be prevented, there are some things to consider when an ER visit is necessary.

The first is an “advance visit.” Pick the hospital in your area where you would go

in case of an emergency and call the hospital advocate and arrange a “no-problem” tour early in the morning. This will increase familiarity and comfort if the services are ever necessary. Keep an updated list of conditions and medications so you are prepared should you need to go.

When there is a need for a visit, call the ER in advance if possible. If not, immediately let the staff know the patient is autistic. Inform them how the person communicates and manage staff expectations in terms of experience and behavior. Offer your assistance to help make the visit successful, like calming strategies. You may need to advocate for changes in the usual protocols. Many people are often involved in an ER visit (medical assistants, nurses, doctors), so you will need to explain this many times to each person. Anticipate triggers for problem behavior, and bring some comfort items (toys, snacks, stuffies, etc.).

#### An Annual Health Check

Sometimes, this is called a “well-child visit” or an “annual wellness visit.” What it is NOT is an “annual physical.” In fact, the physical exam should be just one part of it. The goal of the health check is to create a personalized preventive care plan and set some annual goals for sustaining or improving the quality of health.

An annual health check should include a review of all the conditions and health statuses (including a list of all the specialists, therapists, and others involved in someone’s care). It will also involve screening tests and assessments to determine new or emerging health-related risks. These may be related to developmental status, mental or behavioral health, sleep, nutrition, and other important areas of function.

Each health-related condition – like asthma, seizures, skin conditions, or gastrointestinal problems – should get special attention and an “action plan” for prevention or what to do if things go wrong.

The preventive care plan should also map out the activities that need to occur during the year, like annual flu shots and other immunizations, as well as hearing, vision, or blood tests.

Visits for health-related problems that arise over the year are also a good time to revisit the status of the preventive care plan.

#### Care Coordination

The healthcare system does not have a formal model for collaboration. Most of the time, each discipline – medicine, nursing, pharmacy, psychology – presumes authority and creates their own “care plan.” However, autistic patients require more coordination regarding the decisions being made (this reduces the burden on the family and the risk of conflicts and duplications) and “team-based care” where everyone involved can support the goals.

A great example is the opportunity for behavior therapies to support health-related goals such as blood draws, dental care, or physical examinations. Other health-related behaviors, such as taking medication, can be supported as part of behavior treatment plans.

Unfortunately, the burden is often on families to serve as “care coordinators” to keep track of the decisions and orders from each provider. Here are some things that can help:

- Ask for a written copy of the goals and tasks from each provider. This is not a copy of the medical record (that’s not bad to have) but a summary of conditions, the goal for those conditions, and the activities required to meet the goal. Ask for clarification if the “discharge plan” or visit summary is unclear.
- Make your own “master list” of all the members of the health-resource community, their areas of interest or specialties, and the goals they have set. Then, keep track of the expected activities. If some seem to overlap or repeat, or you have a different sense of what should be prioritized, discuss this with the primary care provider. You can make appointments to see the primary care provider even when you don’t have a problem; just tell them you want to make an appointment for a consultation or preventive care visit.

Finally, most people face healthcare events with doubt and confusion. We often find ourselves stranded without credible social constructs for healthcare and confronted by increasingly complex systems – often created by those without values that prioritize patients – with no clear sense of who controls our care. Some organizations are working towards a model of autism-tailored care, but until then, understanding how these systems work will allow you to be the best advocate for yourself or your loved ones.

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**Filling the Gaps from page 23**

is crucial. This includes training health-care providers to understand and adapt to different communication styles, ensuring that information is conveyed accurately, and that patients have time to process the information and feel heard and understood.

#### It's Important to Understand the Whole Person

Addressing these barriers to care begins with ensuring everyone is on the same page and that information gaps are filled before medical care is provided. Beyond conventional health information, the importance of understanding the whole person lies in comprehending an individual's needs, preferences, and unique characteristics. For those with autism and intellectual disabilities, sensory preferences, behavioral styles, communication ability, and other nuanced traits are integral components of their well-being. A holistic approach that considers the whole person enables healthcare providers to tailor their services effectively. And that can only happen when healthcare providers are able and willing to receive all the information about the person they are treating.

#### The Role of Comprehensive Information Sharing

The biggest barrier – the one that, if removed, would solve the others – is the information gap. Sharing information between healthcare providers, hospitals, human service organizations, and families is not merely about exchanging medical records. It is about creating a comprehensive individual profile that encompasses their medical history, behavioral tendencies, sensory preferences, and any specific challenges they may face and ensuring that this information is available to the healthcare provider before appointments. This is true



**Karen Lindgren, PhD**

for everyone but more so for those with significant and complex disabilities who often have multiple providers.

Through a pilot program between Bancroft and Cooper University Hospital that has shown promising results, we have learned that five key pillars can guide the approach to solving these barriers:

1. Staff education
2. Development of a specialized registry to proactively assess the needs of this population
3. Environmental enhancements such as sensory rooms, mobile carts, and break boxes
4. Streamlined care coordination
5. Fostering strong community connections

It's important to take a proactive approach by reviewing patient charts to identify individuals with autism and I/DD receiving care



**Sally A. French, MSN, APN, PMHNP-BC**

throughout health systems. Patients meeting the diagnostic criteria should be flagged in the system with a care coordination note for easy identification. Leadership can receive daily email notifications listing patients with disabilities scheduled for appointments within the next week. Then, a navigator can contact the patient's caregiver, parent, or DCP to confirm passport information, review available sensory support tools, and assess any additional sensory needs for the upcoming visit or hospital stay.

The navigator can also communicate with the office staff to ensure they are prepared for the patient's visit. Following the appointment, the navigator can seek feedback from the patient's caregiver, family, or DCP to make necessary adjustments for future visits.

Collaborative efforts and continuously improving care delivery processes with input from families, caregivers, and providers are instrumental in enhancing coordinated care and ultimately improving outcomes. This includes implementing strategies such as reducing sensory stim-

uli, providing focused and unpressured time during visits, understanding individual patient needs, and utilizing sensory rooms and break boxes to address challenging behaviors.

Rather than expecting patients and families to conform to rigid processes that may not be in their best interest and could potentially hinder outcomes, the focus should be on tailoring care to meet the unique needs of each individual. This patient-centered approach enhances the overall quality of care and ensures that patients receive the support and resources they need to thrive.

As we move forward, fostering a collaborative approach that prioritizes the holistic well-being of these individuals is essential for advancing healthcare inclusively and effectively. The result is more productive appointments, lower healthcare costs, and improved outcomes.

By addressing challenges such as limited appointment times, sensory overload, education, and communication barriers, we pave the way for a more inclusive and patient-centric healthcare experience. It is about creating awareness and establishing systems that enable effective communication, ensuring that the unique needs of each individual are understood and met with empathy and expertise. As we navigate this path towards a healthcare landscape that embraces diversity and inclusivity, the collaborative efforts of healthcare providers like Cooper University Hospital, organizations like Bancroft, and families become the driving force behind positive change. In this paradigm shift, we find the promise of improved healthcare outcomes, reduced barriers to access, and a future where healthcare is truly accessible to all.

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**Decision-Making from page 21**

parent is required to provide medical insurance coverage for the child. However, the person handling the paperwork aspects, such as getting insurance approvals and submitting claims, can be the other parent. So, it helps for both parents to have permission to speak to and have access to the medical professionals and insurance companies on behalf of the child. Some private health insurance companies allow a child to be covered past age 26, the usual cut-off age for dependents on their parents' insurance. Parents should reach out to their HR or benefits department or contact their insurance company to inquire about the form to complete to extend insurance coverage for a child with a disability prior to the child turning 26 years old.

When a child on the spectrum may be-

come eligible for Medicaid, the family can choose to keep both the private insurance and have Medicaid as the secondary health insurance. Some states allow for families of Medicaid recipients to participate in the Health Insurance Premium Payment (HIPP) Program, which provides reimbursement for private health insurance. There is an application and approval process since it must be deemed cost-effective by the HIPP program of their state to be approved.

Some parents may choose not to have private health insurance and instead just rely on Medicaid for health coverage. However, not all medical professionals and providers may accept Medicaid, so it is important to research the options prior to deciding to cancel private health insurance, which may offer more flexibility in finding or maintaining providers of their choice.

This article was written from the perspective of a Certified Special Needs Divorce Coach to share some best practices and ideas to consider, but it is not intended to provide legal advice. Parents should consult with professionals and specialists regarding the laws and programs in their state. Regardless of where divorced parents and the child may live, finding ways to work together to address the child's healthcare needs is the goal.

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**Mary Ann Hughes, MBA**

**Undervaluing from page 16**

are duly recognized and compensated. The same policymakers must recognize and adequately fund the extraordinary work and value that provider agencies bring to the table. In turn, provider agencies must prioritize investments in training, professional development, and

workplace accommodations to support the Front-Line Workforce in their crucial roles.

The economic undervaluing of the DSP workforce is a symptom of deeper societal biases and discrimination against people with disabilities. It reflects the need for a paradigm shift in how we perceive and value the contributions of in-

dividuals with disabilities and those who support them. As we strive for a more inclusive and equitable society, it is imperative that we recognize the inherent worth and dignity of every individual, regardless of ability.

The undervaluing of DSPs is not just an economic issue; it's a moral imperative. We cannot claim to be a just society

while devaluing the essential contributions of those who support individuals with disabilities. It is time to elevate the voices of DSPs, challenge ableism, and uphold the rights of people with disabilities in every aspect of life.

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### Unite the Spectrum from page 18

the hobbies of most non-autistic individuals. For example, I can spend hours on YouTube listening to the same piece of music as interpreted by different performers, conductors, and instrumental ensembles. Tariq can fiddle with inanimate objects for endless hours.

**Robert:** Stephen and Tariq are both Autistic and couldn't be more different. Stephen has high-level language, and I can have the high-level philosophical talks I imagined having with Tariq. Tariq has little to no spoken language, so we can have no conversations at all. Yet when I see each of them, I get that big, deep pressure autistic hug. Both Stephen and Tariq enjoy long walks with me when we are together. Tariq by holding my hand and silently pulling me around, Stephen by walking beside me and talking about what we are experiencing as two friends and colleagues.

**Stephen:** Tariq and I share autistic characteristics and identities. Our commonalities are irreducible. I am Tariq and Tariq is me.

As opposed to more levels and splits, we propose personalized services for all Autistics, ranging from those having advanced education and fulfilling employment to more challenged individuals who are non-speaking or have medical or mental health conditions. Whenever we are both in the Philadelphia area, we enjoy visiting and accepting Tariq just as he is.

We espouse, teach, and apply the neurodiversity model because it doesn't pathologize and focuses disproportionately on what the person struggles with. In contrast, it focuses on what the individual **can do**. It also recognizes that genetic or other biological variations are intrinsic to people's identity. So, their sense of self and personhood should be given equal respect alongside other forms of diversity, such as gender.

**Robert:** I recently had the privilege to narrate a day in Tariq's life for the National Disability Rights Organization. One of my Autistic clients was overjoyed to meet Tariq for the first time on the video.

Despite clear alternatives, some prominent voices, including parents of autistic children with high support needs, in the autism world are continuing to push for a new category, which they are calling "profound autism." They are completely ignoring autistic voices. The [Autism Self Advocacy Network \(ASAN\)](#) "has continually opposed attempts to split autism into multiple diagnoses. These attempts will not improve services for Autistic people and

are largely based on the desire to segregate autistic people with the most significant cognitive disabilities and support needs." The [Autism Science Foundation](#) is funding research to support this change. This also seems to be supported by the April 2023 [Centers for Disease Control](#) report that 27% of people diagnosed with autism meet the criteria for "profound autism."

The label of "profound autism" does not add to understanding the complex support needs of the heterogeneous group of individuals with both autism and intellectual disabilities. All functioning labels, including "severe autism" and "high functioning autism," actually harm people. Self-advocates and [parents such as Shannon Des Roches Rosa](#) explain with great clarity the view that profound autism is segregation, not progress.

Because autism is a lifelong neurodevelopmental condition that causes significant social, communication, and behavioral challenges, suicide is a leading cause of death in autistic people. In addition to elevated levels of various mental health problems, autistic people are at a significantly increased risk of suicidality (suicidal ideation, suicide plans, suicide attempts, and death by suicide) compared to non-autistic people. [An influential study of diagnosed autistic adults](#) found that 66% had experienced suicidal ideation, which was nine times higher than the general population, and 35% had a suicide plan or had made a suicide attempt.

So, What's the Alternative to Labels?

What parents need at the time of diagnosis and throughout their child's development is clear guidance on which interventions and strategies can best serve their autistic child as an individual to have the best possible quality of life in the community. The [Lancet Commission](#) report actually called for "dramatic action over the next five years to bring desperately needed support and services to autistic children and adults and their families worldwide based upon their individual differences, strengths, and needs." It also mentioned that most autism research to date has been on white males.

Females and BIPOC have never been adequately included in research samples. **Now, there is a real opportunity to change that.** [A new report from the CDC](#) shows autism prevalence in the United States is continuing to rise, now at 1 to 36, as race and sex gaps contract. **Non-white children have been identified as Autistic at slightly higher rates than white children for the first time.** This is good news

that early screening and identification have helped narrow racial disparities in the early identification of autism. Closing the gap in access to services is the next imposing challenge. As opposed to focusing on labels, researchers can focus on how autism shows up differently in females and Black, Hispanic, and Asian or Pacific Islander children. These differences will inform clinicians, schools, and parents on which interventions and services will be most effective for given individuals. Funding varies considerably according to the local school districts, which significantly impacts children and families by race and class.

The humanistic concept of neurodiversity has shown great promise in uniting people from all walks of life across race, class, ability, diagnosis, etc. Having spoken at conferences around the country and internationally, we rarely meet parents or self-advocates who are suggesting a new category for individuals with high support needs. Rather, questions tend to focus on "How do I help my child?" or "How do I get help for myself?" Like many other groups pushing for change and social movements, the autism community has had numerous splits and factions. We don't need more of that.

We do meet some parent-advocates who feel left behind as the stereotype of autism in the mainstream media has shifted from the nonspeaking to the self-advocates. Major autism conferences tend to feature keynote speakers who represent one portion of the autism spectrum and give hope to the families of newly diagnosed individuals. However, many self-advocates clearly speak about the support needs of the entire spectrum. They speak as strongly for themselves as they do for those who are unable to speak. According to two prominent self-advocates, John Elder Robison and Dena Gassner, [there is no epidemic of autism. It's an epidemic of need.](#)

The 4 A's of Autism – Awareness, Acceptance, Appreciation, and Action

I have been teaching the 4 A's of Autism as a way of addressing this epidemic of need.

**Step 1, Awareness,** has been a focus of the autism community for over 40 years, from where autism was considered a rare psychiatric condition caused by poor parenting with a prevalence rate of 5 in 10,000. With a current rate of almost 3%, we are better at recognizing autism at home, in education, at work, and in the community. Additionally, increasing numbers of autistic people are seeing autistic characteristics

in themselves and often verify their suspicions with formal diagnostic procedures. Awareness builds a solid foundation for the following work.

**Step 2, Acceptance,** is where parents, teachers, and others turn away from considering autism as a series of deficits, disorder, and disability towards an abilities-based model that accepts the person for who they are. An example is the difference between holding out a favored activity as a reinforcer to motivate a student to learn mathematics and incorporating that focused interest into learning the subject.

**Step 3, Appreciation,** is where autistic people are valued for their contributions to society. Examples of valuing autistic people include large IT companies actively seeking autistic employees because they know a certain subset of autistic people can engage in computerized geekery at levels beyond most others, to the individuals needing support in most aspects of life who thoroughly enjoy the process of folding laundry with perfect creases faster and with more enthusiasm than their typical colleagues. All employers, large and small, can benefit from the skills and abilities autistic people bring to the workplace.

**Step 4, Action,** is the process of making the three previous A's work as a protocol for empowering autistic people to lead fulfilling and productive lives as the rule rather than the exception.

We believe that new labels will further stigmatize autistic individuals. We need to unite as a diverse, heterogeneous community of autistic people, parents, professionals, and researchers. Let's go forward by focusing on every autistic person's right to access individualized, person-centered services that identify specific needs and personalized support for using their strengths for success in their communities.

This is a human right.

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*Stephen Shore, EdD, is an autistic individual who is a clinical associate professor of special education at Adelphi University. He combines his personal, practical, and academic experiences to promote fulfilling and productive lives for autistic people as the rule rather than the exception. Serving on numerous autism-related boards, his website is [www.drstephenshore.com](#).*

### Therapeutic Visit from page 6

- Explain everything you are doing using simple terms and pictures.
- Bundle services by having multiple specialties, such as vision, dental, psychology, and phlebotomy, available for each visit.
- Ensure individuals have a smooth transition to adulthood in terms of services. Pediatric providers will need to help in-

dividuals and caregivers source quality adult medical providers and provide a warm handoff to the new provider.

- Listen to the staff, caregivers, and parents who are accompanying the individual to the appointment. They know the individual the best and can provide guidance and insights into understanding the individual's profile.

*Mamie Richiutti, MS HAD/HED, BSN, RN, CEN, is Senior Director of Healthcare*

*Services at [Melmark PA](#).*

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**Sensory-Friendly from page 15**

prosocial alternatives she can do when anxious, such as diaphragmatic breathing or listening to music through headphones.

Work closely with families to understand the specific sensory needs of the individual and incorporate their insights into the development of sensory-friendly practice and environment. It is also helpful to seek feedback from autistic individuals and their families to continuously improve and refine sensory-friendly initiatives within the health care setting.

Comprehensive training programs should be implemented to educate health care staff about autism awareness, sensory sensitivities, and best practices for interacting with autistic individuals. This training can help staff members develop a deeper understanding of the unique needs of autistic patients and enhance their ability to provide compassionate care. One such training is available at Rutgers Biomedical and Health Science Center for Autism Research, Education and Services.

Flexibility in medical procedures can be beneficial for accommodating the specific needs of autistic patients. For example, allowing additional appointment times, offering alternative methods for taking vital signs or conducting examinations, and respecting individual preferences regarding touch or proximity can contribute to a more positive health care experience.



**Richard Anemone, MPS, LMHC**

Ann's dentist spoke clearly about each step during the appointment and allowed Ann to hold the dental tool while explaining its use. The dentist also allowed extra time for Ann to process the information before implementation. The dentist provided positive reinforcement and encouragement to use her relaxation breathing techniques throughout the appointment, with rewards for success after the completion of each step.

Health care facilities can offer supportive resources such as visual schedules, noise-canceling headphones, or designated

quiet spaces to help autistic patients manage sensory challenges while receiving medical care.

Cultivating sensory-friendly health care environments for autistic patients requires a multifaceted approach that addresses sensory modifications, communication strategies, staff training, flexibility in procedures, and the provision of supportive resources. By implementing these measures, health care facilities can significantly improve the overall experience for autistic individuals seeking medical care while promoting inclusivity and understanding within the health care system.

#### Resources for Additional Information

1. **Centers for Disease Control and Prevention (CDC):** The CDC provides evidence-based guidelines and resources related to autism spectrum disorder (ASD) and health care accommodations for individuals with ASD.
2. **Autism Speaks:** As a leading advocacy organization for autism awareness and support, Autism Speaks offers valuable insights into creating sensory-friendly environments in various settings, including health care facilities.
3. **National Institute of Mental Health (NIMH):** NIMH researches autism spectrum disorder and provides author-

itative information on best practices for accommodating individuals with ASD in health care settings.

4. **Rutgers Center for Autism Research, Education, & Services:** Rutgers is responsible for coordinating and fostering basic and clinical research focused on diagnosing, treating, and supporting patients with ASD.

*Richard Anemone joined the Institute of Community Living (ICL) in November 2019 as the Senior Vice President of its I/DD division, which includes 13 small group residences funded by the New York State Office of People With Developmental Disabilities (OPWDD). Richard has more than 30 years of experience in the mental health field. He has worked with both adults and children with intellectual developmental disorders as well as psychiatric disorders in residential and day treatment programs, school settings, clinics, and hospitals. He understands the complexities of serving this population – having begun his career as a direct support professional and later worked as an administrator and clinician. Richard has a Master's Degree in Psychology and is licensed as a mental health counselor in New York State. In his private practice, Richard provides counseling, training, presentations, and technical support to individuals, families, groups, and organizations.*

**Breaking Free from page 22**

dreamed of. One person refused to continue with the class because of their experiences with this. As a neurodiverse person myself, I related to this tremendously. It was not until they were finally faced with a different notion of Autism and Neurodiversity that they began to identify and explore their strengths. It is not the role of mental health professionals to correct or cure Autism or to tell people what they are or are not capable of. Mental health support can help people embark on a journey of discovering one's strengths and identifying the necessary tools to accomplish one's goals. Mental health support can help people break free of the need to fit in and finally appreciate themselves for who they are created to be while developing the skills to navigate this world for what it is. I encourage all who Autism impacts to seek mental health

support for this reason, particularly from someone who specializes in working with neurodiverse people. I plead for all of those in positions of power and influence to make counseling and therapy more accessible for all. For families of children with Autism, the school your student attends can assist with finding mental health support for them early on. Ralph Waldo Emerson wrote, "To be yourself in a world that is constantly trying to make you something else is the greatest accomplishment." Mental health support can help those with Autism accomplish this while the world slowly shifts to a more positive view of the diversity of the mind. Mental health professionals can help people break free from the need to conform to the patterns of this world.

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#### Additional Resources

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