

## Understanding and Promoting Autism Advocacy

### Autism Advocacy Advice for Families of Color

By Marina Sarri  
SPARK - Simons Foundation  
Autism Research Initiative

Autism occurs equally in people of different races, ethnicities, and income levels, but autism services are not distributed equally, according to research. As a group, children who are Black, Hispanic, Asian-American, or low-income often receive fewer therapies and services for autism.<sup>1-2</sup> They also may be diagnosed later, which delays their ability to get help. What can parents do to help overcome those differences?

Linda Fleming McGhee, JD, PsyD, has advice for parents who want to be better advocates for their children at school. McGhee, who is a lawyer and a clinical psychologist in Maryland, tests children and teens for learning problems, advocates for them in school meetings, and has written and given presentations about diversity and racial bias.

#### Get Diagnosed with Autism Early

Like many psychologists and autism experts, McGhee says that it is important to



get an early diagnosis because it leads to early help. Most children are diagnosed with autism spectrum disorder (ASD) after their fourth birthday, although many can be diagnosed before age 2, according to a report from a federal autism committee.<sup>3</sup> “Overall, Black and Hispanic children with ASD received evaluations later than white children with ASD,” according to the U.S. Centers of

Disease Control and Prevention (CDC).<sup>4</sup> A delayed diagnosis can lead to delays in providing services for autism.

“Children of a higher socioeconomic status are more likely to be identified [with a disability] regardless of race, and that disparity has remained constant,” McGhee says. When a Black or Hispanic child is also low-income, “it creates this perfect

storm of under-identification and under-assignment of special education services.”

“My number one bit of advice is to get identified [with a disability] as early as possible. Oftentimes children who get the best services are identified before they hit elementary school. So taking advantage of the government-provided services and developmental screenings when your child is young is one of the best things that you can do. If your pediatrician gives you feedback about your child’s development, take that advice seriously. I tell parents, if you have a 2- or 3-year-old, and your child is identified early, you have a much better chance of a better outcome. This advice is for *all* parents,” she says.

States have intervention programs for children from birth through the preschool years. These programs provide free developmental evaluations and services. Those free services may include special education, preschool, play groups, and speech, occupational, behavioral, and physical therapies. Children can be referred for testing by their doctors, parents, or guardians. If the evaluators find a developmental delay, the child may be eligible for services.

see *Advocacy Advice* on [page 32](#)

## Autism Spectrum News Honored by the Autism Society of America with The Daniel Jordan Fiddle Foundation Leader in Adult Autism Award

By Staff Writer  
Autism Spectrum News

The Autism Society of America is thrilled to announce David Minot, Founder and Publisher of Autism Spectrum News and Executive Director of Mental Health News Education, as the recipient of the prestigious 2022 Daniel Jordan Fiddle Foundation Leader in Adult Autism Award, presented at the 2022 Affiliate Conference. David’s passion, advocacy, and collective work have exemplified the Autism Society’s mission and positively impacted the Autism community.

The Daniel Jordan Fiddle Foundation Leader in Adult Autism is given annually to an individual, business, or organization that exemplifies a core value of The Daniel Jordan Fiddle Foundation mission to inspire society by sharing success stories focused on the diverse strengths and talents of Autistic adults. Last year’s award was given to [United States Senator Robert Menendez](#).

“The Daniel Jordan Fiddle Foundation is proud to honor the journalistic inspira-

### David Minot and Autism Spectrum News Receive Leader in Adult Autism Award



tion of Autism Spectrum News in sharing vital information on topics impacting the lives of Autistic adults and particularly creating a platform of expression for Autistic adults,” said Linda J. Walder.

“The Autism Society applauds Autism Spectrum News’ efforts to showcase diverse and varied experiences from Autistic adults, and their commitment to featuring

articles written by Autistic contributors,” shared Christopher Banks, President and CEO of the Autism Society of America. “Autism Spectrum News exemplifies leadership in journalism that is vital to advancing acceptance for the Autism community.”

David Minot, Founder and Publisher of Autism Spectrum News, commented, “I

strongly believe in using Autism Spectrum News as a forum to give Autistic adults a voice. I want to ensure that the neurotypical community sees into the lives of Autistic adults to understand their perspective, their experiences, and to celebrate neurodiversity. Autism Spectrum News is changing how people think about Autism by advocating for acceptance, not just awareness, with equal access, rights, and opportunities.”

Christopher Banks, President and CEO of the Autism Society of America, Linda J. Walder, Founder and Executive Director of The Daniel Jordan Fiddle Foundation, and David Minot, Founder and Publisher of Autism Spectrum News

Autism Spectrum News is a trusted source of education, information, advocacy, and resources for the Autism community that addresses many important topics including Autistic adults and the aging population. This publication inspires knowledge about the strengths of Autistic adults and the challenges they may experience, and shares science-based research that positively impacts the lives of the diverse Autism community.

see *Autism Award* on [page 27](#)

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# Is It Genetic?

## My 40-Year Journey of Misdiagnoses for My Son

By Ellen Feldman  
Regional VP  
Arc of New York

Forty years ago, my son Matthew was born. At the time of his birth, he had no apparent health issues. We began noticing that he wasn't developing like a neuro-typical child when he wasn't hitting milestones like rolling over. Since then, we have gone through countless tests and been given countless diagnoses: Autism, Obsessive Compulsive Behavior, Bi-polar, Anxiety. And from some doctors, severe intellectual and developmental disability with no known cause. And then, in 2022, when Matthew was 40 years old, our long and frustrating misdiagnosis journey came to an end. We finally received the one diagnosis that explains all the others: a genetic change in the [SYNGAP1](#) gene, causing a disorder with an unwieldy name.

SYNGAP1-related Intellectual Disability (ID) is a rare genetic disorder. People living with this disorder, or Syngapians as they are sometimes lovingly called, experience a wide range of neurological issues beyond intellectual disability. They live with challenges such as hypotonia, epilepsy, autism, sleep disturbances, and predictable behavioral challenges that are difficult for the patient as well as the people who care for them. Because of the multitude and diversity of symptoms, some of which intensify or retreat over time, individuals like my son go through years of tests, wrong diagnoses and, in some cases, deterioration of their symptoms.

SYNGAP1 Is a "Young" Genetic Disorder  
With Known Case Numbers Climbing

The SYNGAP1 gene was [first identified in 1998](#). Then it took just over ten years for the gene to be linked to a disease. In [2009](#), a study of 100 people with ID found that three of the people had a broken SYNGAP1 gene as the cause of their symptoms, previously known as [MRD5](#). While some aspects of the structure and biochemical functions of the SYNGAP protein have been characterized in just over 20 years of research in animal models, there is still so much we have yet to understand about the scope of this 13-year-old condition in people.

One thing we do know is that [SYNGAP1 pathogenic variants are a common](#) cause of ID, with the incidence calculated to be [6 per 100,000](#) or 1 per 16,667 individuals. This comprises approximately 1% of all ID cases, making it one of the most common genetic causes of ID, similar to more well-known syndromes that have been studied for much longer, like Fragile X, Angelman, and Rett Syndromes. Last year, the CDC granted an ICD-10 code ([F78.A1](#)) to this disease based largely on the predicted incidence. Barriers to genetic testing, however, currently limit the number of actual diagnoses. As of December 2022, there are more than [1,135 cases](#) of SYNGAP known



Ellen Feldman

worldwide. In Q3 2022 alone, 37 new Syngapians were identified.

### SYNGAP1 and Autism

Anecdotally, we know that many people with a SYNGAP1 diagnosis also have an autism diagnosis. What does research data say about that? [SYNGAP Research Fund](#) shares the following about the connection between SYNGAP1 and autism: [One study](#) of SYNGAP1 patients found 54% also had an autism diagnosis. In [another study](#), the number was 73%. It should be noted that to date, these studies have both included patients younger than four, (the age after which an autism diagnosis is more likely) and include relatively small numbers of subjects (57 and 15 respectively). With continued research, and equal opportunity for a standard battery of testing, those numbers are likely to change. And research that does not start with a SYNGAP1 diagnoses has a different way to describe the link. In fact, recent [research](#) that included over 35,000 individuals (nearly 12,000 with an autism diagnosis) identified SYNGAP1 as a leading autism gene among the 102 autism-associated genes found in the analysis. Whether one starts with autism and looks for SYNGAP1 or starts with SYNGAP1 and looks for autism, they are linked.

### The Value in Genetic Testing

For my family, genetic testing not only *finally* identified the cause behind Matthew's symptoms, but revealed other information that could help us navigate his future health and healthcare. For example, we found that, as a result of one particular well-known gene variant, he is at higher risk for colorectal cancer (CRC). While CRC is not something we can prevent, we can prioritize prevention measures to look out for early signs of the disease. For Matthew, that means beginning surveillance through colonoscopies at age 40 (now!) instead of 45, and repeating them every five years, instead of the commonly recommended 10 years.

Receiving a genetic diagnosis personally affected our family by giving us specific and accurate knowledge and by shining a light on other health issues to monitor. For the broader community, the consequences of specific and accurate diagnoses are just as positive and comprehensive. First, an increase in genetic diagnoses grows the number of patients so it also grows the base of knowledge about the condition and all of its complexity. Second, increased numbers through genetic testing increases the patient pool for clinical trials. In addition to the obvious (more is more), having more identified patients changes the landscape by making our disease more attractive to researchers because of their increased ability to get data, and by making our disease more attractive to industry because more patients to cure results in more motivation to create treatments. More treatments in development in turn means that an individual is more likely to have the opportunity to be included in a treatment trial. And finally, the more we see a range of patients at different stages with the same causal issue, the more we will realize things we don't yet even know to ask about. It will be possible to provide answers to currently unanswered, and even unasked, questions.

### Should You Consider Genetic Testing?

Every individual is different, as is their diagnosis and their experience with a disease like autism or ID, epilepsy, or SYNGAP1. Therefore, the decision to pursue any testing - genetic or otherwise - is extremely personal. One way to look at the question is: if I was to be given new information, what would change? This article has already listed some of the direct changes that come with a diagnosis. But even if treatments are not on your mind or are likely to figure in your family's future, a genetic diagnosis can result in community support.

For those of us in the SYNGAP community, testing led us directly and quickly to one another, despite being scattered around the country and the world. Since we are all dealing with a similar set of medical, behavioral, and scholastic issues, we have built a strong support system. When we share our experiences that sound foreign to others, it often leads to platitudes and ending the conversation due to discomfort on each side. But with other SYNGAP families, we receive understanding, comfort, and similar anecdotes and knowing reassurances. We share our creative solutions to our unusual and tricky problems. We recognize each other's efforts and each other's victories, even when they are invisible to most other people. The ability to connect with people going through the same things takes the experience of isolation that is often felt within families and converts it into a caring and welcoming community. This inevitably results in a sense of belonging and allows us to thrive within a community of people that understands, accepts, and supports one another.

In addition, with increased numbers of patients, we have been able to greatly expand our network of clinical experts, going from no clinician ever having experience with our disease and disbelief over many of its complex issues to multiple centers and a clinical guidelines document that we can hand to our doctors. This has resulted in a fast-track to understanding the disease itself and, what feels like a miracle, we are going to be notified when genetic therapies for SYNGAP1 begin trials. Two companies currently have such products in their pipeline.

It is all of these combined benefits of strength in numbers that led [Probably Genetic](#), [SYNGAP Research Fund](#), and others to team up to help identify more people currently dealing with this complex and severe disease. To do that they have created a [survey](#) that individuals can take to determine whether the symptoms they and/or their children or siblings are experiencing could likely have a genetic cause. Filling out the survey is not difficult, can be done on a smartphone, and takes only about five minutes.

When the results of the survey indicate a potential genetic link, [Probably Genetic](#) sends a free genetic test kit to the person's home. And, following a quick and easy swab of the inner cheek to collect a saliva sample, you send the kit back for processing at no cost. The clinical genetic report will be available for you in eight weeks. The process is painless and gives high-quality results. If you have previously struggled through blood draws, an amniocentesis, biopsies, or other ways to gather DNA for genetic tests, you will be happy to see that this method is easy and reliable.

Let's say you've gone to the trouble to get one or more genetic tests in the past, maybe a panel or copy number variant analysis, and didn't find any valuable information that helped your loved one. The current state of genetic testing is more powerful than even a few years ago. Even if you have identified some genetic differences, repeat testing with current technology is a good idea. For some, the report will share information already known. But for others, it could shed new light on weeks, months, or years of diagnostic uncertainty. A specific and accurate diagnosis can open up a whole new world of information, resources, and community.

The more we learn about diseases like SYNGAP1 and its link to other diagnoses, like autism, the closer we will come to developing - and ensuring we have - the best treatments and therapies for the many warriors (and their families) out there.

**Fill Out This Survey  
For a Free Genetic Test**

*Ellen Feldman is the Board President of the [Animal Care Sanctuary](#), a Board of Governor and Regional Vice President of the Arc of New York, and parent to Matthew, a Syngapian living in New York.*





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# Educational Entitlement for ABA Services: A Right for All

By Brad Stevenson, PhD, BCBA-D, CDE®,  
Rita Gardner, MPH, LABA, BCBA, CDE®,  
and Keri Bethune, PhD, BCBA-D  
Melmark

The old saying goes that if you meet one person with autism, you have met *one* person with autism. This alludes to the fact that people with autism have such a varying set of preferences, interests, strengths, and needs that no two are alike. As a result, the supports people need varies greatly with some not needing any supports and others requiring intensive, round-the-clock services. Regardless of the intensity of supports required, we should all be working towards a society where people with autism are able to access whatever they need without barriers.

Looking at recent advocacy efforts, much of the focus has been on increasing access to insurance-funded **applied behavior analysis (ABA)** services (Autism Speaks, n.d.). This is understandable given the decades of research and support from independent professionals supporting the efficacy of ABA for teaching new skills and reducing challenging behaviors (Association for Science in Autism Treatment, n.d.). Gaining access to these services has been a godsend for many as individuals were able to start learning critical skills that allowed them to be more successful. However, in many areas of the country, families were able to access ABA services independent of insurance for decades. This is because ABA was provided to children through the public education system when schools identified ABA as necessary for children to access their education.

The overlap between ABA and special education is well established, from the fact that the majority of evidence-based practices identified by professors of special education at the Frank Porter Graham Child Development Institute at UNC Chapel Hill are based in ABA (The National Professional Development Center on Autism Spectrum Disorder, n.d.) to leading textbooks on instruction providing attributions to ABA such as “I learned how to teach students with [moderate and severe disabilities] by applying instruction in a systematic fashion based on the principles of ABA” (Collins, 2022, p. XI).

Despite this, access to ABA through a child’s entitlement right of their free appropriate public education (FAPE) as codified in the Individuals with Disabilities Education ACT (IDEA) is not consistent across the United States. Many regions have resisted incorporating ABA into their educational practices for one reason or another. A quick search of legal cases reveals numerous cases where families are seeking special educational services based in ABA. In fact, this was at the heart of the *Endrew F.* Supreme Court case that looked at what amount of educational progress was necessary for children



with autism (*Endrew F. v. Douglas County School District*, 2017). In that case, the family of a child with autism placed their son in a private school that used ABA as its instructional method after public schools declined to provide ABA services and the child was unable to meet his educational goals. The child quickly began to progress once ABA was used as the educational method. As a result, the Supreme Court agreed with the family that the public school district did not provide *Endrew* with a FAPE because he did not make meaningful progress there, whereas the private ABA did.

If you talk to families who were at the forefront of advocating for autism insurance, many will tell you that one of the reasons they pushed for insurance-funded ABA was they felt that it would be easier to obtain those services than through the education system. This is understandable as families needed to secure effective services for their children as soon as possible. However, this dominant focus on insurance-funded ABA has created a system where families feel they have to decide between their child receiving ABA through insurance *or* accessing their education. This has led to the unfortunate practice of families making the difficult decision to un-enroll their children from public schools in order to increase the hours of insurance-funded ABA they receive.

However, insurance-funded ABA is not a replacement for education. There are many critical skills that insurance-funded ABA is prohibited from targeting, such as reading and math skills. This is why if you talk to any insurance-funded ABA provider, they will tell you about the verbal gymnastics they go through to work around these limitations by targeting things like increasing “group responding” and “textual behavior” in order to access funding to teach things like reading without explicitly saying they are teaching reading. Further, many of the

benefits and methods families and advocates fought so hard to secure through insurance-funded ABA are entitlements in special education. This includes a focus on increasing adaptive behavior and communication skills, while decreasing challenging behaviors. It also includes the use of evidence-based interventions such as systematic instruction and functional behavior assessments. This is why many states include ABA as a related service in children’s education services.

As such, it is time for the autism community to focus on advocating for a system where families do not have to decide between having their children access their entitlement of an education or insurance-funded ABA. This is a false choice that forces children to sacrifice half of the supports to which their child is entitled. Children should be able to access *both*. This includes a robust education where they make meaningful progress year over year, and if ABA is the method that facilitates that progress, then schools should provide services based on an ABA framework. Then, those same children should have access to insurance-funded services to support non-school hours.

Creating this system will require a shift in advocacy efforts to a greater focus on ensuring access to children’s federally protected entitlement to FAPE. This will need to be accomplished in a slightly different way than the push for autism insurance because the law guaranteeing children’s educational rights already exists. Therefore, much of the focus will need to be on broader education efforts to inform people of what individuals’ rights are and helping ensure everyone is able to access them. For instance, the simple topic of “meaningful progress,” the term used by the Supreme Court in the *Endrew F.* case, can be challenging. Because each individual with autism is so unique, it can be a difficult to determine what exactly counts as meaningful for each child. Similarly,

the intricacies of state and federal policies can be difficult to navigate. Therefore, a broad based effort to educate everyone about their rights and providing supports to ensuring all children can access those rights is critical at this time.

With that being said, there is also a place for additional legislation in some areas. For instance, schools operate on a fixed budget and many children with autism have more extensive support needs. Therefore, schools often do not have the funding available to supply all the services a child with autism can benefit from. Although federal law prohibits educational teams from considering cost when making decisions (Wettach, 2017, p. 95), the reality is that limited funds does pose significant a barrier for some children. Therefore, advocacy to increase funding for children with more extensive needs could help.

Any shift like this is difficult, as so much has been invested in the fight to increase access to insurance-funded ABA. However, given the many achievements in this area and the unintended consequences that have resulted, this refocus is warranted. This is because doing so is the only way to ensure children with autism are able to access *all* of the supports they deserve, a robust education with needed services available outside of school. The educational entitlement is something no family should give up for their child. We must do better on behalf of all children.

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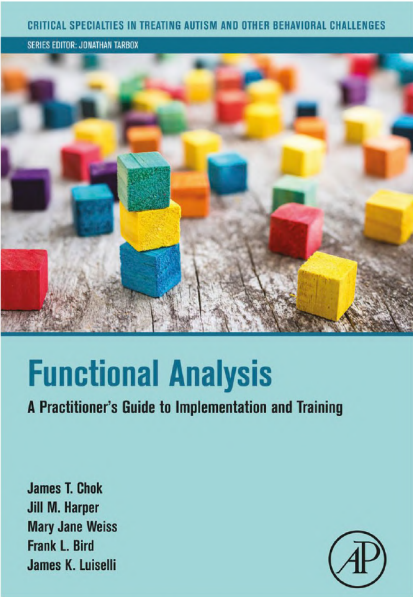
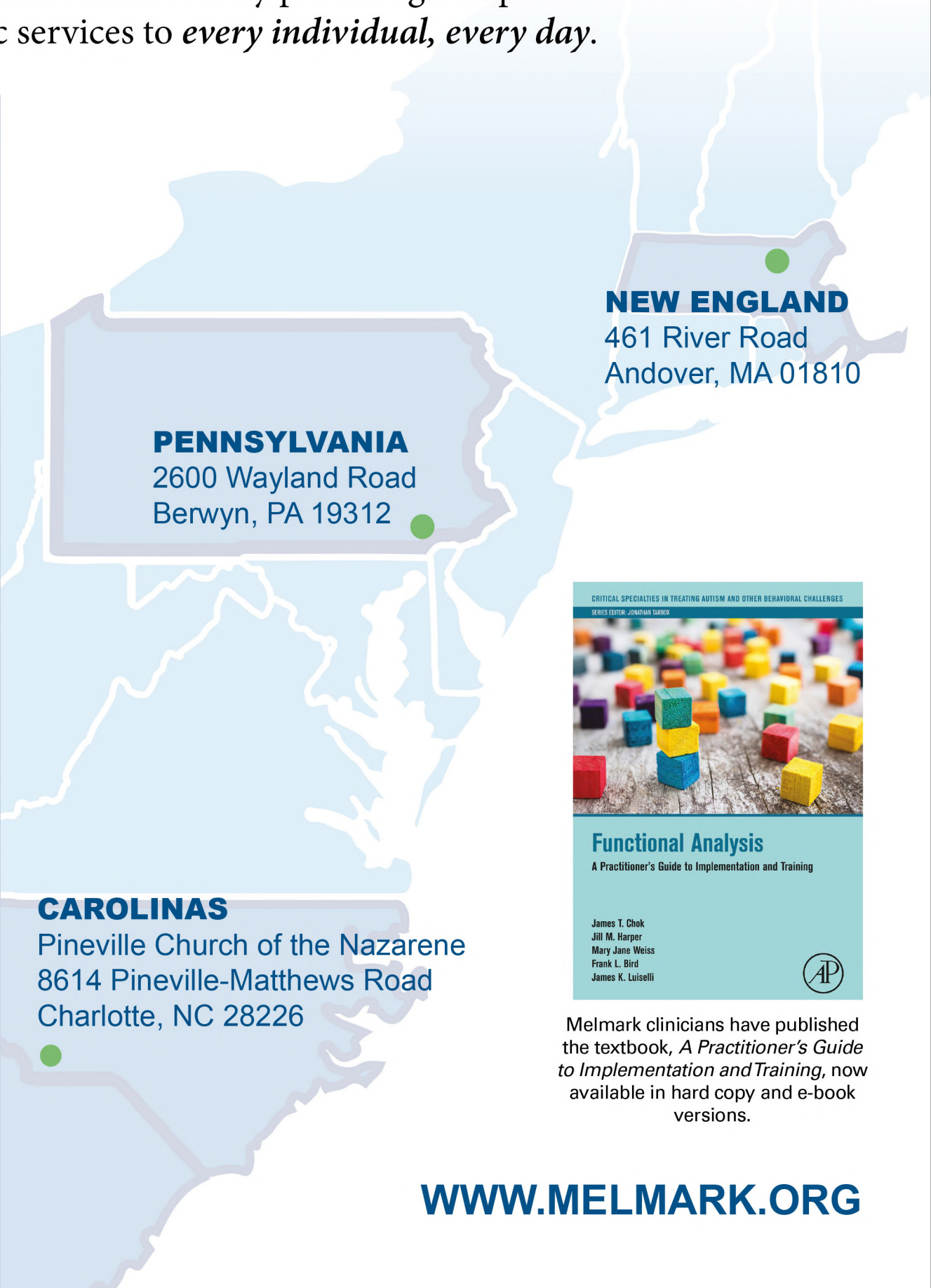
Tyler working on reading skills with Kelly Anglin, Special Education Teacher, at Melmark New England



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



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



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# Autism Without Fear: A Major Flaw in College Autism Programs

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

I currently run New York University's (NYU) Connections Program for Global Students with Autism. But I'm relatively new to higher education. I have a much longer history as a consultant, writer, and Executive Director, and back when my non-profits were engaging in the political battles of the autism world (2003-2013-ish), it was very hard to convince universities to come join us as allies. Whether it was battling Autism Speaks over the word "cure" or the ridiculous notion that we got our autism from vaccines, we advocates thought that our various campaigns provided a great opportunity for universities. The greater institutions could show that they were humanitarian, the faculty brainpower of colleges could be used for a good cause, and most of all, students would be given a real-life, progressive experience that they'd never forget. We reached out to accommodations departments, disability studies programs...

But we got silence. Not even responses saying, "no thanks." Some near-Stalinist, isolationist culture was dictating that the stereotypical bubble of college life...must remain a bubble. It was everyone's loss, and it temporarily discouraged me from ever working in higher education.



Michael John Carley

That's a hump we seem to be over - at least in theory - as we now see colleges attempting "connections" and partnerships with entities outside their campuses that provide either social or employment opportunities for their spectrum students. Another challenge loomed when colleges realized that the tuition money from spectrum students was just as good as anybody else's, and our kids were smart, so why not recruit them in droves??? Well, they did that, but without addressing the social challenges of college; and so the experience for many students was a one-year disaster. Herein, we still lag, as all across the

English-speaking world autistic students are still dropping out at higher rates than neurotypical kids and this is almost always due to colleges making mistakes at assessing what their autistic students truly need. And what about the parents that appear to have done everything they were supposed to do to prepare their kids for college?... Even they are still getting calls to come get their kids and bring them home.

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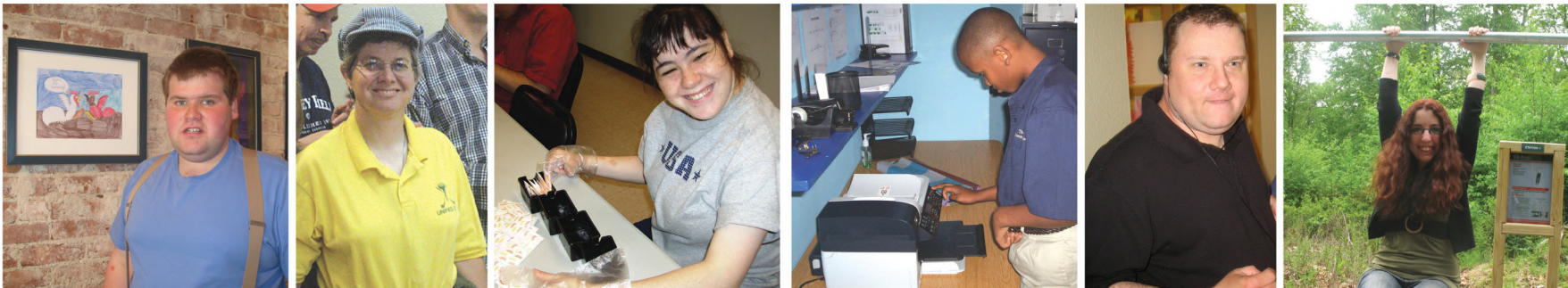
I have autism. And a large part of my hidden agenda in running NYU's program is to either shame, or inspire (I don't care which), other universities to also hire autistics to run their programs for autistic students. I've always assumed that the reasons spectrumfolk have a better chance at success in running such programs were painfully obvious: Autistic students, like anybody else, want to feel the trust that someone "gets" them. We've certainly learned in other arenas of Diversity Equity and Inclusion (DEI) that, to use one blatant example, a program head of African descent will bring forth more reassurance, self-esteem, and stability to a student of African descent, than will what we used to call "the white savior" program head. Well, doesn't this concept apply to every marginalized community?

It turns out that even I may have misunderstood the depth of challenges that agenda faces.

Recently, there was an unfortunate article on college autism programs in the Chronicle of Higher Education wherein the author described and documented the challenges autistic students face at Western Kentucky University's autism program. The picture painted was almost entirely deficit-based. Student challenges were well reported and backed up by research, but the piece failed to speak to the intelligence and/or any postgraduate potential of these students (disclaimer: I was quoted herein, and had some polite but unproductive emails with the author after it was published). I asked my NYU Connections students to read it and tell me what they thought, and those that read the piece didn't like it at all - all noted how Western Kentucky had an emphasis on social skills classes, which often teaches spectrumfolk that our way of doing things is bad and the rest of the world's way of doing things is "appropriate," thereby insulting their core self-esteem. They also agreed that the article made them feel poorly (if not completely mis-) represented. One student, Rosie Lee, noticed the discrepancy that in the article "...it'd be nice if more autistic students had actually been asked about their experiences in college." When the author was interviewing me a few months before publication, she seemed noticeably uncomfortable with acknowledging any benefits with a person with

see Major Flaw on page 22

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# How to Advocate Successfully at School for Your Child with Autism

By Marina Sarris  
SPARK - Simons Foundation  
Autism Research Initiative

You want what’s best for your child with autism, but you’re not a teacher or a speech and language pathologist. How do you get the school’s special education team to listen to your ideas? What do you do if you suspect your child’s Individualized Education Program (IEP) is failing them? Special education attorney Peter Wright has spent years teaching parents how to become effective advocates for their children who have disabilities, through seminars, books, and the [Wrightslaw.com](http://Wrightslaw.com) website. Here are some tips he provided in an interview with SPARK.

### Learn What Scores on Standardized Tests Mean

To understand if your child’s IEP is appropriate, Wright says, you need to understand what the scores on standardized educational tests really mean. Say you’re told that your child received an 85 *standard score* on a reading test. That sounds like a “B” grade. But it isn’t. A standard score of 100 is average, meaning that half of the students score above that mark and half score below it. A standard score of 85 puts the child in the 16th percentile. That means 84 percent



of the students his age scored above him. Make a chart of how your child’s scores have changed over time. That will allow you to see whether he is making progress.

Ask Questions Like a Detective, but Be Nice

Wright urges parents to ask a lot of questions, like the humble TV detective, Lieutenant Columbo, in the 1970s-era show. And be polite like Miss Manners, the columnist who gives etiquette advice, he says. For example, the school principal insists

that the law won’t allow her to provide a service for your child. You are doubtful. But don’t accuse her of misunderstanding the law. Instead, politely ask her to read the law with you, so that *you* can understand it. When you read the law together, she may realize that she was wrong - or maybe others in the IEP meeting will.

Ditch the Smartphone:  
Take Notes with Pen and Paper

Although you want to stay on good

terms with your child’s special education team, be prepared if a disagreement ends up in a hearing or courtroom. Keep notes of every conversation and meeting about your child. Write your notes on paper as the event is happening, or immediately afterward. If you end up before a judge, those notes can become evidence. Wright explains why using a smartphone or laptop to take notes is not the same. “If a person maintains a log on a computer, so often it’s garbage because everyone knows people can edit and embellish that log later on. Computer logs are either inadmissible or not given any weight, but logs written out by hand at that particular time are a powerful piece of evidence if there’s litigation.”

“If It’s Not in Writing, It Wasn’t Said”

If the school does not put an agreement, promise, or explanation in writing, then you should create your own paper trail, Wright says. “When you’re told something, you need to write a letter to the person that says, ‘Thank you for clarifying for me that, because of the budget shortfall this year, all speech and language services in our district have been suspended.’”

By the way, he adds, funding problems “are not a legal defense” for failing to provide a service in the IEP.

*see Advocate at School on page 31*

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Inviting all individuals with a professional diagnosis of autism and their families to join



# S:US' Community Fridge Project: Cultivating Social Justice and Health Equity in Our Community

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

Over the course of the COVID-19 pandemic, the need for social justice to address racial discrimination, health inequity, food insecurity and homelessness became starkly apparent as time went on and the effects of the pandemic became more visible. These experiences were at the forefront of our minds at Services for the UnderServed (S:US) as we are a large non-profit organization based in New York City which supports people who live with disabilities, mental illness and/or homelessness. We also employ dedicated staff who face some of these same challenges or support loved ones with some of these same challenges. S:US' core mission is to drive scalable solutions to transform the lives of people with disabilities, people in poverty and people facing homelessness which is grounded on embracing the solutions that contribute to righting societal imbalances and ultimately creating opportunities for all. As the new CEO of S:US, Dr. Jorge R. Petit, affirms, "At the heart of what we do is a firm commitment to righting the disparities caused by racial discrimination, bias and health



Community members helping themselves to free fresh produce and pantry items at the S:US community fridge in Brooklyn.

inequity and eradicating these within our practices and programs to help us move towards true social justice." In the article "Creating a Social Justice Action Framework for a NYC Social Service Provider," Dr. Petit cited that the American Public Health Association defines social justice as the "...view that everyone deserves equal rights and opportunities – this includes the right to good health." The right to good health includes

access to good, wholesome and nourishing food. Dr. Petit further asserts that the Robert Wood Johnson Foundation defines health equity as the "...means that everyone has a fair and just opportunity to be as healthy as possible. This requires removing obstacles to health such as poverty, discrimination, and their consequences, including powerlessness and lack of access to good jobs with fair pay, quality education and housing, safe environments, and

health care."<sup>2</sup> As a large non-profit serving New Yorkers in need, the management and staff within our ranks sought to take some positive and actionable steps to help level the playing field in righting some of these societal imbalances. The landscape of the COVID-19 pandemic, along with the intention of seeking to cultivate health equity and social justice, inspired S:US' Vice President of Day Habilitation Services, Jajaida Gonzalez, along with Vice President of Individualized Supports Johanna Cepin, and Director of Urban Farms Michael Hollis, to launch the community fridge program. The initiative was created in response to an increased need for food assistance among families served by S:US along with staff and people in the community during the COVID-19 pandemic due to health challenges, food insecurity, inflation, and the rising cost of food. The community fridges are located on-site at [S:US Developmental Disabilities](#) programs and provide fresh produce and basic pantry items to individuals and families in underserved neighborhoods in New York City. People with intellectual/developmental disabilities (I/DD) who attend an S:US Day Habilitation program clean, stock and maintain the community fridges, along with the support of staff, giving them

*see Fridge Project on [page 29](#)*

## Do you have a passion for helping others?

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

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# Building a Better Future: A Blueprint for Diversity, Equity, and Inclusion in Autism Service Providers

By Fatou Njie-Jallow, MHA  
Director of Diversity, Equity, and Inclusion  
The New England Center for Children

In these times of significant staffing challenges, autism service providers across the country are re-examining their diversity, equity, and inclusion (DEI) practices. DEI are central HR issues that foster organizational well-being and improve recruitment and retention. Research has proven that DEI can improve employee engagement, improving outcomes for clients and families. Even with this clear connection to treatment outcomes, Board Certified Behavior Analysts (BCBAs) are not required to take any training on diversity in their treatment approach. It is up to the providers to offer both training and support DEI practices. This article presents a blueprint for DEI action and policy for autism service providers. First, a quick look at what these popular terms mean. **Diversity** is our collective differences and similarities, including individual characteristics, values, beliefs, experiences, and backgrounds. Diversity has historically focused on race and ethnicity but should include all dimensions, such as sexual orientation, gender, and disabilities. **Equity** provides all employees and cli-



Fatou Njie-Jallow, MHA

ents with fair and contextually appropriate opportunities and resources to attain their full potential. **Inclusion** is an active, intentional, and ongoing effort that ensures full participation and an experience of belonging for every employee and client. A DEI program involves three multi-step phases: 1) Discovery and Analysis; 2) Strategic Plan and Execution; 3) Measurement and ROI. The knowledge gained

from each stage will identify opportunities for improvement, educate stakeholders, and drive benefits that result in a better organization. These phases are repeated over time because the learning and improvements are ongoing. To realize any progress on DEI, senior leaders must first acknowledge that the existing societal inequities will also directly impact the experience of providers and those who receive services. Without that perspective, it will be challenging to envision and enact new ways of leading.

Discovery and Analysis

The first step is about discovery, gaining awareness of the types of diversity within and across groups, and the context in which diversity, equity, and inclusion play out for individuals, teams, and the organization as a whole. Typically, a DEI director and committee spearhead the efforts. The discovery process comprises board, executive, management, staff, and family meetings; demographic and opinion surveys; classroom observations; and HR policy and data collection. There will often be broad internal support for DEI with the recognition that much work needs to be done. Management must invest in DEI as part of the operating model. It is not merely an HR checkbox but a way the company does business.

It is important to obtain objective data to underlie the subjective feelings people express. Such data is analyzed to evaluate areas for DEI improvement. For example, the talent lifecycle process should integrate HR operational data (hiring rates, promotion, performance evaluation, access to training, internal mobility, attrition rates, and use of employee benefits) and experience data (employee experience rating, engagement, intention to stay, feedback on organizational culture, growth potential, and career opportunities) to understand all the moments that matter through a DEI lens.

Strategic Plan and Execution

Based on information and data gathered in the Discovery stage, the provider can design and execute a strategic plan for DEI improvement. This entails diversity and cultural training, human resource policies, and hiring and retention practices. The strategic plan should include measurable goals and outcomes. Examples include percentage increases in representation, improved employee survey scores, and higher employee retention. The goals will be measured, and return-on-investment tracked in the next stage of the DEI program.

see DEI Program on page 23

EMOTIONAL REGULATION

EXECUTIVE SKILLS

ASSESSMENT

GOAL BUILDER

STEP 1 CHOOSE IPA

STEP 2 CHOOSE GOAL

STEP 3 FINALIZE GOAL

SELF-AWARENESS & ADVOCACY

CRITICAL THINKING

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SOCIAL INTERACTION

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# Hiring People with Disabilities as Direct Support Staff

## AHRC NYC Advance & Earn Provides Training and Support for NYC Youth With and Without Disabilities

By AHRC New York City

“He has this desire to learn.” “I knew he was personable and had the temperament for the job.” These are the words of some AHRC New York City staff describing Alex DeCarlo, a Direct Support Professional (DSP) who brings a unique perspective to his colleagues and the people with intellectual and developmental disabilities he supports.

### Bringing Different Perspective

DeCarlo has autism and shares his lived experience with the people attending AHRC NYC’s Day Habilitation Without Walls program in Staten Island.

He is a graduate of AHRC NYC’s Advance & Earn program. The program is designed for New York City residents, age 16-24, who are out of school and are unemployed or underemployed. It is funded by the New York City Department of Youth and Community Development. Participants can earn certification as a DSP, like DeCarlo, or other professions of their choice, and work in a paid internship, before being placed in a job.

DeCarlo is certified as a DSP Level 1, having earned his certification from the



**Alex DeCarlo, a Direct Support Professional with AHRC New York City, leads a group from the organization’s Staten Island Day Habilitation Without Walls program in the community.**

National Association of Direct Support Professionals in human services. He interned as a job coach with AHRC NYC’s Employment Business Services in Staten Island nearly a year ago before starting his current position on Aug. 29, 2022.

“The reason I became a DSP is that it’s

a great opportunity to help people out and help people pursue their goals,” DeCarlo, 24, says. Goals may include writing a resume or sending an application to a worksite. “Helping them out is a good steppingstone so they can strive to be better people in the community.”

### Breaking Barriers

He recognizes that he is breaking barriers by becoming a DSP. “I feel like I’ve accomplished a lot, due to me having a disability,” DeCarlo says. “It goes to show that people with disabilities can also get jobs as DSPs.”

Esteban Gonzalez, Community Support Supervisor at Day Habilitation Without Walls, is DeCarlo’s supervisor. He knows hiring DeCarlo set new ground for the organization. “This is a community that could help our field out,” he says. “By employing them, giving them a sense of direction, they can serve as an example to others.”

David DeCarlo and his wife Kathleen Ryan see how their son has changed over the months.

“When he got involved with the internship with AHRC NYC, he became more focused,” David says. “He takes pride in his work. It seems like he has found his niche.”

Alex has matured and grown more responsible, Ryan adds. “He’s more confident in himself,” she says. “That’s hard for so many people, nonetheless for a person with a disability. To help others, you need to be comfortable and confident. We’re both very proud of how far Alex has come.”

### Becoming Part of Solution

Training people with intellectual and developmental disabilities for DSP positions solves two major issues facing the field. It addresses the current workforce crisis facing every provider in the U.S., while providing people with disabilities the opportunity to find meaningful employment.

The U.S. Department of Labor’s Office of Disability Employment Policy and its

National Center on Leadership for the Employment and Economic Advancement of People with Disabilities (LEAD) convened a Think Tank of national experts last year, to identify and make recommendations about the difficulties facing the DSP workforce. One area of focus was an opportunity for people with disabilities to become DSPs. AHRC NYC’s Jonathon Epstein, Program Director of AHRC NYC’s Advance & Earn, was part of the Think Tank.

Among the Think Tank’s potential policy recommendations, released last summer, were:

- Expand training and apprenticeship programs for people with disabilities to become DSPs.
- Eliminate rules, service definitions, and requirements that create barriers for people with disabilities becoming DSPs (e.g., the ability to lift a certain amount of weight, or drivers’ license requirement).
- Replace criteria-based requirements with competency-based requirements.
- Clarify how existing funding sources can be used to support DSPs with disabilities

“Too often what’s available for people with disabilities is shaped by people without disabilities” Epstein said. “When you set up people with disabilities to mentor people with disabilities, they are more likely to be successful because of that understanding and empathy based on experience.”

The New York State Office for People with Developmental Disabilities entered into a \$10 million partnership with the National Alliance for Direct Support Professionals to expand opportunities for professional credentialing for DSPs in the field throughout the state. The three-year agreement will provide bonus incentives for certification to incoming and existing DSPs. AHRC NYC is among 17 NYS providers selected to participate in a state credentialing pilot, with the opportunity for staff to pursue certification through NAD-SP E-Badge Academy.

### Build Up DSP Pipeline

“Unless we take action to increase the pipeline of DSPs and increase the number and quality of DSPs of this workforce, the potential and talent of people with disabilities who rely upon DSPs in the workplace will go unfulfilled,” Taryn Williams, Assistant Secretary of the Office of Disability Employment Policy with the U.S. Department of Labor, told an audience during a recent webinar.

BLS statistics show employers will need to fill 7.4 million direct care job openings between 2019 and 2029, Williams said during the LEAD Center webinar. Williams says BLS projects a 33% job growth in direct care positions between 2020 and 2030. RCM of Washington’s DSP Academy, which launched in 2018 for people

see *Hiring* on page 31



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Raymond Ferrigno, Board President  
Marco Damiani, Chief Executive Officer





# How to Advocate for Your Nonspeaking or Minimally Verbal Child or Adult

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

Over the last decade, there has been an increase in autistic self-advocates coming into the public eye through their incredible means to advocate for themselves - and others like them. These individuals have become a powerful voice for boards, committees, research and quality improvement initiatives across major organizations and groups. Truly, it is an exciting time to see the important insights and contributions autistic self-advocates bring from their lived experiences.

When my daughter, Annie, was diagnosed with autism nearly 20 years ago, the only thing people could relate to the word “autism” was the movie *Rain Man*, in which Dustin Hoffman plays the character of Raymond, a man with autism who was also a gifted savant. Today, we have a greater understanding about the full and diverse autism spectrum, and the uniqueness of each individual.

Annie, who is almost 21-years-old, has autism and intellectual disabilities, and is minimally verbal due to a speech disorder called verbal apraxia. As her mother, I am thrilled to see the progress in the advocacy realm of the autism world. But I am also keenly aware that the “Annies” in the



Amy Kelly, Devereux’s National Director of Family Engagement, and her daughter, Annie

world, like my daughter, still don’t have their own voices. I am her voice. And I am her advocate.

Below are a few suggestions that can help others advocate for those who have no voice, who are nonspeaking or who are limited in their verbal communication:

**Remember, you are the expert on your child/loved one** - As the primary caregiver and/or family member (parent, grandparent, sibling, neighbor, etc.), you know your person best. You are able to care for your child or loved one because you have figured out how to understand them - even

if you’ve had to endure mistakes or tantrum behaviors. (We all have!) Try and tap into that knowledge to advocate on their behalf.

**Teach your audience about your loved one’s autism** - Often, people associate one idea with autism (e.g., *Rain Man*) because they haven’t learned or experienced otherwise. Talk to your audience - doctors, teachers, and community partners - about your child or adult. Share their strengths, challenges, and areas of need. Provide detailed examples and tell stories. By describing your child or loved one in an illustrative way, people will better understand and remember what you shared with them.

**Try new ways to understand your child or adult’s position on various topics** - If you have a loved one who is nonspeaking, you have learned communication comes in many forms. Through challenging behaviors - such as tantrums, turning one’s head, pushing something away and ripping something up - we understand our individuals are communicating displeasure. They also can show happiness in unconventional ways, such as flapping their hands, jumping up and down, and making high pitched sounds. When this happens:

*see Nonspeaking on page 14*



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# Pathways to Resolution of Special Education Conflicts

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

When conflict arises in an educational setting, there are multiple ways to resolve it. Some are small and easily resolved but may potentially lead to bigger conflicts and issues. Sometimes the conflict is substantial, and a resolution harder to achieve. Understanding different available methods of resolving conflict can help families and educators decide the best pathway toward resolution. The expense, time, and adversarial nature of the conflict increases proportionately through each stage of the process. As those increase, a student's path to success becomes increasingly frustrated.

## Prevention

In the educational setting, conflict can and should be avoided before it arises. Using the example of a new school year, Parents and families often face that year, with new teachers, with trepidation. The teacher does not know their child. They may not have a full understanding of the child's particular disability or learning challenge. Parent and student alike may have a lot of anxiety in facing the unknown or transitioning into a new environment. Left unaddressed, there is great risk of conflict arising.



Tara C. Fappiano, Esq.

Working collaboratively, parents and teachers can do much to minimize that risk. An understanding that the teachers or support staff are also getting acclimated to a new situation is key. Teachers need time to know the student, so parents should not assume there will be problems. When that first contact is made, respect for each party's role will go a long way toward collaboration. Those early discussions can focus on agreements as to the best way to communicate, how often, and what informa-

tion may be needed from each party for the student to succeed. Sharing concerns and information openly creates a great working relationship. When two parties establish an open communication path early on, with the student's interests at the center, the likelihood that a conflict will be avoided, or resolved more easily if one arises, is increased tremendously.

## De-Escalation and Problem-Solving

Even in the best of circumstances, conflicts arise in the classroom. Sometimes, the conflict is a small disagreement. Sometimes there is an identified problem, but a different opinion about whether or how to best resolve it. Sometimes, the conflict is bigger. There may be a "task-based" conflict, which usually arises when something about the learning environment is not appropriate for the student. Or there may be a "relationship-based" conflict, whether real or perceived. It is quite tempting, for parents in particular, to assume or perceive there is a relationship-based issue. As an advocate, I frequently hear first from parents that the teacher does not like them, or that the teacher does not want to listen to anything they say, or even worse that the teacher or school has it "out for them." This type of thinking, even if there is some truth to it, gets in the way of resolving what is actually a task-based conflict. If the parties can see through those types of categor-

izations to focus on the actual problem at hand, resolution is much more attainable.

If the parties really are interested in resolution, de-escalation at this stage is crucial. There is still an opportunity to avoid further expense, and to get the student back on track, quickly. So, how to do that? Set up an informal meeting, in person, to speak about what specific issues have been identified with the student, whether in the classroom or from the parents' perspective. Be open to hearing the perspective of the persons relaying the information. If what is being discussed is confusing, seems inconsistent, or is not specific enough, use constructive questioning to find out more. Ask for the other party to propose a solution, then try to discuss those solutions with an open mind. More times than not, the parties can arrive at a proposed solution if both are at least willing to try. If there is a concern, by either party, that this will not fully resolve the conflict, agree when to regroup to evaluate the situation again.

In my work as an advocate, I am very often contacted when conflicts have not been de-escalated. Either the parties have not attempted to do so at all, or there has been a meeting that did not go well. There may be multiple attempts at the school level to de-escalate. The introduction of an attorney or outside advocate into the situation at this stage may cause a school to put

see Resolution on page 30



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## Nonspeaking from page 13

- Consider offering alternatives with pictures and words to explain things more clearly (e.g., icons, lists or social stories) and allow your individual to point at what they like or don't like.
- Offer paper and pen so your loved one can write their thoughts, if they are able.
- Allow them to use a computer or tablet to type or search for things of interest and priority.
- Listen for sounds (squeals or grunts) and watch for physical cues like hopping up and down, clapping or waving hands, or smiling and frowning.

There are so many ways to communicate and, as the caregiver and/or family, it is our job to interpret and decipher their needs and wants so we can share these viewpoints with others. This is advocacy. Plain and simple.

## Understand possible ways to advocate

- There are many ways to be an effective advocate: Advocacy at a personal level or at the local, state, or federal levels. Understanding the systems of care at each of these levels is important and can be a mighty task to master. Think about the medical system, the educational process, funding and waiver structures, and dis-

ability rights. Understanding these areas fully will allow for productive, successful advocacy.

Regardless of where you are in your journey with your loved one, know that the small things you do to advocate for them are *the big things*. Your child or loved one needs and depends on you to help the rest of the world understand who they are, and what they need to grow and thrive. What a privilege and honor it is to represent these wonderful and unique individuals.

Amy Kelly, MBA, MNM, is National Director of Family Engagement at [Devereux Advanced Behavioral Health](#). Amy is the mother to Danny, Annie, and Ryan. Annie is diagnosed with moderate to severe autism, verbal apraxia, intellectual and developmental disabilities, and general anxiety disorder. Amy is the National Director of Family Engagement for Devereux Advanced Behavioral Health, one of the nation's oldest and largest nonprofit providers of behavioral healthcare and serves as a family representative on several special needs boards in the community, locally and nationally. In addition, she participates with other patients and families in efforts supported by the Autism Care Network and serves on an executive committee for the American Academy of Pediatrics, to assist children and adolescents with special needs and the importance of quality care.



# The Unique Responsibility of Neuroexpansive Minds for Cultural Inclusion

By Dawn Prince-Hughes, PhD  
Project Designer and Facilitator  
Project CASY, Yale Child Study Center

As an advocate for those with neuroexpansive minds in bodies that have become commodified bodies, I have come to understand, over the years, that a piecemeal approach to the valuing of difference and extensions of freedoms for all designated expendable in modern culture depends on every such movement to band together. A veteran of many social justice movements, it is clear that as we celebrate the crumbs we seek, we have failed to see that without a root transformation, a society founded on horrendous casual cruelty will simply close ranks after one group or another is finally “accepted.” But as Abraham Lincoln famously quoted, “Those who deny freedom to others deserve it not for themselves...” I believe this especially true of those who’s very innate sensitivities and connections are responsible for them being pushed out of the cultural sphere in the first place.

Since my first awareness of my sensitivities and connectedness with the world, and the healing of those through my years with the Gorilla Nation, I haven’t made distinctions between myself and the living things that share my mind. My heart breaks when I see humanity continuing to make those distinctions, knowing that doing so



Dawn Prince-Hughes, PhD

will ensure never-ending cycles of devaluing and pretending to value those who are different. This is especially heartbreaking when I see neuroexpansive human beings engage in the same subjugation.

I was deeply disturbed recently, reading a piece about the sentience - the neuroexpansive capabilities - of animals other than ourselves, as I work on a book about these ideas.\* There were many examples of obvious and moving altruism and intel-

ligence among our neuroexpansive kin in animal form. In reading about pigs, for example, there were abundant news articles about pigs who saved their human families from housefires, heart attacks, undetected diseases and the like, as well as numerous accounts of them showing ingenuity and nuanced thought and planning. One particular reference that caught my attention was by an autistic colleague. She wrote about factory farmed pigs who, when finding the feed allotment scan tags fallen from around another pig’s neck, will take them and run to the feeders, scanning the stolen tags to get extra food.

What disturbed me, beyond envisioning pigs crammed into dark, poorly ventilated warehouses, desperate for natural food, was my autistic colleague’s lack of moral reflection on the fact that such an action by an animal is inarguably evidence that they possess neuroexpansive minds that are ignored because there is social and monetary benefit in continuing to see them only as bodies to make money from. My colleague’s attitude struck me as some kind of neurological Stockholm Syndrome, reflecting that the ability to compartmentalize, dismiss suffering, and commodify other sentient beings is an evolutionary trademark of the neurotruncated power structure, not the flowering of the sensitivity and connection that is at our core.

On following my questions about pigs and other animals, I decided to read more

on my colleague’s website. There, I found no stories of animals showing their neuroexpansive capabilities. There, they were reduced to simple, commodified bodies. For example, she gives in clear detail her personal recommendations for how to properly cut animals’ throats as they swing upside down on a kill line filled with screaming and terrified friends, fighting with all they have to stay alive. I knew from seeing this process that the line often moves so fast that the stunning of these animals is often botched so that they are conscious while their legs are sawed off, they are skinned alive, or are scalded to death. Perhaps aware of this inefficiency, the website offers that it is even more expedient to put groups of them into gas chambers, where one pulling the lever should look for it to take almost a half a minute for the animals inside, clawing to get out, to “lose posture.” She is careful not to say “lose consciousness” for obvious reasons.

Losing consciousness, though, is exactly what they do. Through our modern history, such euphemistic aloofness has coolly described the killing of those who we consider closer to home when we think of neuroexpansive minds in commodified bodies. Terrible historical examples abound and continue now. That we, as kindred of all of these tortured and liquidated minds, turn a blind eye, is unacceptable in my view.

see *Cultural Inclusion* on page 26

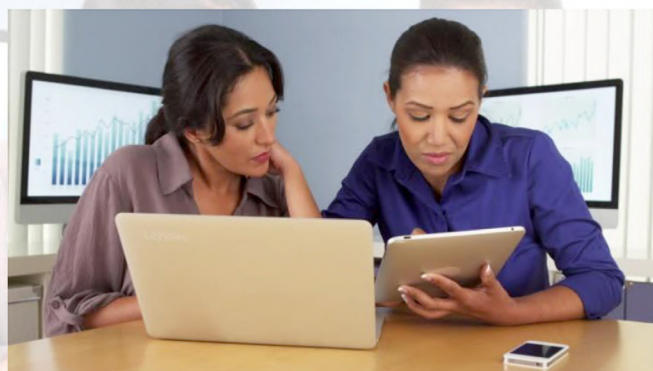
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## Advocating for the Advocate

**By Lisa Morgan MEd, CAS  
Consultant / Author  
Lisa Morgan Consulting LLC**

Experiencing a life-changing event is one of the reasons people start advocating. For autistic people, advocating can mean stepping so far out of their comfort zone socially, it feels like they've lost sight of it. As for myself, I went from feeling invisible most of my childhood, to talking in front of my very familiar students in small classrooms, to speaking to strangers at national conferences. My life-changing event was my husband of 29.8 years dying by suicide. Suddenly, I had important information about crisis supports and suicide prevention for autistic people to share.

So, I started advocating to professionals supporting autistic people in crisis. What I found was that advocating has either been a great mountain-top experience or a challenging, cactus-like prickly one. I love it when I can help professionals understand how to support autistic people in crisis. It's a great feeling of satisfaction and happiness. Unfortunately, I also found myself in situations where I was being unintentionally harmed through my advocacy efforts.

Unintentional is the key word here because the people I advocate to are helping professionals. These are the people who need the important information I have



**Lisa Morgan MEd, CAS**

acquired through lived experience. The people who, when they come to truly understand autism, have the potential to be important culturally competent allies for autistic people. Allies who can save lives.

Harm is what happens when the professionals I'm advocating to forget, or perhaps do not understand that I'm autistic too, which means what I'm teaching pertains to me as well. So, for instance in advocating for crisis supports, I might teach that autistic people who are triggered may not be able to communicate, may have a

regression of skills, or have high anxiety. Then, I may experience professionals who question my competence in being able to advocate because I struggle to answer a question or to talk at all in a moment of high anxiety.

I may also explain how difficult change is for autistic people, how sensory issues can be debilitating, or how anxiety can invoke a slower processing speed. Then, to my surprise, I experience and endure last minute changes to a presentation, or participants are not told to turn their cameras off, or there's an expectation, because I'm the presenter, that I'm in charge of reading the chat, keeping track of time, and answering questions all at once. These incidents are potentially detrimental to my ability to advocate in the moment, invalidating of my autistic self, and hinders the professional relationships I'm trying to build.

Please continue to keep in mind – this is all unintentional. I believe the expectations resulting in the unintentional harm explained above are rooted in the professionals' attempt to presume competence out of respect. So, how can presumed competence and respect result in harm?

The competence and respect are from a different culture.

The culture I belong to, the autism culture, has a different way of showing competence and respect, of which, non-autistic people might feel unintentionally harmed if I were to show them the kind of compe-

tence and respect I understand.

Competence for autistic people leaves room for regulating emotions, triggers, and sensory stimulation. I experienced this first-hand at an autistic-led conference I attended. It was the most comfortable, safe, accessible conference I've ever been to. The autistic people I worked with that day allowed each other space to be ok and to not be ok. There was presumed competence whether someone had to withdraw, pace, cry, leave, or regulate in any way. As soon as the regulation was restored, the autistic person was back to presenting, covering an autistic person who needed a moment, or just whatever needed to be done. I had to use a quiet space to regulate a couple of times that day, but never felt like anyone thought less of me because of it. I knew when I was regulated, I would resume my duties alongside my autistic colleagues with no questions asked. Regulating, withdrawing, and sensory challenges were as much a part of the conference as presenting, networking, and advocating.

Respect for each other came from the understanding that each autistic person could and would take care of themselves in the way they needed to - or ask for assistance. There was no judgment or expectations of having to always be ok in order to present. I was asked to take over for someone who needed space and time to regulate, right

*see For the Advocate on page 29*

## Advocacy on Behalf of Less-Impaired Autistics

**By Karl Wittig, PE  
Advisory Board Chair  
Aspies For Social Success (AFSS)**

In the more than two decades since my diagnosis, I have attended countless autism community events of just about every kind, not to mention numerous others in which issues concerning autism somehow came up. In virtually all of these, I routinely disclosed that I was on the autism spectrum and on every occasion was warmly accepted and welcomed by all those present (in fact, more so than at many other times in my life). As it happens, there was only one exception to this, which took place when I attended the screening, at a local cinema, of a small independent documentary describing the challenges faced by two more-severely autistic children. During the discussion that followed, the film makers and subjects made rather hostile remarks about "so-called high-functioning autistics" who did not face difficulties that were anywhere nearly as serious and in fact were sometimes very successful. I immediately realized that they were talking about individuals like myself and felt very uncomfortable. I knew better than to disclose that I was on the spectrum and left the theater as quickly and quietly as I could, understanding that I was not welcome there.

What I experienced at this event was an example of what is probably the most



**Karl Wittig, PE**

contentious of the many divisions that exist within the greater autism community. While I am the first to admit that autistics like myself have not experienced anywhere near the kinds of challenges regularly faced by individuals like those portrayed in that film, have been very fortunate, and would never compare my difficulties to any of theirs, the fact remains that many of the traits, behaviors, and challenges that I have lived with my entire life are nevertheless typical of the autism spectrum, even if to a

much milder extent. One especially memorable encounter that drove this home for me was a conversation I had at an autism event with the mother of two young adults on the spectrum. One of them was so impaired that he needed to live in a residential facility, but the other was at the time attending a prominent science high school at which he was taking advanced-placement courses in calculus and physics – just as I had done back in my own day. This became even more uncanny when I described, as the hors-d'oeuvres were being passed around, my lifelong selective eating issues, and she responded that her son also had this very problem! Knowing that autism has a strong hereditary component, I realized that these two individuals were at different ends of the same autism spectrum, as by then I knew was the case for me as well.

### Portrayals in the Popular Media

One significant cause of misunderstandings about the milder end of the autism spectrum involves the numerous portrayals of such individuals in the media and popular culture. These have resulted in the widespread impression that such autistics are typically tech billionaires, brilliant physicists, and in one case even a gifted surgeon. While these things are certainly not impossible, and may actually occur in some cases, most less-impaired autistics have never enjoyed anywhere near this level of success. The reality, even for many talented autistics,

is that they struggle to find and maintain employment and perhaps to live independently. Clearly, the media portrayals do a great disservice to the more-impaired autistics who face formidable challenges and will almost certainly never attain such degrees of accomplishment; this has been recognized by the autism community. What is also true, however, is that even among the most talented autistics (i.e., the twice-exceptional) such achievement is quite rare – it is rare enough among the typical population, so the very idea of it being common in the autism community is simply absurd! While there certainly are many autistics with backgrounds in these areas, an alarmingly high percentage of them are either unemployed or grossly underemployed. Throughout the years of my involvement with the autism community, I have encountered countless such individuals. As welcome as it may be that society and the media have finally recognized the breadth of the autism spectrum (this was hardly the case when I was first diagnosed), the recent popular images and conceptions of autistics have hardly done them any service.

Many talented autistics, with areas of strong special interest and ability, are not able to succeed in school because of unaddressed learning disabilities or difficulties in adapting to some demands of the higher-education environment. Even among those who do, finding employment is far

*see Less-Impaired on page 18*



## Using Storytelling as a Self-Advocacy Tool

**By Izabelle Azevedo**  
Visual Storyteller and Mental Health,  
Neurodiversity, and Inclusion  
Self-Advocate

I have always tried to advocate for myself, but I noticed from a very young age that I had difficulties doing so verbally. It takes a while for me to organize my thoughts to be able to speak, and I often say that even though my speaking and writing comes from the same brain, it seems like it's coming from different people. Confrontation is also a hard task for me, even when I rehearse social interactions that might lead to it (which I often do). So, I found in writing, and later in visuals, a way to express myself, how I see the world, how to advocate for myself.

I believe my advocacy journey reached a new level when I started sharing about mental health on social media, in 2018. Back then, I was feeling empty from depression, and felt like no one could understand what I was going through. But once I was writing about it, people who were going through something similar started to reach out. Suddenly I was no longer alone. Those folks reaching out would tell me about themselves, thank me for opening up that space for them, and say they no longer felt alone either. That is when I realized how powerful storytelling can be - so powerful that it can help heal both the one



**Watch Purple Heather - Written and Directed by Izabelle Azevedo**

who's sharing and the one who's receiving the message.

If it wasn't for those sharing their own stories, I don't know if and when I would have found out I am autistic. I will be forever thankful to [Alex Pearson and her TikTok](#)s that showed up to me on a random day in the Fall of 2020 and made me realize I could be on the spectrum. As an adult female who is empathetic, creative, and can communicate, at that time I certainly did not believe I could be autistic. It contradicted what I read about the "condition." I had to hear from those with practical experi-

ence, and other neurodivergent females, to understand the differences in presentation, how good we are at masking, and that, yes, an autistic person can be highly empathetic and creative. Now my life makes sense. And again, I no longer feel alone.

I was officially diagnosed autistic and ADHD in August 2021, at the age of 34. I remember feeling a mix of relief and rage. What if I had known sooner? Would my life be different? I thought of all the women out there who were feeling like I was - broken but far from finding out that they aren't broken. I took some time to process

and grieve, and I promised myself I would use my storytelling skills to help raise awareness about autism in adults, especially in females.

Last April I finally shared my story with everyone, including family and friends. Since then, I started posting on LinkedIn about autism, ADHD in women, and neurodiversity. My posts are usually more than a point of view or quotes from an article. What I share is often personal because my goal is not only to inform, but to connect, and it is harder to accomplish that without being vulnerable. Storytelling has been a tool for human connection since the Stone Age, so I try to use it in my posts, even when I am sharing my point of view. And that is because I want to provoke some kind of reaction from my reader. Otherwise, I am not doing my job right.

Even though I keep talking about writing, and I do use writing more as a self-advocacy medium, I am actually a visual storyteller. I've been making videos (for other people) for a living since 2019, and I just finished my first semester of film school, having previously completed my 2-year associate degree. As you can see, storytelling is more than an advocacy tool and a passion for me. So, in November 2021 out of an impulse to enter into a film festival, I made my first short fiction film, [Purple Heather](#). In this film, I share the story of a

*see Storytelling on page 23*

## Opportunities for Disability Employment

**By Elizabeth Wolleben Yoder, CFP®**  
Director of Financial Planning  
Planning Across the Spectrum

One of the biggest misconceptions we address as financial advisors to neurodivergent clients is that people with disabling conditions cannot work and receive government benefits and supports. Not only that but that government is trying to make sure that you don't work if you have a disability. While the rules can be obnoxiously complicated, the truth is that people with disabilities can work while receiving disability benefits, including Social Security and Medicaid. While the programs are intimidating, they are structured to support and encourage employment.

All the neurodiversity hiring programs are designed to get people into jobs that they can be successful in. The best programs create a culture of inclusion that enable all people to bring their whole selves to the workplace and feel that there will be support when needed to get the job done. One of the biggest challenges to these programs being successful is finding people who are willing to take the job, because they are still afraid that they will be giving up on their benefits. As a disability aware financial planner, the greatest advocacy I can do is to educate my clients and their families understand their opportunities better.



**Elizabeth Wolleben Yoder, CFP®**

### Social Security Employment

For a very brief high-level review, Social Security has two main programs for people with disabilities. Supplemental Security Income (SSI) limits both assets and income. SSI is the baseline for cash benefits provided to a disabled individual. Social Security Disability Insurance (SSDI) is a benefit that a worker pays to earn for themselves or their children through employment taxes. SSI income can decrease when countable income exists by \$1 for every \$2 counted. SSDI is not reduced but stops when some-

one earns above the Substantial Gainful Activity (SGA) amount (\$1,470 a month starting in January 2023). Notably, if someone has successfully worked above SGA for longer than 6 months, they will not be eligible for a benefit based on their parent's work record (the Disabled Adult Child benefit) and will have to rely on their own work history to produce their SSDI benefits.

As part of both programs, earned income can be uncountable for a few reasons. First, if the employed person is a full-time student, income is excluded up to \$2,220 a month but not more than \$8,950 for 2023. In many cases, a full-time student's full income can be excluded from their Social Security benefits, especially if they are working limited hours. When the student leaves their full-time program, they must consider if the long-term benefits of independent employment outweigh the support of their SSI or SSDI income.

Impairment Related Work Expenses (IRWEs) are another way a working person receiving SSI or SSDI can exclude income when expenses related to their disability enables them to participate in their own employment. Notably, if someone is self-employed and working less than 40 hours a month, all their business expenses are discounted from income in this way. Someone is not under guardianship can own a business to allow individuals greater control their income.

Beyond IRWEs, there are also work subsidy programs within Social Security regu-

lations that enables someone paid the same as their peers without disabilities to discount some earnings if they do less work than their peers.

The Social Security Administration encourages people to work towards greater independence because employment reduces a reliance on the Social Security system. This increases the amount available for SSA to give to the most vulnerable people who are unable to work at all and brings more income into the SSDI program through payroll taxes. SSA counselors can be available to share with individuals how long benefits will last and any programs they can take advantage of to make them stretch into any competitive work attempt.

### Medicaid

To many, Social Security is not the lifeline that matters most when considering employment. Medical insurance and access to Medicaid supports are often the most vital benefits. In many states, Medicaid has low asset limits and low-income limits. However, most states also have disabled worker programs to enable someone who is earning money beyond the traditional limits to still be eligible for the benefits of community supports and medical insurance. An individual is not automatically enrolled in the Medicaid program for disabled workers. The employed individual

*see Disability Employment on page 30*

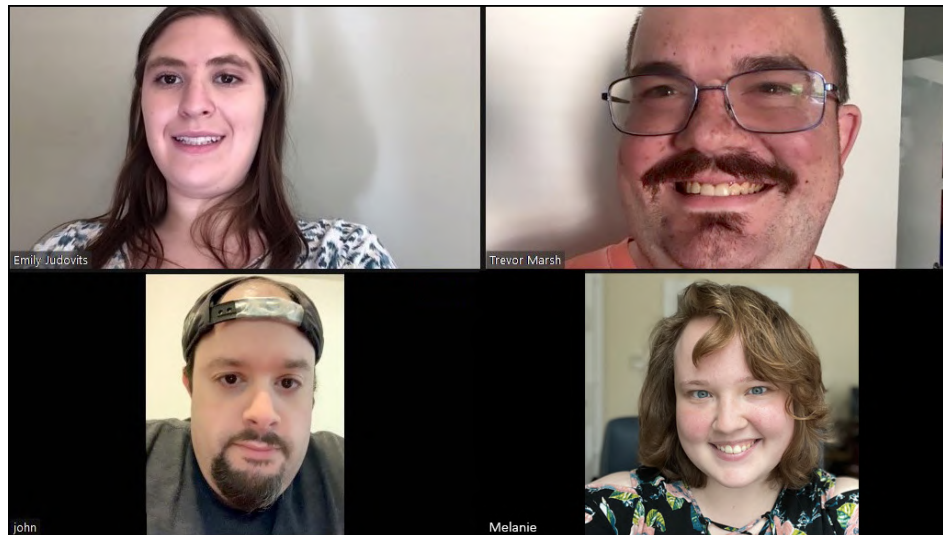


# Supporting Teens and Adults in Becoming the Best Self-Advocate They Can

By Meghan Herring, MSW, LCSW,  
Michelle Heyman, MA,  
Emily Judovits,  
Trevor Marsh,  
Ashley McClennen, MEd, BCBA, LBS (PA),  
John Pagnoni,  
and Melanie Schwartz  
Devereux Advanced Behavioral Health

The creation of self-advocacy is a story that is one of pioneering and revolution dating back as far as 1968 (Glumbić et al., 2022). Today, many self-advocacy organizations target elevating neurodiverse voices and providing space for neurodiverse individuals to advocate for themselves. The current self-advocacy movement has helped neurodiverse individuals find their voice and autonomy. This movement has also helped professionals working with neurodiverse individuals understand their point of view and understand the individual needs of each person (Zuber & Webber, 2019).

The self-advocacy movement has shown it is best to hear the voices of neurodiverse individuals to better understand their viewpoint on this topic. Therefore, it was important to interview neurodiverse adults and include them as contributors to this article. Melanie Schwartz attends West Chester University and consults with Devereux's college preparation



**Three of Devereux CAAPP's neurodiverse self-advocates, Emily, Trevor, and John, attending a Zoom advocacy group. Also pictured is self-advocate Melanie, a neurodiverse student who attends West Chester University.**

course for autistic high school students. Emily Judovits, Trevor Marsh, and John Pagnoni participate in [Devereux's Community Adult Autism Partnership Program \(CAAPP\)](#) and are each meaningfully employed. All passionate self-advocates, Melanie, Emily, Trevor, and John were interviewed to provide other neurodiverse individuals with tips on how to become your own advocate.

## Tips to Becoming a Self-Advocate

The following are the top three tips to becoming a self-advocate from our neurodiverse interviewees:

**1. Find Your Voice** - John, Trevor, and Emily mentioned that being more active and present in meetings surrounding their services and needs made them feel more

in control about their lifestyle choices and support. The neurodiverse adults mentioned that with more learned skills, they were able to play a larger role in their Individual Support Plan (ISP) meetings. ISP's provides assessment results, background information of the individual, and a list of individualized recommended services for an adult with neurodiverse needs, such as autism spectrum disorder or intellectual disability. The interviewees reported that they wished they knew more about the possible services available to them and/or learned skills on how to explain their needs to others at educational meetings and advocate for needs not currently being met. Research has shown that of those autistic individuals who attend their Individualized Education Plans (IEP) meetings, most were minimally involved with the meeting and transition planning (Chandross et al., 2018). When neurodiverse students are more involved in their education planning at a young age, it helps teach neurodiverse individuals self-determination skills and thus has positive long-term effects (e.g., higher academic achievement, higher ratings of quality of life; Chou et al., 2016).

**2. Find a Mentor** - John, Trevor, and Emily all discussed what being a mentor and mentee meant to them and how it has influenced their self-advocacy skills. Emily

*see Supported on page 19*

## Less-Impaired from page 16

more difficult than for their typical peers because interpersonal aspects of the job-seeking process (e.g., interviewing) can be challenging for them. For those who do find jobs, remaining employed is often a substantial challenge, once again due to the social, political, communication, and other interpersonal aspects of the workplace. Of the numerous autistics I have met who reported job losses, in virtually every case it was because of these factors, and never attributed to incompetence, negligence, malfeasance, absenteeism, or any of the more common reasons typical workers are dismissed or terminated.

Even my own case as a technology professional illustrates the erroneous nature of these portrayals. Within the autism community, I am considered highly exceptional because, after a successful student career, I worked as an electronics engineer in research and development at major corporate institutions for nearly thirty years, to the point that I am self-conscious about it. When compared to the "yuppie"-era standards of the 1980's and 90's, however, this same career bordered on the laughable because I was never promoted into any level of management (in fact, I wisely chose not to be), and most certainly did not become a technology entrepreneur, let alone a billionaire. Popular conceptions of less-impaired autistics as such are certainly misleading and erroneous, to put it mildly.

## Polarization in the Autism Community

Although there are numerous divisions within the autism community, both among

autistics themselves and those who care for or work with them, by far the most contentious, in my opinion, is that between the less-impaired community (of which I am a member) and the community of more severely challenged autistics. As I mentioned earlier when describing my own experience, there is substantial hostility on the part of those who have severely autistic individuals in their lives, towards those of us who identify on the autism spectrum but do not live with anywhere near that level of challenge. I have always felt that there is no need for such resentment on their part.

First and foremost, the resources needed for less-impaired autistics are small to miniscule when compared with those needed for the more seriously challenged. While the latter group will need intensive (and expensive) services throughout their lives, the former will need far fewer of these by comparison. More-impaired autistics, who often cannot live independently let alone hold a job, will need to live in residential or assisted-living facilities (perhaps for their entire lives), require extensive social services, and be supported by disability or other benefits. All these things constitute significant costs to their families, taxpayers, and society at large. It is understandable that those caring for them are concerned that available resources (which are already far too limited) will be diverted for individuals who are not nearly as challenged. The good news, as far as I am concerned, is that, with adequate early intervention, this will not be necessary.

Given the dramatic improvements in public awareness about the autism spectrum, autistic children are nowadays routinely identified and diagnosed either by profes-

sionals retained by their families or by the schools that they attend. This can lead to early interventions that will in turn help to mitigate future challenges they would otherwise face. The result will (hopefully) be a much higher percentage of less-impaired autistics who are able to live independently, find employment and, as such, contribute to society rather than be a drain on it. Furthermore, these interventions can usually be performed by existing infrastructures (e.g., school psychologists, counselors, teachers, healthcare professionals, etc.) and as such be of minimal cost to families, taxpayers, and society. They will not significantly drain the resources needed for those requiring more intensive services.

## Meeting the Needs of Less-Impaired Autistics

Despite all these concerns, less-impaired autistics constitute most of the greater autism community. This is mainly due to the expanded autism spectrum diagnosis that has been used since 1994, when DSM-IV introduced criteria for less-severe forms of ASD such as Asperger Syndrome and PDD-NOS, all of which have remained even with the changes introduced in DSM-5.0. The result was a dramatic increase in the prevalence of autism from a few cases in every 10,000 people to about 2% most recently. As such, we are too large a population for our needs to just be ignored. Thankfully, increased public awareness, combined with these large numbers, make that a very unlikely possibility at this point.

As much as early interventions for autistic children will likely improve outcomes in

their future, the fact remains that there are still large numbers of undiagnosed autistics. Some of these have managed, despite their challenges, to successfully become independent and pursue jobs and even careers (as was the case with me), but sadly there are many who were not so fortunate. The high prevalence, which almost certainly holds for the older population as much as it does for diagnosed school-age children, means that there are many who "fell through the cracks," and have either been misdiagnosed with another condition (which they may not suffer from at all), or simply been non-diagnosed (as happened with me). This is especially true for older adults past a certain age for whom proper diagnoses, let alone public awareness, did not even exist when they were children. Consequently, there are large numbers of less-impaired autistics in the overall population who have never been identified, let alone diagnosed, and need assistance. In some cases, they may have received it for different (if not correct) reasons and by alternate means. If such individuals were identified as being on the autism spectrum, perhaps the proper interventions could finally be provided for them, which would in turn lead to improved outcomes for many and a reduction in the costs to society.

For any of this to happen, however, we will need as much support from the entire autism community as we can get. The fractured state of our community will not help further this end, and if anything is greatly counterproductive. We can and need to do better.

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



# Research-Based Recommendations for Building Self-Advocacy Competence

By Carly Werner, MS  
and Dianne Zager, PhD  
Unicorn Village Academy

Self-advocacy, an essential ingredient in our quest for satisfaction and fulfillment in life, is a learned skill that involves self-awareness, social and communication strategies, and behavioral competencies. Self-advocating involves communicating a person's needs so that another person is able to understand and assist them in modifying an environment or situation (Shore, 2006). Being able to identify one's needs and desires and work toward the goal of attaining them can present a challenge for everyone. While most people seem to learn these skills through observation and practice, those on the autism spectrum often need direct instruction. For individuals with autism, these skills present a challenge, especially considering often cited difficulties in self-determination, social interaction, and communication. Merely being able to politely and clearly articulate one's needs and wishes can be difficult for people with ASD. In this article, we focus on research-based strategies to enable and empower adolescents with autism to become effective self-advocates.

There are differing opinions as to the use, meaning and purpose of the term *self-advocacy*. Over the past decade, a socio-polit-



Carly Werner, MS

ical shift within the world of autism theory and practice has led to the emergence of an autistic culture and self-advocacy movement, along with the assertion that autism is a valid way of being (Stevenson, 2015). These are worthy principles and theories. However, our interest here is based more broadly on the development of competency in advocating for oneself regardless of the purpose. More specifically, advocacy skills should be generalizable and employable in varied situations and settings, of course with modifications.



Dianne Zager, PhD

In order to help students with autism build requisite skills for self-advocacy, student participation in planning and managing their own programs and goals is critical. Communication skills related to self-advocacy should constitute a major curriculum component, which can be threaded throughout varied coursework and experiences. For example, teaching students to request a break or assistance through the use of visual aids can, over time, help them to replace maladaptive behaviors with proactive communica-

tion skills. Opportunities to build and/or improve self-determination abilities and self-regulation can be incorporated into almost every learning experience. An example of this includes incorporating a sensory diet into a student's daily routine to teach self-regulation tactics so that when agitated, the student independently will use a chosen sensory item to stay calm. These skills are most effectively taught through well-planned and highly structured activities, which can be taught in school-based and community-based settings.

Studies have demonstrated a positive correlation between acquisition of self-advocacy skills and fulfillment in adulthood (see, for example, Waltz, et al., 2015). To reach goals that are attainable and satisfying, students need to develop self-awareness of their ability levels so that they can develop realistic expectations, with emphasis on special strengths and affinities toward particular activities. Intrinsically tied to self-determination, self-advocacy includes several overlapping skills (Hammer, 2016). Students should learn to:

1. have knowledge of needed services and accommodations and be able to request them
2. know who to ask and where to go to get assistance and support

*see Recommendations on page 24*

## Supported from page 18

recalled a recent situation in which she had to make a difficult decision on where she would like to live. She was able to initiate a conversation with her support staff and stated, "[A mentor] helped me look through different possibilities on where to live." She was then able to make an informed decision with support from her staff. Emily's mentor knew that she was able to make the right decision for herself but was there to provide her with the information and education surrounding each choice.

Mentoring others is just as important as having a mentor. For example, Trevor discussed that he has attended provider resource fairs to talk to individuals about the programs that he attends. Trevor also stated the importance of people understanding the resources that are available to them because he didn't know about these resources himself at one point. John talked about owning his own restaurant one day and employing individuals with disabilities, stating, "I want to give people with disabilities a place to work, building a resume, learning how to cook and be proud of something." John also stated that his hope is that people will understand that neurodiverse individuals are more capable of employment and working jobs "typically" associated with people who have a disability (i.e., bagging groceries).

Although the mentorship described by these interviewees primarily involved that from support staff and from peers, research specifically related to peer-to-peer mentorship is becoming more frequent with a goal

of understanding its efficacy with neurodiverse individuals. Literature already shows that peer mentorship for neurodiverse adults can enhance social interactions, communication skills, and increase social supports in postsecondary settings (Duerksen et al., 2021).

### 3. Enhance Your Problem-Solving Skills

- Melanie, Trevor, and John all reported on how problem-solving skills assisted with their self-advocacy skills. At times while self-advocating, it may be necessary to problem solve. Not willing to understand or being close-minded are just a couple of the unfortunate barriers one can run into while self-advocating. Melanie Schwartz reported. Self-advocate Melanie stated, "Barriers that I have encountered are if a person is not open minded or willing to educate themselves. That is a big barrier. Also, if a person is fixated on grouping people in categories. Neurotypical solutions for neurodiverse challenges is not supportive." As Melanie has grown to be an influential self-advocate, she simplified problem solving while advocating in a few simple steps. "First be able to verbalize what you need. Then, how are you going to make an action plan to get what you need, and finally, make a plan to take those steps to get what you need. If something comes up where you find yourself still questioning you can repeat the process."

Prioritizing self-advocacy skills can help neurodiverse individuals find a job, live independently, help with health self-advocacy skills, and learn the ability to request accommodations (Zhang et al., 2019; Zu-

ber & Webber, 2019), all of which are important skills to increase independence and quality of life.

Melanie, Emily, Trevor, and John identified several important skills needed in order to advocate for themselves including: facilitating and helping to run their own meetings (e.g., Individual Education Plans, Individual Support Plans), using essential problem-solving techniques to help overcome challenges they may encounter, finding a mentor to offer solicited advice, and/or mentoring individuals to access any needed resources. It is important to note that these skills have been corroborated by research and have shown positive long-term effects for neurodiverse individuals.

John wants to let the neurodiverse community know that "self-advocacy is helping those who want to be shown that they can have a voice, you can achieve your goals, never give up, have self-respect and self-worth."

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# Using Explicit Instruction to Teach Self-Advocacy

**By Casey Schmalacker**  
Assistant Director  
New Frontiers Executive Function Coaching

Those diagnosed with Autism Spectrum Disorder (ASD) can benefit from alternative pedagogy, and the utilization of different approaches for more abstract skills should be a primary focus. Self-Advocacy is a set of skills that involve executive functions, social communication, and adaptive functions. When supporting individuals diagnosed with ASD, using explicit instruction can assist in the development of self-advocacy. In order to properly support the development of these skills, families and professionals should understand the components of explicit instruction and self-advocacy so that learning can be scaffolded and developed in a meaningful and purposeful way.

## What is Self-Advocacy?

Self-advocacy is defined as the “ability to assertively state wants, needs and rights, determine and pursue needed supports, and conduct your own affairs” (Izzo & Lamb, 2002). While this is a short definition, there is a lot to unpack in terms of the skills needed to self-advocate successfully. There are core skills needed for each of the components of self-advocacy. These include:



**Casey Schmalacker**

**Goal Setting** - The ability to set goals, whether short term, long term, or even life long, is essential for self-advocacy. If there isn't a goal to work towards, you are not able to inform wants or needs. The “wanting” or “needing” of something is in relation to some goal being pursued.

**Metacognition** - Metacognition, or thinking about how you think, helps inform our wants and needs. Without the building up

of metacognitive skills and strategies, an individual's ability to proactively identify problems will be inhibited.

**Self-Monitoring** - Self-monitoring, or the awareness of one's progression towards a goal or outcome, informs self-advocacy because it is the feedback loop that helps identify problems or challenges that may call for outside support.

**Problem-Solving** - Problem solving is a process that involves recognizing a problem, identifying potential solutions, strategy implementation, and evaluating the effectiveness of the strategy. Key to the self-advocacy process is the ability to identify when you are able to solve a problem independently, or when you may need outside assistance that you will need to advocate for.

**Social Communication** - Self-advocacy is inherently a social skill. Learning the social communication skills needed to “state” and pursue needed supports is essential for learning to self-advocate. Autism Spectrum Disorders are characterized by “persistent deficits in social communication and social interaction” (APA, 2013), and focus on these skills can enable the whole process to actually occur.

**Planning and Previewing** - While problem solving skills can address problems

proactively, through planning and previewing strategies, individuals can learn to proactively identify potential problems. This taps into metacognitive skills as well.

**Comprehension of Rights** - Advocacy is not just about what you want and need, but also requires a base knowledge of what you are entitled too. Teaching individuals what their rights are in various contexts (e.g., academia, workplace, or other entitlements) gives the foundation for identifying opportunities for self-advocacy.

**Persistence of Effort** - Any advocate can illuminate on the need for persistent pursuing of what one is owed. Teaching the when and how of persistency of effort enables individuals to better identify where longer-term outcomes may require continual effort.

## What is Explicit Instruction?

Explicit instruction is a method of teaching that limits implicit learning (learning that is interpretive in nature). Whereas implicit learning is *implied* through independent observation, analysis, comprehension, and application, explicit learning occurs when each phase of the learning process is broken down into component pieces and taught through auditory or visual means.

see *Explicit Instruction* on [page 33](#)

# Autism Advocacy: Inclusion, Empowerment, and Human Rights

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

“Autism isn't this strange alien thing, it's just a different way of thinking and experiencing the world. Some of us will find ourselves more or less compatible with modern living than others, we will all have different needs...but autism is not terrifying or awful, nor is it marvellous and fabulous, it just is” (Rhi).

While autism has existed as a diagnosis since 1933, the only thing new about it is its definition as a neurodiversity. Originally regarded as an intellectual impairment, and stigmatized by society, attitudes toward Autism Spectrum Disorder are changing. The disability empowerment movement, among other human/civil rights campaigns, led the way to looking at autism through the eyes of autistic people, but full inclusion is only on the horizon. This article approaches the topic of autism advocacy from the standpoint of the continued exclusion of Autistic people in this era of diversity.

## Early Recognition in America

“Autism may have been recognized in the USA as early as 1846 by a phrenologist conducting a census on people who were then known as ‘idiots.’ One such



**Annie Kent, MA**

man, 59-year-old ‘Billy,’ was considered intellectually incapacitated, although in many respects he demonstrated superior cognition. His verbal abilities were severely limited, but his musical pitch was perfect, and he knew more than 200 tunes. And there were others whose combination of skills, strengths, and deficits puzzled the examiners...If Billy were alive today, his disability, and that of others documented in 1846, would likely be diagnosed as autism” (Donvan and Zucker).

## Autism Is Not a Disability

Autism is typically defined as a developmental disorder of variable severity, including difficulties with social interaction and communication, and restricted or repetitive patterns of thought and behavior. This description characterizes autism as an aberration instead of a range of differences in brain function and behavioral traits.

Diversity is defined as being composed of differing elements or qualities (Diversity), while a disorder is an abnormal state involving dysfunction, distress, and deviance. Current thinking favors viewing autism as a psychological diversity, innate to human beings.

## Human Rights

The Americans with Disabilities Act, 1990, prohibits discrimination against people with disabilities in public accommodations, employment, transportation, government services, and telecommunications. The intent of such legislation was, and is, to ensure that an individual's abilities, and not their impairments, are the focus of decisions affecting their lives (Guide to Disability Rights Laws | ADA.Gov).

In Canada, the laws protecting people with disabilities include [The Canadian Charter of Rights and Freedoms](#) and [The Canadian Human Rights](#). In 2010, Canada

ratified the [UN Convention on the Rights of Persons with Disabilities](#). Yet decades later, while the law dictates the availability of accessible services, advocates are still fighting for adequate funding of home and community-based services for children and adults.

## Barriers to Inclusion

In 2016, the Province of Ontario eliminated government-funded access to behavior therapy for autistic children aged five and over. A public outcry forced the government to reverse its decision, announcing \$200 million in funding over the subsequent four years.

In 2019, Member of Provincial Parliament Amy Fee submitted an article to the Toronto Star criticizing the state of autism services: “Parents [are] overcome with emotion just talking about their daily struggles to find help... Most of the families I spoke with...don't understand why a small number of children get service, while the majority are on wait-lists... There's a wait-list to receive a diagnosis, a wait-list to access provincial funding and another for private providers. All this waiting is adding to their stress and keeping children from accessing much needed therapy.”

There are still over 54,000 children registered in and waiting for core services through [Access OAP \(Ontario Autism Program\)](#).

see *Human Rights* on [page 27](#)



# This is What Autistophobia Looks Like: Why Autistic Advocacy Matters

By Bernard Grant, PhD  
Writer, Editor, and  
Neurodiversity Advocate

**T**he Researcher - A lot of people do not like Autistic people. Which is a common topic in Autistic spaces. But many allistics who want to advocate with us, as allies, stop talking to me when I mention attitudinal barriers to accessibility. Or else they find creative ways to avoid the topic.

Like last summer, when a postdoctoral researcher asked me what I thought was the biggest problem Autistic children faced. I mentioned attitudinal barriers, bigotry.

"What else?" she asked. As if research means rejecting answers you dislike in favor of the answer you'd prefer.

I reminded her that she asked me about *one* problem, the biggest problem, and explained that autistophobia causes the most problems for Autists. I recalled but didn't mention an episode of the [Autism Stories podcast](#) in which Michelle Baughman notes that Autists can't live as their authentic selves without experiencing ostracizing and bullying because we live in an ableist society where the neuromajority instantly dislikes us (Blecher, 2021).

She reads from Emma Wishart's memoir "[But You Said...?!: A Story of Confusion Caused by Growing Up as an Undiagnosed Autistic Person](#)", reflecting my



**Bernard Grant reading short fiction in  
Downtown Seattle as a Jack Straw Fellow in 2015**

own experiences:

"It seems that there's something indefinable about Autistic people that some other people can immediately sense without even talking to us some kind of aura of our differences. Some people are just instantly made uncomfortable by us, whether it's our different ways of expressing ourselves, our "incorrect" body language, or something even more vague, such as a feeling."

Some people are repulsed by us. They make this judgment subconsciously and instantly within milliseconds of meeting us. This happens to me a lot but happens to be most noticeable when I'm upset. As a result, I've learned to never show any emotion in public. Something similar may lead many people to the erroneous assumptions that Autistic people don't have emotions. In truth, many of us have emotions so enormous and tumultuous that we have to keep

them strictly in control at all times."

Avoiding showing emotions in public is a form of masking, passing as nonautistic, like how many queer people have historically passed as straight to avoid stereotyping, discrimination, bullying, exploitation, and death. Codeswitching. Camouflaging. Adaptive morphing.

Masking, while Autists can and do choose to do so consciously, is often an unconscious trauma response. The practice causes Autistic burnout, mental health problems, self-spite, and identity loss, while teaching the allistics around us that their comfort matters most. The reality is that people who only seem to accept you when you pretend you aren't who you are do not accept you.

The Employers

Years ago, while working as a caregiver, I drove one of my clients to his first job. He was Autistic, a nonspeaking adult in his early twenties. Each shift, he stood in a warehouse untangling computer cables. The agency thought this would be a great job for him since he liked computers. Though he was the same age as many college seniors and recent graduates and untangling cables is not working with computers - it's menial labor the company didn't want to pay (much) for.

*see Autistophobia on [page 25](#)*

## Honoring My Limitations as an Autistic Entrepreneur

By Doug Blecher  
Founder and Executive Director  
Autism Personal Coach

**I** am an autistic entrepreneur. That is a sentence I couldn't have uttered that long ago. As far as the entrepreneurship part goes, I've run a business that I founded in 2013 called [Autism Personal Coach](#). With the help of so many others, my company has turned into a business that is stable and growing ten years later. At Autism Personal Coach, we coach autistic adults and teens to get their needs met and desires fulfilled. Now in terms of my autistic identity, that's something that I've more recently learned about. I first self-identified, then through professional assessment learned that I'm autistic in the last year.

I think, at least for me, learning about my autism has prompted the question, "I'm autistic, now can my life improve with this new information?" Ever since I can remember, I have been on a quest for self-growth and learning that I'm autistic has felt like a lightning bolt in terms of the speed I'm learning about myself. It's been a framework to understanding myself. That framework has allowed me to understand that being autistic for me is about understanding and honoring my limitations. When I understand and honor these limitations, I have the opportunity to live a life beyond my greatest expectations.



**Doug Blecher**

As an entrepreneur you have to work hard for your business to survive and thrive, there really isn't any way around that. However, I know in particular as an autistic entrepreneur it's so easy to become burnt out no matter how much you love what you do. All of the hustle and bustle has made me realize that if I don't honor my sensory needs, I'll be of no use to my clients, staff, and to myself.

I used to have so many meetings in the community: networking meetings, meet-

ings with my staff, meetings with clients, meetings with those that were interested in learning more about our coaching services. If someone requested a meeting I would almost always say yes and not think twice about it. Every time I go into the community, the amount of energy it takes me to drive to an appointment and deal with all of the sounds, lights, and visual stimuli just completely drains my energy.

Since truly understanding my sensory needs for the first time I've had to advocate for myself. I have either dramatically cut back on these meetings or found other ways to connect with people that didn't involve me going into the community. I must honor the limitations of my sensory differences.

One of the biggest realizations I have had since learning I am autistic is understanding my communication needs. I have discovered that processing information in spoken conversations and responding to this information is not only difficult, but incredibly draining. Due to processing things at a slower pace than most people, I need more time to formulate a response and that's quite often impossible in these conversations because the demand of our world is to respond and respond quickly when talking with someone else.

Even if there isn't an expectation to respond to someone, it still is exhausting, so much to take in. Then take that a step further in work conversations where I have to process the information and stay focused enough to give coherent responses. These

challenges are why I have had to advocate for myself and make a few changes that have been incredibly helpful.

I have moved to more conversations with my staff that don't require spoken language. An example of this is that I have started using Google Chat in meetings with some of my staff more often. I also am constantly using subtitles during Zoom meetings to conserve energy and stay focused and responsive to the person I am communicating with in these meetings. I must honor the limitations of my communication differences.

Learning about my autism has led me to be a much more successful entrepreneur. When people think of advocating for yourself at work to get the accommodations needed to be successful, I believe they rarely think about the boss or leader of an organization having to do so. However, I'm here to tell you that on a daily basis I have to advocate for my needs at work.

What that looks like for me is explaining my sensory and communication differences to my staff, clients, and all of those people who are interested in our coaching services. I have to not only explain those differences, but also ask for accommodations to allow me to better help them.

Every single time I advocate for my needs it's a scary process. I worry about judgments and acceptance from others due to my low support needs and the lack of

*see Entrepreneur on [page 22](#)*



# Putting My Lived Experience to Good Use

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

**A**s an autism self-advocate, I wear many hats: writer, public speaker, advisor, educator. One of my roles is LEND Program Faculty at Boston Children's Hospital and UMass Boston's Institute for Community Inclusion. The [LEND Program](#) (an acronym for Leadership Education in Neurodevelopmental and related Disabilities) is a graduate level interdisciplinary training and treatment program for future leaders in maternal and child health. The operative word is "interdisciplinary," as every cohort of LEND Fellows consists of graduate students and professionals from a variety of disciplines: law, medicine, psychology, audiology, physical therapy, etc. There are also designated slots for Family Fellows and Self-Advocate Fellows who bring the knowledge gleaned from their lived experience to the classroom. My official title is Self-Advocate Faculty Member, and just like when I was a Self-Advocate Fellow, this designation indicates my area of specialization. In essence, self-advocacy is my field of expertise.

The capstone of the LEND Program is the Disability Policy Seminar in Washington, DC co-sponsored by several [partner organizations](#) including the Autism Soci-



**Gyasi Burks-Abbott, MS, speaking at the Advocates for Autism of Massachusetts 15th Anniversary Celebration Gala in 2019**

ety of America and the ARC of the United States. After a year of weekly lectures, clinic visits, home visits, interviews with state agencies, and volunteer work with community-based organizations, the Fellows take a trip to DC for a three-day conference and an opportunity to speak with legislators. The goal of the Capitol Hill visits is to educate members of congress about disability-related bills and ask them to sign-on as co-sponsors. And the most

powerful tool in the advocacy toolkit is the personal story.

When I speak to lawmakers, I know it's important to come prepared with fact sheets, statistics, and other supplemental material. But I'm also aware that the most compelling information is the impact a particular bill will have on a constituent like me. That's what will capture their imagination. Legislators certainly go to congress with their own priorities, but they are there

to represent us, and they very much want to be re-elected. Caught in a storm of requests, obligations, and demands coming from all sides (while they reign, it pours), a legislator may feel lost at sea. My story can be their compass.

One bill that I look forward to discussing with members of congress is the Supplemental Security Income (SSI) Savings Penalty Elimination Act, a bipartisan piece of legislation [introduced](#) by Ohio Senators Sherrod Brown and Rob Portman, a Democrat and a Republican respectively, that would raise the amount of assets a beneficiary can keep in their bank account from \$2000 to \$10,000 (\$3000 to \$20,000 for married couples). The SSI Savings Penalty Elimination Act is particularly timely as it was introduced in 2022, the 50<sup>th</sup> anniversary of the start of the SSI Program. It's a perfect opportunity to take [stock of the program](#) and revisit rules that haven't been updated in decades. Though I am no longer on SSI, I can still tap into the well of my lived experience and talk about how when I was in my 20s (I'm now 49), I was always caught in the position of not being able to make enough money to be self-supporting but making just enough to potentially jeopardize my benefits. A bill like the SSI Savings Penalty Elimination Act would have been a game-changer.

In my role as a citizen member of the

*see [Lived Experience on page 32](#)*

## Major Flaw from [page 8](#)

autism running a program for autistic students. Only when the article came out did I realize why.

I know of only three other people with autism running a college program in the US for students with autism. One, [Sara Sanders Gardner, who runs Bellevue College's Neurodiversity Navigators Program](#), was also interviewed for the Chronicle piece, and they too were not pleased with it. In response to the Chronicle piece, Sanders Gardner told me, "When given the opportunity to focus on autistic student strengths and address real social barriers and solutions, the author instead relied on the tired trope of 'fixing the broken disabled student' so they could 'fit in.'"

Granted, autistics running autistic programs will only work if, when given the chance, we lucky trailblazers create programs that are markedly better than the programs run by even the most well-meaning neurotypicals (and some are both brilliant, and good friends). But I know that my autism gives me that advantage. I know that my being autistic creates a trust that others don't have. I don't have to be good, or smart - Just the fact that I share the same "juice" inside me means my students won't feel anywhere near the frustrating obligation to explain themselves to the people

that are supposedly in charge of their care. I have an advantage to help me get them to hear solutions to the [executive functioning challenges](#) surrounding homework, to the often crippling [anxiety towards asking a peer for their phone number](#), to seek help from a professor when it feels one is falling behind in their work, or to inquire about their future potential because someone has actually "been there." There is less shame in them coming to me because they suspect I've been in their shoes. And when I tell them they can have a future? I speak from proof, not hope.

[Finally, I trust them.](#) I trust them to make good and solid rules for the weekly group meetings and of many items that reflect their self-interest. And of the hundreds (maybe thousands by now?) of answers I get at the end of the one-on-one meetings I have with roughly half of them, I have never heard an unintelligent response when I ask my finale: "Do you have any burning questions for an older person with autism?"

At a minimum, there have to be dozens of people like me who are qualified and capable to do a better job than the vast majority of neurotypical-run programs. We're not that unique anymore. What deserves the credit are the people that hire us, because clearly they're going out on a limb. Ergo, college administrators are under subliminal pressure to NOT hire us...because

they are still focused on deficits, or risk, when the idea is brought up.

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One painful fact (that even I struggle with) is that, by design, university accommodations departments send the signal that their disabled students are problems to be solved rather than assets to be mined. That's just how, on a semantic level, "accommodations," work, even if we need them. Maybe someday a really great brain will figure that one out and create a truly inclusive campus of high learning. But until then, more program heads that provide students with a sense of shared experience will allow them to feel more understood, heard, and cared for with authority. Please understand that sometimes, even the most wonderful neurotypicals can't create something out of nothing.

The culture will change. We never lose these battles when we act on behalf of either humanism or ethics. It just remains to be seen how soon, or how long, it will take before we see more folks like me running college programs for autistic students.

As a start, it would probably go a long way if we bravely confront colleges (and maybe journalists) for their colonialist, deficit-thinking attitudes - however unconscious. Too many folks who think them-

selves progressive are still looking at disability as a negative. Like us spectrumfolk with social stuff, they need this explained to them. Because when entrusted to their own moral and ethical compasses, they're clearly failing.

*Michael John Carley is the Facilitator of the "Connections" program at New York University for their worldwide autistic students, and he also has a private, Peer Mentoring practice. In the past, he was the Founder of GRASP, a school consultant, and the author of "Asperger's From the Inside-Out" (Penguin/Perigee 2008), "Unemployed on the Autism Spectrum," (Jessica Kingsley Publishers 2016), "The Book of Happy, Positive, and Confident Sex for Adults on the Autism Spectrum...and Beyond!" (Neurodiversity Press 2021, where he recently became the Editor-in-Chief), and dozens of published articles. For more information on Michael John, or to subscribe to his free newsletter, you can go to [www.michaeljohncarley.com](http://www.michaeljohncarley.com).*

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understanding that our society has about that. Almost every single time I don't want to advocate for myself, but I always go

back to why I'm advocating for myself.

Every time I advocate for myself and get what I need, I'm able to help so many other autistic people get what they need. That inspiration is quite often enough to

push me forward to honor my limitations by allowing others to know what my limitations are. I am so excited to know that I am autistic and see where understanding and advocating for my limitations will lead

me in the coming years.

*To learn more about Autism Personal Coach visit <http://autismpersonalcoach.com> or email [doug.blecher@autismpersonalcoach.com](mailto:doug.blecher@autismpersonalcoach.com) with any questions.*



# A Call to Action: The Need for Advocacy in Healthcare Access in Autism

By Tracy Kettering, PhD, BCBA-D,  
Ashley Fuhrman, PhD, BCBA-D,  
and Christopher Perrin, PhD, BCBA-D

Although specific estimates vary substantially, autistic children and adults have a higher prevalence of comorbid medical conditions than those reported in non-autistic individuals. Among the most commonly reported comorbid medical conditions are neurological disorders, including epilepsy, gastrointestinal (GI) conditions, allergies, otitis media, metabolic disorders, and sleep disturbances (Bauman, 2010; Soke, 2018). Individuals with autism also have a higher mortality risk, largely driven by accidental injury and death, but also likely due to underlying health conditions (Al-Beltagi, 2021).

Challenging behaviors, such as self-injurious behavior (SIB), are more likely to occur in individuals with more complex physical health and many studies have reported relationships between SIB and underlying medical conditions (see Charlot et al., 2011; May & Kennedy, 2010; for a review). Some researchers suggest that autistic individuals with SIB should be further evaluated for medical conditions that could be contributing to SIB (Bauman, 2010; Alberts & Kettering, 2022).

Although autistic individuals have increased contact with healthcare providers



Tracy Kettering, PhD, BCBA-D

for both emergency and nonemergencies, they tend to have more unmet healthcare needs and overall poorer quality healthcare that impact the overall quality of life (Nicolaidis et al., 2015; Walsh et al., 2020). Despite knowledge that certain medical conditions occur at a higher rate in autistic individuals, diagnosing medical conditions can be difficult. Communication difficulties may affect a person's ability to self-report symptoms (May & Kennedy, 2010; Nicolaidis et al., 2015; 2016; Walsh et al., 2020). Sensory processing differences may impact an autistic person's ability to



Ashley Fuhrman, PhD, BCBA-D

detect pain or accurately locate discomfort (Bauman, 2011); challenging behavior and compliance with medical procedures and exams may also result in difficulty in having successful exams. There is also some evidence that medical conditions may present differently in autistic individuals, suggesting that healthcare professionals (HCP) may have more difficulty identifying a medical condition or illness, even when a successful exam does occur (Bauman, 2011).

In survey research, autistic adults and the caregivers of autistic children also



Christopher Perrin, PhD, BCBA-D

report that comfortability of autistic individuals during appointments may impact the success of the visit. Sensory concerns with physical space, including lighting or crowded waiting rooms, may also impact the success of a medical appointment (Saqr et al., 2018; Walsh et al., 2020). Both autistic adults and caregivers of autistic children also note a lack of knowledge and training for HCP as barriers to care (Walsh et al., 2020). A lack of flexibility for accommodations, negative attitudes, and

see *Healthcare Access* on page 28

## DEI Program from page 11

Facilitator-led executive and staff DEI training build foundational awareness, leadership competencies, and critical practices needed to create an inclusive culture. The training will help leaders and staff align systems, infrastructure, and expectations.

The next level of training is education and awareness for all employees with a DEI curriculum. The goal is to embed DEI thinking and practices in everything the provider does. Having a shared understanding of DEI goals is crucial to foster a top-down, ground-up inclusive culture. Many providers establish a DEI web page for resources and communications about DEI happenings to reflect the importance of DEI to the organization.

The DEI Director and human resources department are the center points for the DEI strategic plan and execution. Take a deep dive into how HR systems and processes are implemented and identify areas where bias or inequity may exist in the employee lifecycle. Recruitment, onboarding, development, retention, and exit practices should all be viewed from a DEI perspective.

Diversity hiring panels can bring needed DEI perspectives. An effective men-

torship program is a key to increasing connections and a sense of belonging. Reassess benefits, work-life balance, and flexibility. Consider the power of transparency in job design, classification, and compensation.

On the promotion front, candidate selection should be blinded, and skill-based interviews should be added. The retention focus should include promotion rates, talent review results, performance ratings, and, when necessary, switch assignments. The exit process should include attrition rate, the cost to replace, and time to fill.

Implement a DEI recruiting strategy. While autism service providers strive for authentic diversity, often, these workers are hard to find. Here in Massachusetts, my provider, [The New England Center for Children](#), has demographics that match state averages for providers – 77% white and 78% female. This represents both a challenge and an opportunity for DEI.

Create a pipeline for historically underrepresented staff. To counter the dearth of minority workers in autism services, providers may consider instituting or partnering with local colleges on special education or BCBA graduate programs. Such professional development programs create

more diverse and better-trained staff.

Executing your DEI plan is about the interchange between a provider's talent and culture and building a more diverse staff. Company culture is often how things are done. Engagement is how we think about how things are done. DEI lives through the small moments of company culture and interaction just as it does in the big policy moments. Hopefully, training, understanding, and policy together provide a DEI lens through which to see how to improve.

### Measurement and ROI

Like any business initiative, the DEI effort should yield measurable outcomes and a return on investment (ROI) for the provider.

Metrics should reflect challenging (objective) and soft (subjective) outcomes and be measured annually. Examples of hard metrics include expected percentage gains in the representation of identified groups, employee satisfaction scores, employee retention, equitable bonus, salary increases, and promotions. Examples of soft metrics include employee morale and engagement, feedback in manager and employee performance reviews, public

recognition, employer awards, and social media praise.

The results of the DEI program should be communicated at all levels to demonstrate the ROI and value to the provider. Communications include infographics for executive management and community affairs; web content, memos, and newsletters to staff; and company videos for prospective employees.

Establish benchmarks of performance for sustainability and long-term success. The provider should periodically review DEI initiatives, resurvey employees, and update goals.

In conclusion, all provider employees should feel that their work has meaning, that their voice is heard, that they see themselves in other people around them, and that they accept the differences. When people feel valued and appreciated, they function at full capacity and feel part of the mission.

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## Storytelling from page 17

high school senior who finds out she is autistic. The story is heavily inspired by my own journey and I released it to the world last September on a [YouTube channel](#) I

created with the intention to share more stories from and about us.

I truly believe in the power of storytelling as a tool to shape and change perspective. More than that, it can be and has been a tool for advocacy and healing for many folks out

there, including myself. If we don't share our stories, and if we don't have others' stories to relate to, how can we learn about ourselves and the world around us? For me in particular, it has truly been a big part of my self-acceptance and healing process, and I

know that I am making a tiny but mighty impact in other people's lives as well.

*Izabelle's work can be found at [Cloud-ful.Tv](#) and [RedSkirtMedia.com](#). You can follow/contact her on [LinkedIn](#).*



# Autistic Lived Experience: When I Learned that Helen Keller Believed in Eugenics

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

To say that learning about this for the first time felt like a punch in the gut is a gross understatement. Though I heard it from what I consider to be a credible source ([the PBS documentary series The U.S. and the Holocaust](#)), I nonetheless could not bring myself to believe the truth because I didn't want to believe it. Taking this kind of a leap simply would not happen out of the gate, so I sought verification. That's when I confirmed the shocking reality while anxiously searching online.

Helen Keller's [eugenics](#) leanings are expressed in no uncertain terms in [an article she wrote for The New Republic in 1915](#) in which she explicitly admits to supporting infanticide in the case of "a poor, misshapen, paralyzed, unthinking creature." In her own words: "It seems to me that the simplest, wisest thing to do would be to submit cases like that of the malformed idiot baby to a jury of expert physicians...they would act only in cases of true idiocy, where there could be no hope of mental development...decide whether a man is fit to associate with his fellows, whether he is fit to live."



Sam Farmer

Keller's [friendship with Alexander Graham Bell](#), the inventor of the telephone, serves as additional evidence. [Bell was a leading eugenicist](#) and his views on the subject influenced hers. As the honorary president of the [Second International Congress of Eugenics](#), Bell pushed for the sterilization of those he considered a "defective variety of the human race," including the deaf, for whose eradication he advocated. Furthermore, deaf people should be forbidden to intermarry for fear that they

would have deaf children. Ironical, to say the least, in that Keller was both deaf and blind yet befriended him and dedicated her autobiography to him!

Unthinkable, and impossible to reconcile with what I was taught about Helen Keller before all of this surfaced. I learned while in grade school that she became deaf and blind as a result of an illness when she was less than two years old, had an exceptional teacher in [Anne Sullivan](#) from whom she learned how to read and communicate, and is a model of how one can triumph in the face of seemingly insurmountable adversity.

I was not taught, but read years later, that Keller attended and graduated from Radcliffe College, became an [advocate for the disabled, devoted herself to the advancement of civil liberties and women's suffrage, and fought for the rights of workers and African-Americans](#). Her induction into the [National Women's Hall of Fame](#) and her [Presidential Medal of Freedom](#) speak to the significance of her many accomplishments.

The integration of the more popular narrative about Helen Keller with the eugenics narrative is akin to trying to force a square peg through a round hole. These sides of Keller are too contradictory for both to be representative of the same person, and yet, they are. This reality has been particularly difficult for me to process, in part because

this woman has been a hero of mine, not only as one of the great advocates for the vulnerable in society, which is what I aspire to as an autistic self-advocate for the neurodiversity community, but also because I, too, have triumphed in the face of adversity, having worked hard and succeeded at earning happiness and success in spite of the stigma my community is up against. I can't see a satisfactory resolution to my inner struggle, a conflict between two irreconcilable aspects of a woman whom I want to continue to regard as one of my heroes but whom I am not sure I can continue to view in the same light.

It has been said that [Keller eventually "moved away" from eugenics](#). According to the book [The Radical Lives of Helen Keller](#) by Kim E. Nielsen, [she had altered her views by 1938](#), having publicly argued for the life of a blind baby, declaring that the baby still had a chance to have "vision more precious than sight" and that the truly disabled were those who had "eyes of ignorance." I am not convinced that she genuinely and completely left eugenics behind at that point in her life. Considering her words about the Bollinger baby in [The New Republic](#) article and her assertions about the blind baby as documented in [The Radical Lives of Helen Keller](#), it seems as

*see Helen Keller on page 30*

## Recommendations from page 19

1. understand their strengths, talents, and interests
2. create personal goals and follow a path to achieve those goals
3. make choices
4. use appropriate language when advocating for their needs and wants

Educators can provide choice-making opportunities beginning at an early age. Some examples include: "What would you like to do next?" or "Where would you like to sit while working on this task?" Additionally, it is of paramount importance to teach students when and how to say "no". Using their words to avoid or leave unpleasant or dangerous situations is a critical life skill.

One often-noted method of improving student self-advocacy skills is through student involvement in the IEP process (Test & Neale, 2004). Special education law (IDEA 2004) mandates that all students must be included in program planning to the best of their ability. Some helpful ideas for encouraging IEP participation include:

1. beginning inclusion of children in school meetings in the primary grades
2. keeping language simple and conversation clear with visual aids as needed

3. emphasizing students' strengths
4. raising awareness of areas of need
5. addressing the student directly in the meetings.

Students should be prepared to participate in the IEP meeting in a meaningful and effective manner, articulating strengths and weaknesses, as well as program preferences. The purpose of the IEP meeting should be explained clearly, followed by the student's demonstration of understanding of the meeting's goals and their role in the meeting. It can be helpful to role play how the meeting will look, with specific reports and interaction so that students will know what to expect. Strategies can be reviewed and questions that might be asked in the IEP can be rehearsed. Teachers can take advantage of this learning opportunity to show how steps taken in preparing for IEP meetings may be generalized to other situations (Ellis, et al., 1991).

When students with autism can effectively advocate for what they want and, thereby, gain access to preferred activities, expressions of negative emotions and inappropriate behavior tend to decrease (Wood, 2019). The adoption of a positive psychology and strengths-based perspective in self-advocacy instruction (Dykshoorn & Cormier, 2019) refocuses intervention efforts away from reducing deficits and toward enhancing those activities or skills that yield social connections and well-being.

## Conclusion

Self-advocacy is the process of communicating one's needs and wants effectively. For individuals with autism, this skill often needs to be taught directly. Self-advocacy instruction can be incorporated throughout the daily curriculum to build proactive communication skills, social-awareness, self-determination and self-regulation skills. The IEP process, for example, provides several opportunities for developing self-advocacy competency through student preparation and engagement. By preparing students for IEP conferences, educators can cultivate students' self-awareness and empower them to advocate for their needs, leading to increased independence and fulfillment. Student participation in planning and managing their own goals is essential to building self-advocacy competence.

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# “Putting Me in My IEP”

## Encouraging Self-Advocacy in Younger Students

By Amanda Bailey  
Individual and Family Services  
Support Specialist  
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Parents and guardians may not know that students can participate in their Individualized Education Program (IEP) team meetings at any age and not just during post-secondary transition planning in high school. In describing the IEP team, the Individuals with Disabilities Education Act states “the public agency must ensure that the IEP Team for each child with a disability includes ... [w]hen appropriate, the child with a disability” (IDEA, 2004).

Appropriate participation will vary at any given time for an individual student. This provision is an opening, however, to engage younger students in their education in order to foster self-advocacy skills throughout their schooling. Nothing about us without us can and should be established as early as possible if only to avoid the horrifying scenario of a student being invited to the IEP table for the first time at 16 and discovering a team of adults has been talking about them, behind their back, for years.

Student participation in the IEP process does require disability disclosure. Once



Amanda Bailey

so. Children may visit the meeting space ahead of time. Previewing who will be sitting around the table and their roles is important. If the principal is to be present, for instance, the child should know they are there as a support for other grownups and not because the student is in trouble.

For very young students or those who are not yet at ease communicating in a meeting with the team, stopping by to say hello or being there to greet staff as they

arrive is a good start. As students are ready, they may directly share what is working at school and what they would like to be different. They may be able to stay for longer periods to hear progress updates and pose goals. Keeping the focus strengths-based and solution oriented during their participation will set the tone for the rest of the meeting. The team is talking about a whole person, not a series of objectives to be met.

The IEP team can talk about standard scores and percentiles very abstractly - and without parents' concerns being heard. The impacts of relative weaknesses in working memory and processing speed are made real when a child tells their teachers, “I have a hard time keeping all the ideas in my head” and “[The aide] made me mad when she kept telling me to do something over and over in front of my friend and she didn't wait.” Everyone is more inclined to listen and want to help. In this case, my first grader was then able to offer feedback on the team's ideas and suggestions.

Students who are not comfortable at the table can be interviewed separately to gather their input. This can be recorded (with consent) and played for the team or sent ahead of time to help inform the conversation. Their voice in the room, however it is shared, is a powerful tool. Others may want to write or dictate a letter to the team, draft slides to present themselves or be

shared on their behalf, or create an art project to capture their life at school.

### In the IEP

Post-secondary transition planning should incorporate educational preferences, employment, and life in the community (IDEA, 2004). Though obviously subject to change, young students often have a sense of something they are interested in learning about, a possible career, how they would like to spend their spare time, etc. Even without a dedicated space on the IEP form, a child's vision can be incorporated through parent input developed with the child. A vision can encompass the next year, several years out, and/or extend into adulthood. Transition periods should be highlighted (e.g., “In middle school, I want to...”). Practicing self-determination conversations early helps to ease pressure around what may feel very high stakes later in their education.

Accommodations are a good entry point for younger students into their IEPs. If they have sensory sensitivities, for instance, they are the experts on when they may require accommodations to successfully participate and what will work best in those situations. Starting from existing accommodations,

see *My IEP* on [page 31](#)

### Autistophobia from [page 21](#)

Ludmila Praslova writes that discrimination against Autists is a systemic problem, as most workplaces favor neurotypicality (Praslova, 2021). She cites a 2020 report in which 50% of managers surveyed refused to hire neurodivergent professionals even though Autists have proven to be more productive (140%) in the workplace than the neuromajority.

My client was someone who'd hacked into our caregiving agency's network from his living room - miles away from the main office. He also somehow memorized his mother's credit card number, which he used to buy digital products.

He hadn't, however, lived with his parents for two or three years at this time. He rarely saw his parents, as they rarely visited, and he was only allowed to leave his neighborhood for doctor's appointments and short trips to fast-food drive-through windows and occasionally a short walk.

He mostly remained trapped in his home, understimulated, underestimated, and pathologized as someone who supposedly “couldn't understand anything.” Never mind that if he wasn't researching online or taking apart and resembling his computer, he spent his time watching nonfiction TV shows on technology and culinary arts.

This young man was clearly intelligent, focused, and interested in how things worked. Somehow no one around him seemed to see his intelligence. Or his adulthood. Everyone treated him like a five-year-old, the way many of them often treated me, speaking to us in the voices and language they reserve for babies and small children.

### The Psychiatrist

My psychiatrist told me I'm “very stable.” Three months later, he said he wanted to prescribe antipsychotics. When I asked why, he said he wanted to treat my social phobia.

“What social phobia?” I asked.  
“Your autism.”

As if there's some inherent link between an Autistic neurotype and social anxiety. What he was responding to was my lifestyle of rarely leaving my home. Staying home affords me comfort, joy, and the predictability and productivity I need to live and work well. I love working.

I also love my home as I'm less disabled inside my home where I can control my environment. And it makes sense to spend most of my energy here if I spend the bulk of my energy earning money to pay for this home.

There's also a pandemic, multiple viruses sailing in our air.

I also told him I hadn't experienced social phobia in years, that autism is not an illness and needs no treatment, and reminded him that I come to psychiatry to treat my trauma-based depression and anxiety.

Treating autism is like treating homosexuality: bigoted and nonsensical. It makes no sense to treat a person's core self. Treat the problems that harm that core self.

### Our Society

Society talks openly about racism homophobia. So, I often wonder why so many inclusion discussions, especially mainstream discussions, avoid the reality that the reason Autists struggle to find and maintain stability in school, at work, and even at

home and in their communities is due to the negative attitudes people have towards us.

This is bigotry, neurobigotry. Autistophobia. Ableism takes many forms, yet Western society ignores this reality, as Jonathan Mooney observes, writing for *New York Times* (Mooney, 2019):

“We know more than ever about the long-term effects of systemic sexism and racism. But do we fully understand, and condemn, the effects of systemic ableism? Do we even call it that? I don't think so. In 2001, the United States Supreme Court ruled in *Board of Trustees of the University of Alabama v. Garrett* that there was no history of systemic discrimination against people with disabilities.” Disability is largely a result of how people interact with their environments. When we talk about the problems Autists face, much of them are caused by Autistophobia. Bigotry at school and work lead to depression, (social) anxiety, financial insecurity, and suicide. Police find us suspicious (Knapp, 2021). Many allistics find themselves anxious around us, if not repulsed, and try to change our behavior. Which can make us anxious.

The ease with which I understood my Autistic clients as a caregiver a decade ago left a profound impression on me and helped me realize why I'd always felt like an alien. These days, as a life coach, when I find myself involved in a back and forth of relaying messages between allistic parents and their Autistic children, I understand that cross-neurotype communication amounts to cultural differences, not any kind of “deficit.”

People understand this about migrants. But the medicalized deficit model blocks many from seeing Autists as a social group, one united as an ethnicity. No one is in-

dependent. We are all interdependent. So, Autists won't be enabled until the people around us learn the neurodiversity paradigm and change their attitudes towards us. Until society changes its attitudes towards us, I will continue to advocate for inclusion.

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### Cultural Inclusion from page 15

There are many alarming and destructive examples of this dangerous embracing of commodifying attitudes toward other living things perceived as expendable where the status quo is concerned. Apologist speakers among our own marginalized group abound.

Modern, connectively truncated influence has driven an obsession with homogeneity, and increasingly raised a maniacal rejection of inward and outward difference to a hellish art form. The lives (and deaths) of sentient, neuroexpansive beings is foundational to daily life and underscores the danger of using gifts evolutionarily tooled for a better, more compassionate future are pressed into service for the structure we were put here to change.

We are living in a time, however, that leaves no doubt regarding the path of “neurotypical” destruction. There is a resounding call for us to examine our complicity - complicity eased by successful masking, perfected in fear of falling into an even lesser category, perhaps seven to be included among those we join in subjugating. Somewhere, though, in the connective way of being that is our gift, we know that the plight of animals, the bleeding gouge of the clearcut forests, the polluted and evaporating waters, the recent pestilence on the land, all serve as irrefutable examples of the default trajectory of disconnected modern neurotypicality.

Unable to see shades of lived nuance and constitutionally lacking organs of exquisite sensitivity, the truncated, neurotypical gaze rakes over the bodies of neuroexpansive life - whether designated autistic, animal, any other undesirable caste, or nature itself - they assess them only in terms of cost, threats, or utility. They can't or won't see them.

Modern neurotypical humans, in the history of all life on the planet, are the only ones who have ever engaged in the kinds of enslavement, torture, greed, and insatiable appetite for killing we face now. Only the basest hubris would see these developments as progress. From my perspective, modern humanity are the “neurodivergent” ones. I would argue that what is currently called neurodivergence - expansive sensitivities, processing styles that include every part of the environment, a sense of kinship with living things - are actually the natural state of a reality imbued with consciousness.

On some level, autistic people feel this.

To a lesser extent, perhaps, the neurotruncated also feel it. Imagine if I had used the very gift that ensured my resonant identification with gorillas to build a career based on killing them for human consumption. How macabre and shocking people would be if I used my neuroexpansive understanding of the gorillas' ways of being as a means to teach poachers how to more skillfully ensnare them. Think about the revulsion if I were to write monographs about the best ways to fatten gorillas up by cutting off their newborn testicles with no anesthesia, or how to place gorilla mothers in body cages for months before, during, and after the birth of their children so that they couldn't touch them or fight back when their children were stolen. Imagine the public outcry if I detailed how to cut gorilla throats as they hung upside down, fighting with all they had to stay alive. What outrage there would be if I included on my official website that you could put them in groups in gas chambers and it would take 20 seconds for them to lose consciousness as their lungs seared and they clawed the walls.

If I recommended these things, the public would think I had lost my mind, and rightly so, even though these very realities are accepted when they apply to other neuroexpansive minds that are no different in any definable way. But why? Why get upset over the violent imprisonment and destruction of a gorilla, but not a pig? Is it because one is deemed “high functioning” in the power structure's estimation and the other “low functioning?” What about a duck? A cow or chicken? A tree or forest? The living Earth, itself a conscious organism? Because many of us have accepted the profitable dissociation that is foundational to, even defining of, the current, neurotruncated power structure, we have excepted the bodily commodification of other neuroexpansive minds.

In mimicking neurotruncated behavior, we have been able to ignore not just the suffering of farmed animals. We have been complicit in the reality that 70% of all indigenous animals have been wiped out in the last 50 years. And as Covid loosens its grip on the world, it is easy to forget that it, like N1H1, SARS, Ebola, Bird Flu, and Swine Flu, we're all the result of humans demanding to eat the bodies of others with different minds - farmed and free - at a pace and volume that cages and stacked in barns and wet markets become petri dish prisons because a monolithic, neuro-retentive pathology continues un-

checked. The lungs of the living planet are scorched and wheezing in the ashes of the Amazon and the coals of the Congo fires set to clear land for more sentient animals to be raised as saleable bodies, a planet-wide gas chamber. Fires, droughts, dust storms, ocean acidification, floods, hurricanes, tornadoes, and wildfires - all happening at an historically unprecedented intensity.

The horrific list of such abuses and their resultant impact on the planet, normalized by the neurotypical power structure, is endless.

I understand. We have blended to survive. We saw early in our sensitive, connected lives how the current, homogenized power structure treats neuroexpansive minds in commodified bodies (in our case currently, commodified at the hands of “experts,” money and resources won to “cure” us, by those in power who make money studying us, the lucrative warehousing of our bodies, and on and on). Such is the unrelenting pressure on us from the soulless, utilitarian world that you'd think we'd all just be silent diamonds at this point. We find ourselves in an impossible state of suspension between getting along with an unexplainably violent humanity as we, with our exquisitely sensitive abilities, hear the desperate call of a natural world around and within us. It exhausts us, but, like other neuroexpansive animals, it continues to be on us to go the vast extra time and distance to communicate with humanity, leaving little voice for those so like us.

In my experience, though, ignoring all that lives around us does not resonate with our true selves. What does resonate with us, by definition, is an expansive awareness of interconnection - even if it is damaged and dormant. We know, personally and painfully, that the unfortunate truth is that the more different your mind, the more humanity has permission to harm you.

We are, these days, becoming more assertive where our specific voices are concerned. We have pushed back against a terribly unjust power structure and have begun to assert that valuable ways of being exist on a complicated neurological spectrum. Though so far, we have failed to understand that we are ignoring the implications of our own message by ignoring that all sentient minds have innate value, we can pledge now not to be comfortable engaging in the very thing we decry.

I believe we are constitutionally, and rightly, more sensitive to this kind of compartmentalized dissonance and the suffering it compounds. We are becom-

ing proud that we see things holistically, without arbitrary cultural filters. It is a gift that accounts for our ability to make clear connections between disparate phenomena, and to draw complex lines between one concept and another in ways unfathomable to more truncated minds. This state of natural connection should also give us a unique empathy and solidarity with all minds who are trying to kick their way out of boxes and chains, literally and socially.

We can start a new, inclusive movement by leading the way back to the primal awareness, the connective wisdom, we were born with, because we are first and foremost, in all ways that matter, neuroexpansive minds. We know that physical form is empty of meaning. We know personally and painfully that the acknowledgement, the valuing, of our minds is everything.

Intuitively we know we are at a crossroads at which our way of being must be embraced as a roadmap to survival for all living beings and the Earth as a whole, as we represent the response of our dying planet, calling for translators and healers. Our movement, both as a social force and on an individual and evolutionary level, is intimately connected with solving every intersectional existential problem today.

We can speak so uniquely to the catastrophic failings that brought us to this point of crisis. When we on the neuroexpansive spectrum truly embrace our way of being, we can feel secure sitting on the front lines with lions, find meaning in sharing the megaphone with monkeys, in the comforting of cows, and the singing with sows; singing with the trees, living lullabies for the land, humming the Earth itself. It is not only valid, but imperative, that we use our gifts in harmony with a sustainable future for all living things.

\*I didn't have to look far. There are currently more than 2,500 peer reviewed papers concluding animal self-awareness, their ability to think and feel in complex ways, an ability to recall the past and understand the idea of future, to be truly compassionate and altruistic, to feel remorse and experience a moral consciousness.

*Dawn Prince-Hughes, PhD, is a long-time autism advocate and bestselling author. She is currently designing and facilitating the Autistic Ethnography Project at Yale. For more information, please contact [dawnprince1964@gmail.com](mailto:dawnprince1964@gmail.com).*



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### Autism Award from page 1

"I started Autism Spectrum News 15 years ago with a mission of improving the lives of autistic individuals and supporting their families and the professional communities that serve them by providing a trusted source of science-based information, education, advocacy, and a roadmap to quality resources," said David. "Autism Spectrum News actually began as a newspaper-style quarterly publication, and last summer we made the transition to become online-only, allowing us to provide our extensive library of over 1,200 articles and 60 back issues to the community to read and share for free. In fact, a fabulous autistic young adult named Vincent was instrumental in this transition as we worked together to create article posts from PDFs of back issues."

"From the beginning, our esteemed [Editorial Board](#), of which Linda is a founding member, has worked to ensure that 100% of the information published promotes safe and proven-effective interventions and treatment methods that guide our readers

in the right direction. **It has always been my goal to learn from and advocate on behalf of autistic adults who are all too often marginalized in our society as "less than."** I am proud to say that we have published many [articles written by autistic adults](#) over the last 15 years, covering many important topics, some of which include:

- Their personal journey to independence
- Autistic contributions to the workforce
- Promoting self-advocacy
- Personal stories on receiving an autism diagnosis
- Gratitude towards family members and caregivers for supporting them in their younger years
- Life experiences with dating, relationships, and marriage
- Coping with depression and anxiety

- Explaining that language matters because autism is a part of who they are and not an illness that can be cured

And we'll continue to feature important stories and articles like these from autistic adults."

David concluded, "I want to acknowledge the hundreds of authors that have volunteered their time to contribute to the publication. Autism Spectrum News is a collaborative effort and for me it's a labor of love. Thank you again for your recognition of my work. I'm so honored to receive this award and I consider myself lucky to be in a position where I can make such a positive impact in the lives of so many autistic adults."

*If you or someone you know would be interested in submitting an article to Autism Spectrum News, please take a moment to review the [Editorial Calendar and Article Submission Guidelines](#) and email your proposed article topic to David at [dminot@mhnews.org](mailto:dminot@mhnews.org).*



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

### Human Rights from page 20

#### What Do Inclusion and Empowerment Mean for Autistic People?

Inclusion is the practice of providing equal access to opportunities and resources for people who might otherwise be excluded or marginalized. Inclusive organizations reach out to people with disabilities, seeking to understand their differences, and fostering a sense of belonging.

#### Benefits of Inclusion

Inclusion leads to empowerment, which provides:

- Greater opportunities for friendships
- Increased social networks
- Greater respect for others
- Shared learning opportunities
- Reduced isolation
- Higher academic achievement
- Access to a wider range of school/employment resources
- Increased collaboration and participation (CLT Development Team)

While accommodating the needs of autistic people can be legally decreed, as long as autism misconceptions remain, many of us will face significant hardships. According to a UK study led by Simon Baron-Cohen, director of the [Autism Research Centre at the University of Cambridge](#), almost half of autistic people lack sufficient money to meet basic needs, whereas one quarter of neurotypicals struggle with poverty (Salman).

My own experience with finding reliable employment is that I'm either overqualified or underqualified for jobs I apply for. Differences in the way I think, and process information diminish employers' judgments of my suitability for jobs.

Along with Autism and ADHD, I have

mental health issues stemming from lack of early diagnosis, being forced to live in a world that is not designed for me - or for other neurodivergent people. Having to mask or camouflage as "normal" to pass as neurotypical is physically and emotionally draining.

#### Words of Empowerment: Sticks, Stones, and Slurs

It is too easy to speak without thinking, to not genuinely listen and connect with people. When words are used in the wrong way, or uttered with the wrong tone, they can cause great psychological pain. Words hurtful to autistics include risk, disease, disorder, impairment, deficit, pedantic, and obsession.

#### Person-First Language

A significant component of accessibility for people with disabilities is *Identity*. Historically, people have been referred to as their impairment, which destroys human dignity. For example, we've referred to *a schizophrenic, blind man, deaf-mute*, as opposed to putting the person first, i.e., *person with schizophrenia, or a person with visual (or auditory/hearing) impairment*. We still pity the mobility impaired as confined to a wheelchair rather than empowered to be more independent (Kent, 2003).

We now believe that disability doesn't define a person's identity, and people are more than their disability. Many autistics don't feel impaired. We identify with our uniqueness and often prefer "Autistic Person" over "Person with Autism."

#### Why Inclusion and Empowerment are Essential

Diagnosing autism has long been a matter of experts observing a person and attempting to match what they say and do against established criteria. While enormous gains have been made toward autism awareness, it is past time to create a world that autistics understand, embrace, and ultimately can engage with. We are human beings; genetically and neurologically different but thinking and feeling folks with strengths

and challenges outside the "norm." People tend to fear divergence from "normal," and that fear can lead to framing those who are different as lesser beings.

#### Pathways to Empowerment

The theory of neurodivergence is replacing the concept of autism as a disability or disorder. Empowerment of autistic children and adults comes from presuming intelligence and teaching to our differences. Some of us exhibit behaviors deemed "undesirable," even bad. But those behaviors might be the only means some autistics have to convey their needs or distress.

Understanding autism necessitates entering our world, not forcing us to enter yours. Validate self-advocates and seek knowledge about the autistic mind from those with autism. Make the effort to forge bonds with us; seek to understand our world, our reality, and how we find meaning. Get to know us as fellow human beings, worthy of dignity.

"Inclusion is intentional. It is about identifying and removing barriers so that everyone can participate to the best of their ability" ([The Inclusive Class](#)).

*Annie Kent, MA Psychology, spent two decades working in public sector disability, mental health, and addictions advocacy and education. Diagnosed with three closely related categories of neurodiversity, a lack of awareness and understanding led to Autistic burn-out and retirement from the field. She remains an active advocate, engaging remotely with several Autisms, ADHD, and Disability organizations and forums. For more information, email Annie at [anjolie1031@gmail.com](mailto:anjolie1031@gmail.com).*

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## Healthcare Access from page 23

misinterpretation of behaviors are commonly reported (Saqr et al. 2018; Walsh et al., 2020).

### Advocacy Recommendations

Given the barriers to quality healthcare and the increased prevalence of medical comorbidities in autistic individuals, an increase in advocacy in access is critical. Advocacy requires the collaboration of HCPs and behavioral health practitioners (e.g., Board Certified Behavior Analysts) alongside autistic individuals and their caregivers.

### Recommendations for Healthcare Professionals

When it comes to advocacy by HCPs, individual practitioners may be limited in some areas of advocacy efforts by system or payor requirements (e.g., number of billable appointments per day, reimbursable activities). In what follows, we provide general recommendations for advocacy and encourage consideration of how greater system-level modifications may increase the likelihood of sustainable change. Recommendations are aimed at increasing the likelihood of a successful and comprehensive appointment that results in an improved healthcare experience for both the patient and HCP.

**Additional Training** - Surveys of both autistic adults and HCPs have noted that HCPs are often unprepared to see patients with autism (Zerbo et al., 2015). In 2022, medical students in both the US and UK reported that they do not receive enough autism-specific training during medical school and have low confidence in treating autistic individuals (Malik-Soni et al.). With the increased incidence of autism, all HCPs should assume that they will treat autistic individuals. Until universal autism training becomes a consistent part of pre-service training, practitioners should seek out training, including continuing medical education credits focused on increasing competence to treat individuals with autism.

**Awareness and Preparation** - It is important that HCPs have awareness of their autistic patients' preferences and concerns such that they can develop accommodations to improve the healthcare experience for both the patient and themselves. HCPs should consider existing screening and scheduling processes and determine whether or not the process allows the provider to adequately prepare for appointments with autistic patients. For example, HCPs may be better prepared for an appointment if they have an understanding of the patient's communication abilities (e.g., spoken language, alternative and augmentative communication) and sensory needs.

The use of a questionnaire (e.g., the Autism Healthcare Accommodations Tool; AHAT) or phone interview prior to an appointment is one way for HCPs to ensure awareness of preferences and concerns. Nicolaidis et al. (2016) found the use of the AHAT, which guides autistic individuals or their caregivers to create a unique accommodations report for their HCP, resulted in improved healthcare experiences.

**Individual Accommodations** - HCPs might extend appointment length to allow for the additional time or schedule multiple appointments that may often be needed for autistic individuals to become accustomed to the environment and willing to cooperate with necessary components of evaluation. For example, caregivers of autistic individuals who cannot self-report symptoms or who may engage in challenging behavior may prefer to meet with the HCP first to discuss concerns and review medical history prior to bringing their child to an appointment, which can be overwhelming for caregivers (Walsh et al., 2020).

We recommend that HCPs accommodate individual preferences identified prior to the appointment but also consider some standard practices such as incorporating choices during appointments (Rispoli et al. 2013). For example, HCPs may provide the choice of waiting in the car instead of the waiting room, a choice between where to sit in the exam room (e.g., a chair instead of the exam table), or what examination procedure to conduct first. For those that do have the ability to communicate symptoms, HCPs should also be open to communicating in the way that the individual is most comfortable (e.g., reviewing written notes that they bring to the appointment, Nicholadis et al., 2015).

**Diagnostic Considerations** - The HCP should be aware of behavioral needs and the patients' specific topographies of SIB or aggression. It is important to understand that these challenging behaviors should not just be attributed to autism, but could be correlated with underlying medical causes such as pain or discomfort from allergies, headaches, or constipation (Al-Beltagi, 2021; Nicolaidis et al. 2016). For example, HCPs may consider the use of an observation checklist, such as the Risk Assessment Checklist for Self-Injury in Autism-Medical (RACSA-M; Alberts & Kettering, 2022), to gather information on possible behavioral indicators of underlying medical comorbidities.

It is critical for HCPs to understand the possible need for additional diagnostics for patients who cannot self-report symptoms. While some individuals may engage in SIB, others may not have clear observable symptoms or observed symptoms may differ that those typically used for diagnostic purposes. SIB, when it does occur, may not always correlate with the location of the underlying condition. For example, the HCP may need to refer the patient to a specialist (e.g., otolaryngologist, GI) with experience working with autistic individuals to rule out possible medical comorbidities, especially if those individuals have SIB. Overall, HCPs should consider more comprehensive exams and testing, especially for medical conditions that are an increased risk for the population. For example, allergy and food sensitivity screenings as a standard assessment due to the inability to report GI pain (Al-Beltagi, 2021).

### Recommendations for Behavioral Health Practitioners and Caregivers

Autistic individuals often receive therapies (e.g., applied behavior analysis) during which behavioral health practitioners (BHPs) have recurring appointments with the individuals and their caregivers. This ongoing and collaborative relationship that

BHPs often have with autistic individuals and their caregivers positions them to have a significant role in healthcare advocacy for the population.

**Awareness** - To ensure full awareness, BHPs should design data collection systems in a way that may help to identify underlying medical conditions (e.g., challenging behavior). For example, practitioners should separate data collection for different topographies of challenging behavior. That is, instead of using the broad category of tantrum, consider collecting data separately on yelling and SIB or separate head- and body directed SIB. To identify these changes, BHPs may need to modify the way in which they graphically depict the data. For example, they may change from analyzing the data as responses per minute to responses per day and be in a better position to identify possible cyclical patterns of responding possibly related to a medical condition (e.g., menstrual cycle; May & Kennedy, 2010).

It is also important that BHPs familiarize themselves with behaviors and symptoms that may be correlated with underlying medical conditions and design data collection systems to monitor these when necessary. This data collection may go beyond the targets of the behavior interventions. For example, collecting data on stool consistency (e.g., Bristol Stool Chart; Lewis & Heaton, 1997), repetitive eye blinking, or excessive sleepiness (Copeland & Buch, 2019) that may correlate with medical conditions.

BHPs should also be aware of patients' past and current medical conditions and treatments (e.g., psychopharmacological intervention). When graphing relevant behaviors, providers should graphically indicate times when changes to medical treatment (e.g., increase in medication dosage) occurred to allow for visual analysis of the possible impact of the change.

**Collaboration** - Practitioners should conduct frequent and ongoing collaboration with the autistic individual and their caregivers as well as with HCPs. Collaboration is especially important for individuals who cannot self-report symptoms as the collaborations can result in increased advocacy and earlier detection of possible medical comorbidities. We recommend that BHPs consider the following recommendations:

- Hold regular caregiver meetings to ask about concerns and discuss possible behavioral indicators of underlying medical comorbidities (e.g., RACSA-M; Alberts & Kettering, 2022).
- Assist families in setting up data collection systems for home that may help answer medical questions (e.g., sleep logs).
- Develop written reports or summaries of data on behavioral indicators that families can provide to HCPs.
- Encourage families to stay up to date on well checks and request appointments when behavioral indicators may suggest a medical comorbidity.
- Guide families through resources and tools such as the AHAT (Nicolaidis et al., 2016) or RACSA-M (Alberts & Kettering, 2022).

- Request permission to communicate with HCPs to provide data summaries and consider attending appointments when a caregiver requires additional assistance.
- Partner with HCPs on the development of additional research or tools to help continue to raise awareness of medical comorbidities (Alberts & Kettering, 2022; Copeland & Buch, 2019)
- In cases where caregivers have expressed that challenging behavior interferes with autistic individuals successfully accessing healthcare, behavioral health providers should consider targeting medical appointment success as a treatment goal.

### Conclusions

Meeting the healthcare needs of autistic children and adults may require a more comprehensive and individualized approach to care and diagnosis. Through training, awareness, accommodations, and collaboration, practitioners may better advocate to meet the needs of autistic individuals.

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see *Healthcare Access* on page 32



### Fridge Project from page 10

an opportunity to help others while connecting to members of their community. The program currently has fridges at two group homes managed by S:US in Brooklyn and the Bronx and with the intention to expand to additional locations over the coming year.

The community fridge program is also supported by the harvests from [S:US Urban Farms](#) which has grown over 8,000 lbs. of fresh fruits, vegetables and culinary herbs with the help of adults with disabilities along with donations from two food pantries, Let Your Heart Not Be Troubled and 9 Million Reasons in New York City. On a weekly basis, our Direct Support Professional (DSP) staff and volunteers from our day hab programs pick up food from the food pantries and S:US Urban Farms' harvests, bring it back to their program site to unpack it, store it in the refrigerator, freezer or pantry, organize the items and pre-pack it in preparation for their weekly delivery. On the day of delivery, the group of volunteers and staff load the donations into a van, travel to the site, clean and disinfect the community refrigerator along with the shelving next to the refrigerator, and organize all of the items so that the donations can be easily presented and retrieved. As S:US Chief Operating Officer Monica Santos shared, "These fridges will not only benefit surrounding communities but also provides the people in our day programs with a meaningful opportunity to serve at the local level."

DSP Omar mentioned, "It feels great, if overwhelming a bit, to do this work. During the pandemic, I kept seeing lines for soup kitchens wrap around the block, people are hungry and more (people) are becoming homeless. I got into this work to help people and the people in the community. It is a great feeling. We pack the food into the space so it is organized and that there is enough to go around. I want to teach the people that I support to reach out to other people and to help as well. They are so enthusiastic... each person gets their own job done and when it is completed, they want to help in the next area! The drive to help is so strong. They are so engaged in the activity of volunteering, they want to feel that they belong to something, that they can help other people. There is praise in their work as volunteers, but we also praise them because they are helping people who are less fortunate than they are."

As S:US President & CEO Dr. Petit has said, "The Community Fridge Program offers people with I/DD meaningful op-



**People supported by S:US replenish the community fridge weekly with grocery staples like fruits, vegetables, canned goods and more.**

portunities to support and engage with their local community, which is proven to improve the quality of their life and mental health." Jason, a person supported and volunteer from an S:US day program in Queens shared, "...I like helping out with the community even if I don't get any awards for it. I work from my heart with some things like volunteering. It feels good to help other people especially those that are hungry." Staff at Jason's day program report that he and his peers can't wait until Friday, their day to volunteer at the community fridge. After they complete their volunteering they say "Good job!" to each other. Travis, a DSP who supports Jason and his peers, reports, "...people in the community will time their arrival and get in line when we are there re-stocking the pantry so that they will have access to free nutritious food. It is good energy to help people... which I observe in our volunteers. It is always good to do good. It is always good to help because at some point in life, we will all need help." Ronald, a volunteer from the same day program in Queens, added "I like helping out. I like being useful, going to the food pantry and getting the food... it makes me feel good."

Malcom is another DSP from an S:US day program in the Bronx that supports our volunteers with this endeavor. He helps Sy and Rafael in their role as weekly volunteers and reports that they absolutely love volunteering and helping out in the community. People will often line up and wait for the food as they restock the refrigerator. Malcom expressed, "I've seen this done before and I always wanted to do something like this... when

the opportunity arose, I was happy to be part of this program. It gives people access to things that they wouldn't normally have access to and it models helping other people for the participants of the day program. Some people wait while we clean the area and organize the food. Other people will wait until we leave because of their pride, they don't want to be seen taking food. But the fridge is always empty when we return the next week. It's in an impoverished area and it feels so good to help people in this community." Judith, a DSP from an S:US day program in Brooklyn shared, "I like working with the volunteers who attend the day program. They are very hands on and really want to help. I like being there with them. It is a wonderful thing to see and it is a part of my job that I love."

The community fridge program has made stewards of the participants of S:US day habilitation programs, the volunteers and staff at S:US Urban Farms along with our DSP staff and additional staff within the Developmental Disabilities division. Each week they volunteer wholeheartedly – they pack, unpack and re-pack food items, clean, organize food and non-perishable donations so that neighbors and people in the community can have access to nourishment and needed resources. They embody social justice and promote health equity by caring for each other in their tasks as volunteers for those in need. Each participant, whether person supported or staff member, helps each other take responsibility and models respect and generosity for people who are struggling.

There is a word in Pali called paramita which is a Buddhist term often trans-

lated as "perfection." It is described in Buddhist commentaries as noble, character qualities generally associated with enlightened beings. Energy is one of the paramitas and as the writer, yoga teacher and Buddhist scholar Cyndi Lee describes, "...energy can also be interpreted as whole-hearted enthusiasm."<sup>3</sup> When the staff support and witness the people from S:US day programs volunteer for the community fridges and see all of the hard work that they pour into making the food pantries neat and orderly, each person in this endeavor embodies a whole-hearted enthusiasm in their devotion to help their neighbors and the larger community. The S:US staff that work hard each week to model the qualities that S:US strives to cultivate in this city also embody whole-hearted enthusiasm. We are grateful to everyone at S:US who helped create and maintain our community fridges, plus the food pantries Let Your Heart Not Be Troubled and 9 Million Lives, who contribute resources weekly to share with our neighbors in need.

Our community fridges are just one part of S:US' mission to provide advocacy and support to those in need and to our mission to right societal imbalances and provide opportunities for all. Our essential workforce, especially our direct support staff, support people with I/DD to lead rich, engaged lives in the community, help people with a wide range of tasks, including activities of daily living, with the overall goal of encouraging them to lead independent lives and to be integrated into and volunteer within their communities. These supports are part of a larger framework of advocacy that S:US provides every day to people in need. We are grateful to all of our staff for their commitment to embody these qualities and to promote our mission. We will continue to advocate for people living with disabilities, hunger and/or homelessness through our endeavors in order to have a positive impact to those in need within our communities.

*Lori Lerner, LMSW, RYT-200 hr., is Coordinator of Family and Wellness at [Services for the UnderServed \(S:US\)](#).*

#### Footnotes

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2. [www.rwjf.org/en/library/research/2017/05/what-is-health-equity-.html](http://www.rwjf.org/en/library/research/2017/05/what-is-health-equity-.html)
3. "The Dharma of Engaged Practice" workshop training with Cyndi Lee at The Tibet House in NYC, NY on October 22, 2022.

### For the Advocate from page 16

after taking the time to regulate myself. It was so freeing to be able to take care of myself the way I needed to without worry about how others might react. These happenings assisted my ability to advocate in the moment, validated my autistic self, and strengthened the professional relationships

I was trying to build.

Advocating for the advocate would not be necessary if professionals genuinely understood autistic advocates are autistic people. People who think, communicate, and experience the world differently than non-autistic people. They are advocating for themselves as much as they are for the autism community. Everything they advocate for pertains

to them as well. It would work out perfectly, if, when professionals learn something about autistic people from autistic advocates – they practice what they've learned as they work with those autistic advocates. It may require them to move out of their comfort zone, exactly where autistic advocates usually reside, but, only for a while, then perhaps we can all feel proficient enough to work together with-

in new, culturally competent comfort zones.

*Lisa is owner of Lisa Morgan Consulting LLC, where she advocates for crisis supports and suicide prevention for autistic people. Her website, [www.autismcrisisupport.com](http://www.autismcrisisupport.com), contains her books, articles, resources, and research. Lisa can be reached at [lisamorganconsulting@gmail.com](mailto:lisamorganconsulting@gmail.com) or through her website.*



### ***Helen Keller from page 24***

though she set aside her belief in eugenics in some cases but not in others, depending, perhaps, upon the nature of the disabilities under consideration. Furthermore, I haven't been able to find any evidence of an outright, public repudiation of eugenics. The jury is out on this, at least in my mind, and so my inner struggle with Keller persists.

Like other autistics, I feel a need for most things in life to make sense, to be logical and explicable. As is common across our community, I have a penchant for analytical thinking as a means of helping me make sense of the world. When I analyze something about which I am passionate but without arriving at a resolution, I can't help but continue to analyze. Letting go becomes next to impossible. Consequently, overwhelming emotions come over me. Tears have been shed. I have been ruminating on this matter for months, not knowing when I'll stop. Many challenging

questions and thoughts have surfaced:

Prior to recent decades, [treatment options for autism were limited](#), leading to [widespread misdiagnosis and wrongful placement in psychiatric institutions](#). Had I lived back in Helen Keller's day and been institutionalized because of my autism, would she have deemed me unworthy of life or of the right to reproduce? Institutionalization may very well have been sufficient grounds for her to advocate for "sterilization."

- Why was I taught a half-baked version of Helen Keller's story when I was younger? To protect me and others from a reality about Keller which the powers that be saw fit to withhold, perhaps because eugenics didn't fit the narrative they wanted disseminated about her? If so, their attempts at whitewashing didn't work out so well. The full truth has a way of coming out, and when it did, it triggered an internal firestorm.

- Who among those I consider my heroes are truly worthy of this designation?

- How can it be that a woman with a proven track record of disability rights advocacy condones infanticide for a disabled baby for whom she would logically be expected to advocate? Where did she draw the line between entitlement to life and its justified denial?

- Why can't I just tell myself that Keller was a complex, unique, and multi-layered individual who defies explanation and consider the case closed? Not being able to let go may have something to do with my tendency to hyper-focus on tasks or thought processes of importance to me, a common attribute among those of us on the autism spectrum.

Why does all of this matter? Though Helen Keller is long since deceased, her legacy remains popular and those who champion who she was and what she stood

for should know the whole story. More importantly, heroes matter, and society needs them more than we may realize. They inspire us to move forward, to reach for higher ideals, to become better versions of ourselves. Those who I call my heroes matter enough to me such that when something about them is revealed which forces me to question how I view them, intense, prolonged emotional distress ensues. Our heroes should therefore be held to a higher standard. They should be chosen with great care.

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### ***Resolution from page 14***

up more barriers. But, an advocate skilled in negotiation and experienced in conflict resolution can do a great deal to achieve de-escalation. In my experience, most families want there to be de-escalation above all else. So, in deciding whether to retain an advocate at this stage they should understand the approach that will be taken before moving forward.

#### **Facilitation**

If conflicts cannot be de-escalated, the next stage of conflict resolution is the involvement of a neutral. In the education setting, that would usually involve a mediation. A mediator uses a variety of techniques to work with the parties to facilitate a resolution of the conflict. A mediator does not judge the facts, or rule on the law - but they understand both. A skilled mediator also understands that there is stress, emotion, and prior history between the parties that may be influencing decision making. A skilled mediator will also seek to guide the parties toward realistic agreements that

will resolve the conflict, with practical application, and good measures of success. Mediators do not issue rulings; they help parties come to an agreement on their own.

It is not required that the parties participating in mediation have legal representation, nor is mediation mandatory under most circumstances. There are also varying venues or programs used by school districts, depending on location. Some districts rarely use mediation, while others will participate, but not meaningfully, while still others embrace the process. So, before agreeing to mediation, families should understand the process in their particular case. They should inquire whether the school district will have an attorney represent it. They should have a clear understanding as to whether there will be a cost to the parties for the mediation process. Many mediators will hold pre-mediation meetings to discuss these types of logistics.

An advocate or attorney who is skilled in negotiation also can be a tremendous asset in the mediation process. Successful mediations will result in a settlement of the issues. It is also important to understand whether the settlement reached at media-

tion will result in a written agreement that may later be enforced. If so, mediation is a way to avoid the need for expensive litigation. Litigation is also invariably a lengthy process and will never result in immediate solutions in the classroom that will help a student in the short term.

#### **Arbitration**

Arbitration is an alternative way to resolve disputes outside the courtroom. An arbitrator is also a neutral. Unlike a mediator, the arbitrator listens to the evidence from both sides and issues a decision. Arbitration may be binding, which can help the parties avoid litigation, and can be faster than litigation. But it can also be expensive, as both sides will almost always retain attorneys and the arbitrator must also be paid a fee. The arbitration process also does not allow the parties to compromise, collaborate, or work on a solution together. So, the risk of loss is much higher.

#### **Avoiding the Courtroom**

Litigation should be viewed as a last re-

sort when conflicts arise in the educational setting. There are times, however, when litigation simply cannot be avoided. For example, there may be a concern of waiving claims or defenses under the applicable law. Attorneys should be consulted whenever a parent is concerned of such a risk. However, litigation does not foreclose the ability to resolve a dispute through negotiations, mediation, or arbitration. These options should always be considered, as the goal should always be to get students back on the path toward success, quickly, with minimal disruption.

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### ***Disability Employment from page 17***

must actively apply and be accepted into the program to have the continued benefit of health care and waiver supports.

Some states are doing away with strict Medicaid asset and income caps. While there is no clear momentum here, advocates should look to their neighbors to see if it makes more sense for them to stay restricted by tight income and asset rules or to move to a state that can offer them more opportunities. The studies of Medicaid expansion programing are finding that fewer people with chronic conditions are delaying health care overall,<sup>1</sup> which can leave to fewer costs for individual and the state's program. Beyond health care, Medicaid programs for community support and inclusion are very often the reason to keep Medicaid well into a working adult's life. Advocates should become aware of their own state's Medicaid legislation around work with a disability and if there is any

legislation to encourage greater participation in meaningful work.

#### **Saving While Working**

If an individual is eligible to use an ABLE account (has a disability that has a documented start prior to age 26 regardless of when diagnosed), the ABLE to Work Act of the Tax Cuts and Jobs Act of 2017 gave working adults with disabilities the ability to contribute up to an additional \$12,880 to their ABLE savings account if they earned that much. This ABLE to Work contribution is over and above the annual contribution limits of an ABLE account. This Act primarily benefits people who would have contributed the full amount to their ABLE account in a year through gifts or contributions of their own from their SSDI or other income (i.e., rental income, settlement, inheritance up to limit). Saving into an ABLE account allows someone who is on an asset protected program to continue us-

ing money as needed vs requiring a spend down to a low asset cap.

Asset caps are being reviewed by legislators, including the long standing \$2,000 asset cap for SSI. Advocates are pushing for the higher asset cap of \$10,000 to allow more flexibility. While we advocate for the federal laws to change for SSI, that doesn't mean that the Medicaid programs will change at the same time, and the Medicaid programs are the most in need of protection. Individuals with disabilities will always need to be mindful of the interaction between different programs they are using and be aware of the most important programs for them to be as independent as possible. We recommend an ABLE account over a special needs trust of any kind because the person would be able to manage their own account or with assistance.

#### **Benefits of Work (Summary)**

The benefits of work are not just an in-

come, but connection to a broader range of experiences and communities. Work allows people to invest in a purpose. How much someone works is highly dependent on their personal goals and personal needs, but some work may be better than being afraid to work at all.

*Elizabeth Wollen Yoder, CFP®, and her work can be found at [www.planningacrossthespectrum.com](http://www.planningacrossthespectrum.com). You can reach her at or her colleagues at [contact@planningacrossthespectrum.com](mailto:contact@planningacrossthespectrum.com).*

#### **Footnotes**

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### Hiring from page 12

with disabilities, was highlighted during the webinar.

“With the right training, people with disabilities are capable of doing the job,” said Susan Cook, Chief Innovation Officer at RCM of Washington. “Their passion and level of unique self-experience brings an additional level of support that’s invaluable. Recognizing oneself in the staff provides a model for them to set the bar high for themselves.”

### Extensive Training, Internship, and Support

AHRC NYC’s Advance & Earn 20-week training, included an internship with AHRC NYC’s Staten Island Employment & Business Services as a job coach. He supported a person who was responsible for maintaining AHRC NYC’s Staten Island offices. “I noticed that the person I supported was having troubles with tasks. So, I broke it down into smaller steps. That really helped,” DeCarlo recalls.

Gonzalez says DeCarlo came well-trained from Advance & Earn. DeCarlo is responsible for the safety of the people in the program, including their overall health and medication needs when in the community or the program. Recently during Dungeons & Dragons Day, DeCarlo encouraged people to participate. “The key was socializing today,” Gonzalez says. “The pandemic hurt socialization skills. Alex talks to everybody and makes sure that anyone in the room is seen and their voices are heard.”



**Alex DeCarlo participated in AHRC New York City’s Advance & Earn program, where he earned his Direct Support Professional Level 1 Certification. Today, he works as a DSP with AHRC NYC.**

DeCarlo’s work ethic shined during his internship, which began last February, says Crucelina Motta LaSalle, AHRC NYC’s Hudson River Services, Assistant Regional Manager, who supervised Alex during that time. “Alex always welcomed instruction,” she says. “He would tell me, ‘I learned something new today and I will use that moving forward.’ And he always did.”

Upon earning his DSP certification in

June of 2022, DeCarlo experienced mixed emotions. While he was honored to be certified, he also knew the Advance & Earn program was coming to an end. “I was happy sad,” he says.

DeCarlo was attending the College of Staten Island when he met Gonzalez, who was a student mentor with AHRC NYC’s [Melissa Riggio Higher Education Program](#). A partnership among AHRC NYC, [The City University of New York](#) and the [New York State Office for People With Developmental Disabilities](#), the program provides a fully inclusive higher education opportunity for students with I/DD in New York City. When DeCarlo saw Gonzalez at the Advance & Earn graduation last year, he mentioned that he was looking for a DSP job.

The two are comfortable with one another. Gonzalez mentors DeCarlo if he encounters challenging situations on the job. He enjoys collaborating with staff and the people he supports. “All the people at AHRC NYC tend to treat the people we support with the utmost respect,” DeCarlo says.

With his certification, DeCarlo says he still learns something new each day. “To express the sentiment of the great Charles Darwin, evolution is an everyday part of life moving forward,” he adds. “People can change and become better people and better workers.”

As for the future? DeCarlo says he hasn’t figured that out yet and will take it one day at a time. For now, he’s finding the work rewarding.

“Alex has been through it; he knows what life is like with disability,” Epstein

says. “He’s just a natural mentor for other people with disabilities. He understands their lived experience far better than anyone without a disability.”

“I take this whole thing as a win for Alex as a person and our agency,” Gonzalez adds.

### About AHRC New York City

AHRC New York City is the largest organization supporting children and adults with intellectual and developmental disabilities (I/DD) in New York State. Its mission is to advocate for people who are neurodiverse to lead full and equitable lives. Its vision is to help create a socially just world where the power of difference is embraced, valued, and celebrated. AHRC NYC was founded by parents of children with disabilities more than 70 years ago, when supports and services were unavailable to meet their children’s needs. For more information, visit [AHRCNYC.org](#).

### About AHRC NYC’s Advance & Earn

Advance & Earn is a free program that pays New York City youth to start their careers. Offered through Staten Island Workforce Development Center, Advance & Earn helps jumpstart careers through comprehensive GED test preparation, employer-recognized training, credentials and certifications, and paid internships. To explore a career as a Direct Support Professional, contact [Advance@AHRCNYC.org](#).

### My IEP from page 25

we ask our children what they are currently accessing, what they are not using any more, and what else may help.

For students not yet ready to participate in their IEP meetings, there can be a self-advocacy goal encompassing understanding themselves as a learner and being able to share what they need in different settings. Older elementary students may have objectives to partner with providers on developing personal goals. My sixth grader has given input when crafting a self-report form for data collection.

### General Suggestions

- Treat IEP development like a process rather than a one-off conversation. Students can then be included throughout its crafting.

- Practice. Smaller clinical discussions and informal meetings with one or two adults are less daunting than annual meetings with everyone present. Having the student email the staff about issues is another means to practice self-advocacy. When a proposal came up in a larger team meeting that we suspected our fifth grader would not want to have implemented, he wrote (with support) to the special educator to ask for time to work through his concerns. They were able to come up with a different plan together.

- Encourage staff to ask the student directly for input during the year to familiarize the adults with including students in decision making. When a teacher was unsure how our child would respond during a lesson about autism acceptance, we had her ask him if he wanted to be

present or not. While being clear he did not need to self-disclose his autism, choosing to participate in class discussion about autism among his kindergarten peers normalized neurodivergence for all of them from the start.

- Seek other opportunities for children to practice advocating for what they care about. My then-second grader was able to attend a community meeting about a town playground rebuild project to lobby for certain equipment, for instance.

- Meet children where they are. Saying no or sharing that they are not yet comfortable participating is self-advocacy, too.

Ultimately, self-awareness and self-advocacy are critical skills for autistic people throughout their lives as their needs and

the contexts around them change. Practicing from an early age to get their needs met empowers them in the long term to become confident, self-determined adults.

*Amanda Bailey is an Individual & Family Services Support Specialist at AANE and COPAA and is a Massachusetts PTI-trained educational advocate. The neurodivergent parent of two autistic sons, stories about her children are shared with their permission. Amanda can be reached at [amanda.bailey@aane.org](mailto:amanda.bailey@aane.org).*

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### Advocate at School from page 9

#### Stay Calm, Using These Techniques

Parents may be upset if they believe their child is being wronged or their views are being disregarded. But emotions can get in the way of effective advocacy, Wright says. If you believe your position is under attack, pretend that you don’t notice. The person who is criticizing your views probably does that to other people, he says. So, realize that “it’s not personal.” If the meeting is getting heated, and you have to address the person who spoke harshly, do not make eye contact, he says. Instead, stare at a point on the wall six inches away from the person’s ear while you speak. “That technique can help you maintain control. And never embarrass that individual in front of others,” he says.

#### Learn How to Draft a “Letter to a Stranger” to Get What You Want

If you disagree with something the school did, send a letter that tells your story in such a way that a stranger who reads it will want to help you, Wright says. Although you may be addressing that letter to your school, it may eventually end up in the hands of a hearing officer or judge, a stranger who may not know a lot about autism or special education, he explains. “By the time the stranger gets through reading the letter, you want them to feel like, ‘Oh my gosh, this wrong needs to be righted, and I’m going to do what I can to help.’”

To do that, the letter needs to tell your story from beginning to end, and to describe in detail what happened. Avoid opinions or conclusions. Instead of say-

ing your child was angry about his homework, describe what happened: “When I asked my child how much homework he had completed, he stood up, picked up his book and threw it on the floor, smashed his fist into the door, ripped the curtain off the wall, and slammed the front door,” Wright says. Someone reading that description will respond emotionally, he says, “and emotions are what drive decisions.” As he explains, a good letter “will convince the person with the power to provide the services, to *want* to do it.” Be aware of timelines. If you’re planning to put your child in a private special education school and you want the public school system to pay for it, you have to send that letter at least 10 business days before you withdraw your child from public school. See a [companion article](#) for more information on this topic.

### Resources

- Read a Q&A article with Peter Wright on [special education law and advocacy](#) during the COVID-19 pandemic.
- Wright’s website, [Wrightslaw.com](#), and book, *From Emotions to Advocacy*, provide more information on special education law and advocacy.

- Watch a recorded webinar with attorney Gary Mayerson on “[Advocating for your Child during the COVID-19 Pandemic](#).”

*Interested in joining SPARK? Here’s [what you should know](#).*

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Advocacy Advice from page 1

How to Refer a Child  
For a Developmental Evaluation

To refer children before their third birthday, contact the early intervention agency in your state from this [list](#).

If your child is 3 or older, the CDC offers this advice: “Call any local public elementary school (even if your child does not go to school there) and say: ‘I have concerns about my child’s development and I would like to have my child evaluated through the school system for preschool special education services.’” For students in kindergarten to 12<sup>th</sup> grade, parents may contact their child’s school to request an evaluation.

A child who receives services before elementary school probably will enter kindergarten with an Individualized Education Program (IEP) already in place. An IEP says what types of services a child will receive and how often.

School officials and parents may not agree on whether a child has a disability, or on what services he or she should receive. What should parents do to increase their chances of being heard?

Collect Information About Your Child

Teachers and school administrators like data, and McGhee urges parents to collect some. Many parents may not be able to take their children to autism specialists for detailed evaluations, or to hire special

education lawyers or advocates to push for autism services.

But parents can collect information about their child’s development from their child’s pediatrician and healthcare providers, teachers, and tutors, she says. Parents can take doctor reports and teacher comments to a school meeting, and ask for evaluations and services.

“You have to advocate like hell for your child. There is no other way that I can say it: you have to be persistent. You have to ask for [special education] meetings. You have to bring in any data that you have,” she says.

The Impact of Racial Trauma

That advice is good for all parents, regardless of race or ethnicity, but she had some advice specifically for parents of color.

They may have seen statistics showing that Black and Hispanic students do not do as well as white students. And they may have experienced racial trauma themselves, she says.

Racial trauma or race-based stress is a reaction “to dangerous events and real or perceived experiences of racial discrimination,” according to an article in *American Psychologist*.<sup>5</sup> Some doctors believe that racial trauma is related to Post Traumatic Stress Disorder, but it was not included in the American Psychiatric Association Diagnostic Manual.

Because of their experiences, some par-

ents may be fearful that an autism diagnosis will lead to lower expectations at school. “There is this fear that their children will not have a good outcome, plus the system has shown many parents of color that there is some mistreatment and discrimination,” McGhee says. “Some parents are fearful that their child is going to be stigmatized and warehoused.”

She and other psychologists work with parents “to figure out the best pathway forward for their children.”

“Most of the time the best avenue is to have their children identified with autism spectrum disorder if they need services,” she says. “A lot of clinicians are in the practice of emotionally moving the parents through this process.”

Resources

- To learn more about IEPs, watch a SPARK webinar on [Creating Meaningful Individual Education Plans](#).
- Read the SPARK article, “[How to Advocate Successfully at School for Your Child with Autism](#).”
- Find free information, trainings, and resources about special education, advocacy, and disabilities in your state at the [Parent Center Hub](#), the website of the Center for Parent Information and Resources.
- Watch a [SPARK webinar](#), “Do Implicit

Racial Biases Matter in Autism?,” with Brian A. Boyd, Ph.D., director of the Juniper Gardens Children’s Project and associate professor of applied behavioral science at the University of Kansas.

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Healthcare Access from page 28

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Lived Experience from page 22

[Massachusetts Developmental Disabilities Council](#), I relied on my lived experience while advocating for a bill to create higher education opportunities for students with intellectual disabilities, autism, and other developmental disabilities who were unable to meet the state’s high school graduation requirements. And even though I never participated in the type of program being proposed (an opportunity to attend a state college or university without graduating high school), the bill still resonated with me because of the chance I was given to go to community college while finishing up the requirements for my high school diploma. The following is an excerpt from my testimony before the Massachusetts State Legislature:

“Space doesn’t allow me to chronicle the events leading up to my definitive diagnosis of Infantile Autism at 17, but suffice it to say, the process eclipsed most of my last two years of high school. Thanks to the program at Santa Monica College, I was able to finish up the requirements for my high school di-

ploma while taking college courses, and my class schedule reflected my unique portfolio of strengths and weaknesses. Indeed, I was in the Scholar’s Program taking advanced classes in English at the same time as I was being assessed for a learning disability and taking classes in remedial math.... Many factors have contributed to making me the person I am today, but a significant stage in my development was spurred by being exposed to college life even though I hadn’t finished high school.”

There was already a voluntary program with agreements between participating school districts and state colleges and universities to accommodate students whose learning challenges prevented them from completing high school. And my testimony probably held far less weight than the testimony of people who had participated in that program. However, I still felt a sense of accomplishment when the [bill became law](#) mandating and expanding the program statewide.

An area where I hope my advocacy proves effective is in helping alleviate the fear many parents express about what will

happen to their autistic children after they’re gone. My mother had the exact same fear, and when she was diagnosed with lung cancer and given six months to a year to live, she did her best to plan for my future. Unfortunately, the disease progressed too quickly preventing my mom from doing much of anything. However, she had already laid the groundwork for my independence. In a way, she had been preparing me my entire life. Equally important, I wasn’t left to handle everything on my own.

The message I want to spread is most eloquently expressed by a member of the Jan/oansi, a group of hunter-gathers living in the Kalahari Desert. In his book [Nobody’s Normal: How Culture Created the Stigma of Mental Illness](#), medical anthropologist Richard Roy Grinker tells the story of Geshe, a nine-year old boy who cannot speak and would probably be diagnosed with autism. When Dr. Grinker asked Geshe’s father if he worried about what would happen to their son after he and his wife passed away, the father gestured to his neighbors and said, “we’re all not going to die at once.”

Even though I live in a more individualistic culture than the Jan/oansi, I still benefited from a similar community spirit after my mother passed away. The village rallied around me.

Friends and family chipped in to assist with mundane tasks and to show me that there was a life after mom. In fact, this is when I was introduced to the LEND Program and a whole new world of disability advocacy. And in this world, I’ve found a sense of belonging and purpose where I’m always welcomed, and my perspective is valued. My presence is also treated as unremarkable. I’m just part of the furniture, just another seat at the table.

*Gyasi Burks-Abbott, MS, is a writer, public speaker, and autism self-advocate who serves on the boards, committees, and commissions of several autism and disability organizations. He’s contributed to and written articles for anthologies, blogs, and journals. Gyasi’s autobiography, [My Mother’s Apprentice: An Autistic’s Rites of Passage](#), is available on [Amazon](#). He can be reached at [burks1900@yahoo.com](mailto:burks1900@yahoo.com).*



**Explicit Instruction from page 20**

The goal of explicit instruction is to take nothing as a given and teach each portion of skill. Individuals with ASDs benefit from explicit language when learning new tasks (Muller, et al, 2008).

In their 2017 paper, Hughes, Morris, Therrien, and Benson identify 5 main pillars for utilizing explicit instruction. These include:

- Segmenting Complex Skills
- Drawing Attention to Important Features through Cognitive Modeling
- Promoting Successful Engagement through systematically faded supports and prompts
- Providing Opportunities for individuals to respond and receive feedback
- Creating purposeful practice opportunities (Hughes, Morris, Therrien, Benson, 2017)

Each component plays an important role:

**Segmenting Complex Skills** - In order to use explicit instruction, it is essential to break down abstract and complex skills into teachable units. Each of the skills needed for self-advocacy can be broken down into component skills. For example, problem solving, as presented above, has 4 main components. The second portion, identifying solutions, is not a single skill. Segmenting out this complex skill can include portions on:

1. Reflecting on previous strategies
2. Brainstorming skills
3. Assessing available resources

## 4. Feasibility of strategies, and more

For these abstract skills, the segmenting should be focused and designed for the particular individual. The level of segmentation required will also be determined by the individual.

**Drawing Attention to Important Features through Cognitive Modeling** - Cognitive modeling is an approach where an educator (parent or professional) *thinks out loud* to help model the cognitive processes to navigate through a problem or situation. Once the skills are segmented, there are more components: when to use a skill/strategy, how to use a skill/strategy, or how to adapt a skill/strategy to the current situation. Each of these questions should be modeled in order to encourage explicit learning. For example, when teaching self-monitoring, one can use questions like:

- How are we doing in relation to our goal?
- How do we know this?
- Who are the best people that can support us with this?

**Promoting Successful Engagement Through Systematically Faded Supports and Prompts** - While explicit instruction calls for a deep dive into the granular, it is also necessary to slowly fade out supports and prompts. This piece is twofold: first to assess how much learning has occurred, and second to encourage the individual's confidence that they are able to implement the new skill independently. In terms of self-advocacy, most important here is pulling back the prompts to see when and where independent skills and strategies are being implemented. Those teaching these skills may need to step back and allow a little struggle to occur. For example, an in-

dividual may be struggling in a class or a work setting, but educators (parents or professionals) should not immediately interject. Early on in the process they may use prompts like "can you solve independently?" which can lead to an answer of "no I can not, so I need to ask for help." As this prompt becomes successful, supporters of the learner should slowly remove that prompt to identify if the individual begins to ask themselves, "can I solve this independently?" thus kicking the strategy into gear.

**Providing Opportunities for Individuals to Respond and Receive Feedback**

- Through each of the previous pillars of explicit instruction, it is important to encourage the individuals to participate in the process. Their responses can help illuminate where there may be gaps in comprehension or where a skill is not segmented enough. Also, encouraging that feedback is not criticism, but rather that this is a part of the entire explicit instruction process can help balance an individual's confidence, with their need for corrective feedback. With self-advocacy, it is extremely important to tie all of this to an individual's goals so that they clearly understand the 'why' of it all.

**Creating Purposeful Practice Opportunities**

- One of the challenges with teaching abstract skills to learners diagnosed with ASDs is the translation from the abstract to the concrete. The application of skills and strategies, separate from the scaffolded environment, requires many of the core skills identified above. Through the creation of opportunities to practice and utilize these skills, individuals are exposed to the actual environments in which they will need to use the skills. This opens the door for a plethora of questions from the individual to better understand how to use these skills in

context. For self-advocacy, identifying opportunities like IEP meetings, interviews, office hours, and more, can help them see these strategies in action.

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## Greater Hudson Valley, NY, Support Groups

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

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

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

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

For more information, visit the website [www.aane.org](http://www.aane.org) or contact the facilitators:

Bonnie Kaplan - [Parenttalk@gmail.com](mailto:Parenttalk@gmail.com) | Judith Omidvaran - [Judyomid@aol.com](mailto:Judyomid@aol.com)

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

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

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

For more information, contact the facilitators:

Anna L. Nasci, OTR/L, MS, NCC, LMHC | Masako Hashimoto, MS, NCC, LMHC - [OpeningDoorsWestchester@gmail.com](mailto:OpeningDoorsWestchester@gmail.com)



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Autism Spectrum News (ASN), published by the 501(c)(3) nonprofit organization Mental Health News Education, began as a quarterly print publication in 2008. In response to readership feedback, ASN became an online-only publication in 2021. ASN was developed to provide the autism community with a trusted source of evidence-based information and education, the latest in scientific research, clinical treatment best practices, family issues, advocacy, and vital community resources.

ASN raises the level of the autism field by serving as a central repository of quality, practical information written by leading professionals in autism service delivery and research. The publication's content guides individuals, parents, and service providers in the right direction from the very beginning while taking efforts to avoid the promotion of unsafe and unproven interventions and treatment methods.

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

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