

Legal Issues and the Law

Advocating for the Overlooked Needs of Autistic Individuals in the US Criminal Justice System

By Tyler T. Whitney, PsyD
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Emory University School of Medicine
Psychiatry & Law Service

Over the past 7-15 years, many forensic/clinical professionals working in the US criminal justice system recognize the need for significant change within the US criminal justice system for autistic individuals to be treated humanely and with dignity. “Recently, a diverse team of autistics, family members, researchers, criminal justice system professionals, and policy-makers formed the Global Autism and Criminal Justice Consortium” (Lindsay Lawler Shea DrPH, 2021). The Global Autism and Criminal Justice Consortium,¹ under the leadership of the Policy and Analytics Center, AJ Drexel Autism Center, Drexel University, released a policy brief in April 2022. This policy brief came after a world summit regarding the increasing rate with which individuals with autism are encountering the criminal justice system globally was held in October 2020.



The policy brief outlines recommendations for change that span the US criminal justice system as well as criminal justice systems worldwide.

A case review and analysis of my forensic cases to date shows, autistic people are being overlooked and not given the support

they need during initial law enforcement interactions and in the courts by attorneys and judges at the state and federal level. In addition, because of neurological, cognitive, and behavioral differences that exist in autistic individuals, research suggests that “autistic individuals may have more

negative impact on autistic people’s mental health than that of non-autistic people.”²

Social communication differences are regularly observed by clinical/medical professionals familiar with autistic individuals in the criminal justice system. However, in the US criminal justice system, even when an autistic individual verbalizes their autism diagnosis early in the legal process, the arrest, criminal processing, which includes interviewing, often proceed mechanically despite the autistic person not having appropriate support. A 2022 United Kingdom study suggests that attorneys reported that less than half (48%) their ASD clients were treated as “vulnerable adults.”³ Similarly, in the same United Kingdom attorney study,⁴ when the UK cases got to court and there was a seated jury, only (53%) were informed that the defendant was on the autism spectrum and how that may affect their presentation or communication in the courtroom.

This is problematic for the criminal justice system on many levels. First, high functioning autistics (HFA) are often proficient

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

Rethinking Guardianship: Empowering Autistic Individuals and Preserving Rights

By Haley Moss, Esq.
Attorney, Author, and Advocate

Often when I encounter families with young autistic kids, they are admittedly very anxious about their child’s future. *Who will take care of my child when I die? How can I make sure I am an active decision-maker in their lives when they reach adulthood, especially if they are non-speaking or have an intellectual disability?* The fears, and questions, are valid and endless; while I am not a parent, I appreciate the concern.

However, the only answer they’re often presented with outside of financial planning is guardianship. You want control when your kid is still in secondary school but is over 18 but hasn’t aged out or graduated under their individualized education plan (IEP)? Guardianship. You want to control their financial future? Guardianship.

The pressure towards guardianship is everywhere – including estate planning attorneys, financial advisors, K-12 teachers, and a litany of specialists and therapists. Yet it doesn’t reflect the real needs of autistic people who need support, attainable



Haley Moss, Esq.

interdependence, and their rights intact. About 1.5 million adults are under a guardianship or conservatorship today,¹ and the majority of them are young people with intellectual and developmental disabilities.

At its core, guardianship is a tool to help care for a person with a disability. Realistically, guardianship is a legal proceeding in which a judge appoints a third party to make decisions on somebody else’s behalf because that person is deemed incompetent. Typically, that person is a parent or family member, but could also be a professional who is a complete stranger. It is an arrangement that is relatively simple to enter, yet incredibly difficult to end.

What’s intended as a legal last resort when no other options can ensure a person’s wellbeing has essentially become a default that leads to a “civil death”² where one does not have the right to make their own decisions about health care, finances, relationships and marriages, and other major life things. It’s also hard to come back from that “civil death” for those who do not have the endless time, resources, and publicity to come back to life (think: Britney Spears³). At its very worst, guardianship can lead to abusive situations.⁴ While guardians gain an inordinate amount of control over another human being, wards under guardianship lose some of all of their of civil rights, including but not limited to where they live; where they work; what

kind of medical care they get – or whether they will get any medical care; what they eat; who they spend time with; and whether they will get married.⁵

I find myself very fortunate that my parents did not consider guardianship as an option for me. They were in the same shoes of many of the anxious parents I meet today – *Who will take care of my child when I’m no longer here? How can I make sure their future is secure?* But they also believed that perhaps someday, I’d be able to make my own decisions about the job I have, where I would live, if I could vote in local, state, and federal elections. I probably would be fighting an often-unjust system in a personal capacity otherwise, the strings always being controlled by somebody else, the very opposite of the self-determination we so desperately hope people with disabilities have access to.

Here’s the thing; legally, better alternatives to guardianship that are far more compassionate and respect a person’s autonomy already do exist, and depending on where you live, there is greater progress. Options like special needs trusts and

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

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Table of Contents

Legal Issues and the Law

- 1 [Advocating for Autistic Individuals in the US Criminal Justice System](#)
- * 1 [Rethinking Guardianship: Empowering Autistic Individuals](#)
- 6 [ASN Interview with Rita Gardner, President & CEO of Melmark](#)
- 8 [The Power and Potential of the IEP](#)
- 10 [The Importance of Special Needs Trusts for Children with Autism](#)
- 11 [Autism, Online Offending, and Victimization](#)
- 13 [Rights and Challenges for Autistic People with Communication Disabilities](#)
- 13 [Navigating the Legal Rights and Entitlements for Students with Autism](#)
- 14 [Understanding the Role of Pendency in Tuition Reimbursement Cases](#)
- 14 [Understanding and Resolving Conflict in Divorce with Autistic Children](#)
- 15 [Navigating Legal Challenges in Autism Healthcare: Services and Coverage](#)
- * 15 [Autism and the Law: When Trouble Comes Our Way](#)
- 16 [Enhancing Communication and Accessibility for Individuals with Autism](#)
- 17 [The Dangers of Engaging in Child Pornography - Preventing Heatbreak](#)
- 17 [Strategies for Navigating College for Students with Autism](#)
- * 18 [Autistics, Law Enforcement, and Unfortunate and Tragic Encounters](#)
- 19 [The Invisible Struggle: Autism Diagnosis in Immigrant Families](#)
- 19 [A Call for Reform of the Least Restrictive Environment](#)

Supporting Autistic Adults

- 5 [New Curriculum and Pilot Program Affirms Adults Want to be Loved](#)

Employment

- 9 [Creating Inclusive Work Environments for Employees with Disabilities](#)

#ActuallyAutistic Self-Advocates

- * 12 [Kaelynn Partlow, Star of the Hit Netflix Series “Love on the Spectrum”](#)

Supporting Families

- 20 [The Promise of Quality ABA: What Value-Based Care Means for Families](#)
- 21 [“It’s Special” Podcast with Tracey Spencer Walsh, Esq. and Dr. McCarton](#)

Travel

- 34 [Mesa, Arizona: An Inclusive and Accessible Travel Destination](#)

- * *Article written by an Autistic Adult*

Editorial Calendar

Fall 2023 Issue

Supporting Parents, Caregivers, and Family Members

Deadline: August 30, 2023

Winter 2024 Issue

Understanding and Accommodating Varying Sensory Profiles

Deadline: December 6, 2023

Spring 2024 Issue

Navigating the Healthcare System

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New Curriculum and Pilot Program Affirms Adults with Autism Want to be Loved

By Victoria Pettiquoi-Morgan, LICSW-C, LCSW, I Aspire to Be Me, LLC, and Matthew Ratz, MEd, Passion for Learning, Inc.

I Aspire to Be Me, LLC (I AM) is a service provider committed to dispelling the myth that adults with autism do not seek meaningful intimate relationships. It's important for society to recognize this population can and *does* desire intimacy, just like everyone else. Unfortunately, they often lack the resources and training necessary to access these opportunities fully. Frequently, providers avoid any discussion of sex fearing it taboo; however, by avoiding even the mention of the word, we shield those we support from being able to fully explore sex, sexuality, and intimate relationships for themselves. This is why I AM created a pilot program called "Sex in DCity." Funded by a grant from the Organization for Autism Research (OAR), I AM convened a cohort of 15 participants from a range of demographics; six of our participants were individuals diagnosed with autism or I/DD, five participants were direct-support staff who attended steadily, and the remainder were clinicians, facilitators, and behavioral health leaders. We were able to partner with a local DDS service provider



for consistent meeting space, and several of our cohort members were individuals supported by the provider. Collectively, we proceeded through the curriculum together over the course of 20 weeks, moving through lessons and experiences that broadened all of our horizons.

I AM's goal was to develop a comprehensive curriculum designed specifically for adults with autism and intellectual and

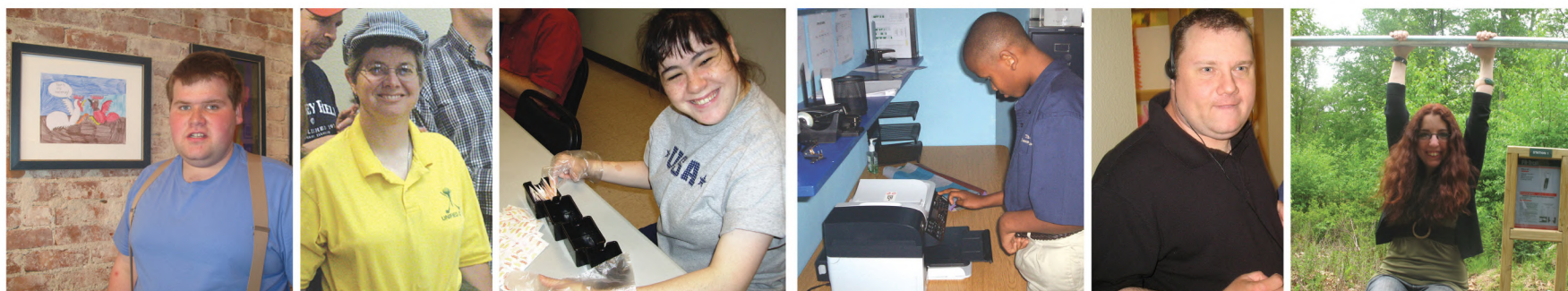
developmental disabilities (I/DD) so they could understand human sexuality better and have more successful sexual encounters when desired. I AM wants those on the autism spectrum to know their sexuality is valid and that there are ways for them to pursue fulfilling relationships. Sex in DCity is designed to fill the gap that exists when it comes to providing sexual education, resources, and support for adults

with autism. I AM's curriculum is tailored specifically for this population and focuses on building relationships as well as understanding the physical aspects of sexuality. It covers topics such as communication, consent, safety, body image, healthy boundaries and more, and we approach each topic in straightforward, developmentally appropriate, and honest ways. All of these are areas that adults with autism need information about so they can be empowered to make informed decisions about their personal lives.

It is vital to understand that everyone has unique needs when it comes to relationships and intimacy. That's why the Sex in DCity program was created with adults with autism in mind. Throughout our workshop, we provided up-to-date training and information so that our participants can have meaningful, safe intimate relationships if they so desire. We are excited to be publishing our curriculum and we hope it will help to make a difference in the lives of those on the autism spectrum. The goal of our Sex in DCity program is for adults with autism to feel empowered and knowledgeable when it comes to their sexuality. Our mission is to create an inclusive environment where all forms of sexual expression are welcomed, respected,

see *New Curriculum* on page 16

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Autism Spectrum News Spotlight on Excellence: An Interview with Rita Gardner, President & CEO of Melmark

By Staff Writer
Autism Spectrum News

David Minot, Executive Director of Mental Health News Education, the non-profit organization that publishes Autism Spectrum News, interviewed Rita Gardner, President and CEO of Melmark, a multi-state, non-profit human service provider with premier private special education schools, professional development, training, and research centers across the country.

David Minot: Hi, my name is David Minot, and I am the Executive Director of Mental Health News Education and the founder and publisher of Autism Spectrum News, where our mission is devoted to improving lives and the delivery of care for young and adult autistic individuals while supporting their families and the professional communities that serve them by providing a trusted source of science-based education, information, advocacy, and resources. Today we're speaking with Rita Gardner, President and CEO of Melmark, a multi-state human service provider with premier private special education schools, professional development, training, and research centers across the country. Melmark is committed to enhancing the lives of individuals within diverse communities with autism, intellectual and developmental disabilities, and their families by providing exceptional, evidence-based, and applied behavior analytic services to every individual every day.

In her role as president and CEO, Rita leads operations and management of Melmark service divisions in New England, Pennsylvania, and the Carolinas. Prior to her appointment as president and CEO in 2015, Ms. Gardner served as executive director of Melmark, New England, based in Andover, Massachusetts, which she co-founded in 1998. She also founded Melmark Carolinas in 2018 and a second New England day school in 2022.

Ms. Gardner and Melmark New England were honored to be named the Women's Edges list of the Top 100 Women-Led Businesses in Massachusetts for five consecutive years from 2018 to 2022. Ms. Gardner was honored with the CBIZ National Women Transforming Business Financial Strength Award, as well as the CBIZ Overall Winner Award in 2022. She is a Board-Certified Behavioral Analyst, a trained public health professional, and has devoted over 40 years of her professional career to the field of community-based services for children and adults with a diagnosis of autism spectrum disorder, intellectual and developmental disabilities, acquired brain injuries, severe challenging behaviors, and medical fragility.

Ms. Gardner is also an accomplished and persistent legislative advocate. Her public policy work has positively impacted services for individuals diagnosed with autism and developmental disabilities across the United States. It is my pleasure to introduce Rita Gardner. Thanks so much for being here with us today.



Watch the Interview with Rita Gardner, President & CEO of Melmark

Rita Gardner: Thanks so much for inviting me, David. I really appreciate it.

David: I also want to mention that Melmark has been partnering with Autism Spectrum News for over 10 years and has contributed almost 40 articles to our library, which is provided online to access without a paywall thanks in part to advertising support from Melmark.

How about we begin by talking about Melmark, New England, which you co-founded in 1998. Melmark, New England is celebrating its 25-year anniversary this May of 2023. What are you most proud of over the past 25 years?

Rita: I think it's really hard, David, to pick just one thing that I'm most proud of. I think at the outset we certainly had a vision of what we wanted to accomplish, and the first part of that was really replicating Melmark's mission at the outset. We are very lucky to have partnered early on with Melmark, Pennsylvania, which really was committed to the mission of serving individuals with developmental disabilities in a way that was close to home and of high quality. And we wanted to apply an evidence-based and applied behavior analytic framework to that. I think we're very proud of the fact that we've met both of those goals and we work every day to continue making sure we hit those goals.

David: Care and compassion is the first core commitment that is identified throughout the Melmark web site and publications. Can you tell us how this and the other five core commitments are woven into your day-to-day operations?

Rita: Yes, those core commitments come from Melmark's original mission and certainly they've been changed a little bit over the years and have been updated. But what we're really looking at is how those core commitments are reflected in everyday practice at the point of care. What make sure that we weave supports into the design of our systems of care that ensure those things can actually have outcomes in the delivery of services. In every meeting that we have, we begin with mission moments, talk about our compassionate care, and someone will talk about how something is tied to a core commitment. An example of

this could be a best outcome for a student who achieved 90% of their goals on an IEP. Another example might be a situation where multiple staff had to work together on an unusual problem that reflected a unified culture. What we're doing at each of those core commitments is creating an opportunity over and over that the resources support the weaving of those core commitments into our daily mission of care.

David: I noticed that Melmark has established a strong organizational commitment for a Diversity, Equity, and Inclusion initiative. Can you explain the thought process that led you to take this particular action?

Rita: I would actually say that plan articulates ongoing actions. So, as you said in describing my background, as I'm trained in public health, which is a bit different than a behavior analyst, special education teacher, or a psychologist. Public health is always about equity, access, inclusion, and how people get services. From the time that we defined and built the original Melmark location in New England, we were looking at who gets access to our service and how do we partner with other stakeholders. Early on in the late 1990s and early 2000s, we were working with the government around legislative bills; for example, in Massachusetts, a Medicaid waiver to access applied behavioral analysis (ABA) services. And within that language, we worked to answer the questions: How do people get access? Is the bill in multiple languages when you apply? Those kinds of things. We've been doing that since the 1990s and we've done it on multiple levels of bills. We evaluate what the demographic makeup of our students is, what schools come to us, and what staff do we serve. And then, with the horrific issue of George Floyd, it wasn't just enough to just do it. We had a very bright staff member who came to me and said, "What did you do?" I met with him for about two hours, and we talked about all the things we did. He then asks, "Why do we, the staff, not know any of that?" And I said, "Sure, we need to articulate that in a DEI plan." That was the impetus. This well-spoken young black man who worked for us said, "Wow, that's why you do all of that." We were able to articulate that into a very comprehensive DEI plan, some of which is reflected

in the interview. I do think it falls naturally with the Founders' vision of how the world should operate.

David: Melmark has influenced the quality of human service delivery in Pennsylvania, Massachusetts and most recently in North Carolina and South Carolina. Going forward, what is your vision to effect change for other states in need?

Rita: We would like to continue to expand our public policy work. Across the country, we've seen the access that insurance-based services have given to individuals for ABA care. But with that, there are some concerns in terms of how those services are run - how profits are being made. I would argue that, as important as ABA insurance services are, the focus should be on the full implementation of the Individuals with Disabilities Education Act (IDEA) under a free and appropriate public education. For many individuals in the United States, that is the only entitlement a child will get. It's an entitlement for inappropriate public education.

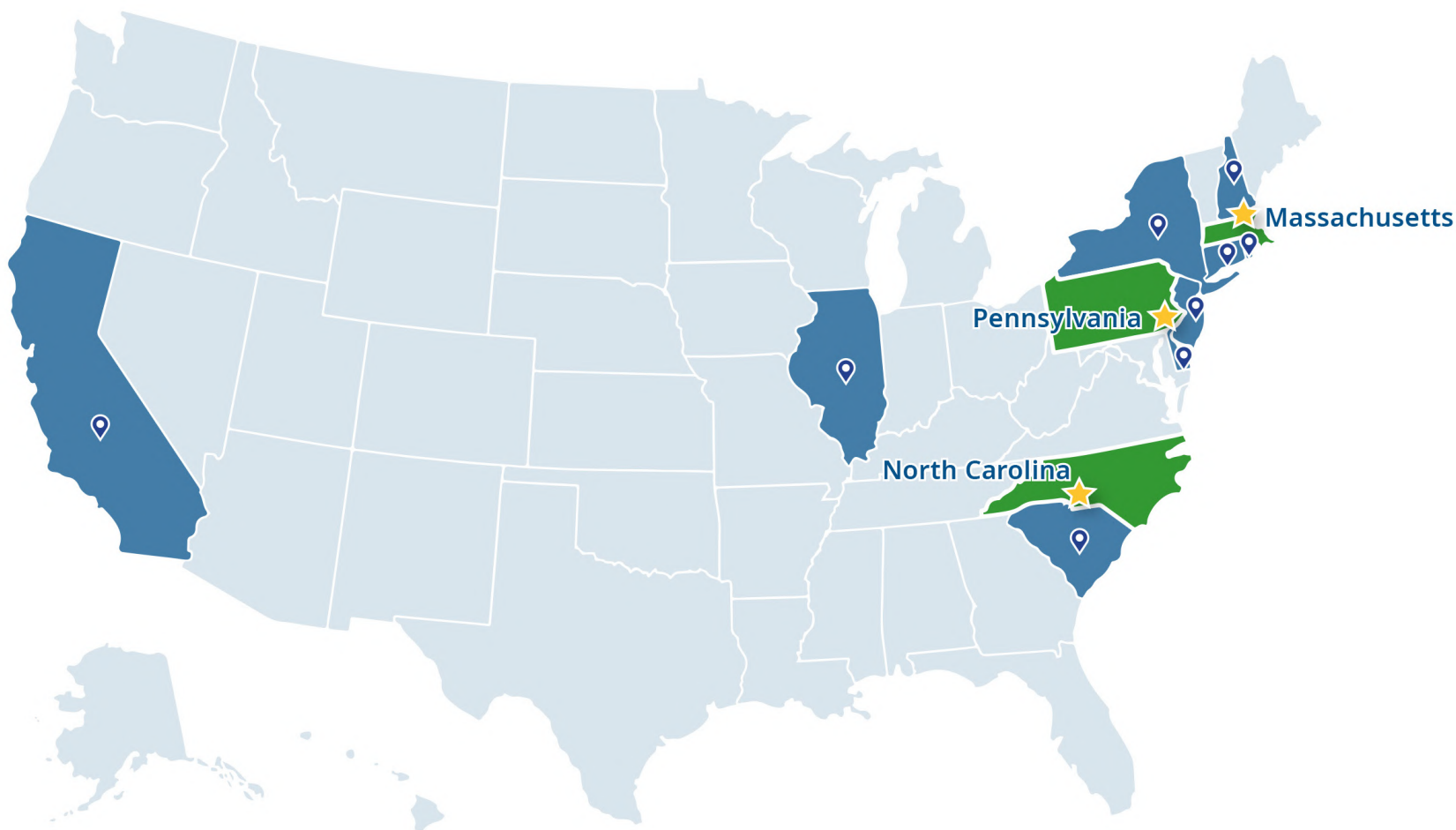
When I look at individuals in special education or with disabilities and particularly the autism population, I'm concerned that the implementation is so inconsistent across the United States. And so, we're trying to work at the federal level with other stakeholders, because right now under faith, it's individual cases that make up case law. We really need the Department of Education at the federal level and the Office of Special Education Programs (OSEP) to do their job in terms of monitoring our states really implementing faith, or else we are writing off a generation of children. And I hate the idea that we see people pulling their kids from school to go to ABA clinics. And then when insurance runs out, we're still right back where we started.

I think ABA insurance is an incredible accomplishment and would be great for after school care and weekends. But I still think primarily special education and interdisciplinary teams should be at the core of every child's services. And it shouldn't be just that you're born in Massachusetts or you're born in a state that provides good special services. It's a federal law and the implementation should be consistent across the United States.

David: Absolutely, I agree. Let's talk about your staff for a moment. I recognize that you have over 1,000 staff across Melmark divisions. With human services currently undergoing a huge staffing crisis, how do you respond to ensure quality delivery of services?

Rita: We have probably closer to 1,200 staff members and we should probably have 1,400. So that tells you where we are.

see Melmark Interview on page 22



- 📍 California
- 📍 Connecticut
- 📍 Delaware
- 📍 Illinois
- 📍 New Hampshire
- 📍 New York
- 📍 New Jersey
- 📍 Rhode Island
- 📍 South Carolina

★ Current Melmark divisions are located in these states.

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Frank L. Bird, Helena Maguire,
Jill M. Harper, Rita M. Gardner,
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James K. Luiselli



Melmark clinicians have published the textbook, *Clinical Systems and Programming in Human Services Organization, EnvisionSMART™: A Melmark Model of Administration and Operation*, now available in hard copy and e-book versions.

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Melmark is a multi-state human service provider with premier special education schools, professional development, training, and research centers. Programs and services include children’s day schools, after-school and residential programs, and adult day and adult residential programs serving hundreds of individuals. Other services include public school consultation and family outreach services, a formal professional development program including onsite graduate education, and the EnvisionSMART™ Expert Speaker Series.

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The Power and Potential of the IEP

By Ellen D'Amato, PhD,
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Georgia Efthimiou, MA, BCBA,
Kristen Daneker, MS, BCBA,
and Howard Savin, PhD,
First Children Services

To address the inequity of limiting special needs children from obtaining an appropriate public education, the Individualized Education Program (IEP) was implemented in 1975 across the United States school systems. The IEP is an educational road map for children with disabilities. It is required by federal law under the Individuals with Disabilities Education Act (IDEA) and is a regularly updated document that outlines specific goals and milestones for students to achieve based on academic need. IEPs are created by a team composed of teachers, parents, school administrators, other school staff such as psychologists, and sometimes students themselves. Schools will evaluate a student to determine whether they qualify for an IEP or 504 plan.

All students receiving special education services have an IEP. Students with IEPs can have autism, intellectual disabilities, orthopedic impairments, brain injuries, deafness, vision impairments, speech or language impairments, or other disabilities that require specialized help with



school. IEPs are developed, revised, and reviewed during annual review meetings in conjunction with a representative from the sending district and parents develop the working plan for delivery of special education services. IEPs include the following components:

- the student's present level of academic achievement and functional performance
- statement of measurable and annual goals
- description of student's progress towards meeting the goals

- participation with non-disabled peers
- accommodations needed to measure academic achievement and functional performance
- projected date for the beginning of services and anticipated frequency, location, and duration, additional considerations (behavioral, communication, visual)
- transition services when appropriate (for students aged 14 and up)

Special Education services outlined in IEPs can include: occupational, speech or behavioral therapy; one-on-one help from a tutor or aide; or instruction from special education teachers who are trained to work with students with unique needs. Students in special education may spend the majority of their day in general education classrooms and can receive their specialized services there, or they may spend their entire day in a special ed classroom, depending on their needs. Most school districts try to include students with disabilities in classes with their nondisabled peers as much as possible, in accordance with federal law.

Potential Areas of Parental Concern or Contention

What if I Disagree with the School's Decision About Service Eligibility?

If a school decides a child is not eligible for an IEP but parents believe their child should have one, or if a parent disagrees with the services a school is providing, there are various options to resolve disagreements. One of the best strategies for parents to keep in mind is that they are very central to the IEP process. Parents should listen carefully to the evaluations and recommendations and understand that their child may need accommodation rather than a modification. An accommodation doesn't change what is being taught meaning their child will still use the curriculum that all students use. A modification changes what is being taught, meaning the curriculum is changed or modified to give the student the best chance of learning it. Parents can also pay for private evaluations if they want another opinion on recommendations for academic support, though

schools aren't required to adopt recommendations that come from private reports.

Out of District Placements

When a Child Study Team (CST) determines that a student's needs cannot be met within the district, they may initiate the out of district process to consider whether an alternative school placement would better meet the student's needs. Being placed out of district is very restrictive, and schools are tasked with ensuring they are providing necessary support in the least restrictive environment (LRE) possible. Often, out of district placements are a last resort option when numerous support attempts within the child's regular district placement have proven insufficient in meeting the child's academic needs. Out of district placements can be challenging to secure from both availability and appropriate fit standpoints.

Where Legal Issues Can Arise

As previously noted, the IEP is legally mandated and carefully described. Despite the best efforts of the IEP team, things outlined in IEP documents are not always followed as written. Districts can find themselves in hot water from a legal perspective if they fail to implement an outlined related service level or to work on an identified goal. Parents are full and equal members of the IEP team and should familiarize themselves with the IEP process, as well as the legal weight an IEP document holds.

Above all, parents should feel empowered to ask questions if something is confusing or doesn't sound right during an IEP meeting or when reviewing an IEP document. Some questions parents should ask about include:

- What specific data will be taken and how will data be taken?
- How will progress on a goal be measured?
- When are changes made if progress isn't happening?
- What does this goal mean?
- How will specifically designed instruction (SDIs) be implemented (as SDIs detail accommodations and modifications that a student requires for learning but are not necessarily tied to a specific, measurable goal)?
- Who is responsible for each goal and SDI?
- Can the related service level be specifically quantified by frequency and duration in a given time period versus vaguely described (e.g., child will receive two, 30-minute speech sessions per 7-day cycle versus child will receive up to 60 minutes of speech per cycle)?
- What is the preferred method for parents to communicate with the school?

see *Power of the IEP* on page 20



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Creating Inclusive Work Environments for Employees with Disabilities

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

Historically, adults with disabilities have faced high levels of discrimination in the workplace environment. The [Americans with Disabilities Act of 1990](#), or ADA, was enacted in an effort to eradicate discrimination against employees with disabilities while also requiring employers to provide reasonable accommodations to employees with disabilities, and impose accessibility requirements on public accommodations.¹ Even with positive intentions of the ADA, a recent statistic from the [U.S. Equal Employment Opportunity Commission](#) reported that in 2019, only 17.9% of disabled American adults were employed and 24,238 disability discrimination claims were resolved by the Commission.² In the article, “The Latest Disability Discrimination In The Workforce Statistics 2023 You Shouldn’t Ignore,” they shared “...61% of disabled employees have experienced discrimination in their workplace.”² These statistics emphasize that employers need to be steadfast at establishing and promoting policies and procedures that cultivate inclusivity, fairness, and equitable workplace environments for employees with disabilities. Carl Richardson, a member of the Disability Employ-



Urban farmer Rauly (in blue shirt) cultivates soil in raised beds at an S:US supportive housing

ment Subcommittee of the Commission on the Status of Persons with Disabilities in Massachusetts, expressed “...according to the last census, almost 20% of people have disabilities... by not hiring people with disabilities, you’re segmenting yourself from 20% of the population [that] have an incredible and talented pool. You’re hurting yourself financially.”³ Therefore, it is important to shed light on organizations and companies that provide opportunities

for employment for people with I/DD and disabilities, foster an inclusive work environment, and adopt holistic approaches in the workplace.

In 2013, S:US’ [Urban Farms](#) team started the program with nine volunteer participants at four garden sites spread across the four boroughs of New York City where S:US has supportive housing programs – in Queens, the Bronx, Brooklyn, and Manhattan. The initial aim was to grow

vegetables, herbs, fruits, and flowers with involvement from buildings residents and volunteers. Michael Hollis, S:US’ Urban Farms Director, takes an innovative and progressive approach to managing our urban farms program, our urban farmers, and our volunteers. Michael shares, “If S:US has access to a backyard of a group home or a building with supportive housing, we should absolutely leverage that outdoor space to grow vegetables, herbs and fruits, and provide a rich resource for our residents and the people who can work in our gardens.” Since 2013, S:US’ Urban Farms has expanded to include 650 participants, mostly volunteers, 23 of whom are people with disabilities who are employed and work in the gardens, located at 73 different sites in New York City. The program has grown to include beekeeping for honey cultivation, construction, and repair of garden beds. Training is provided for all volunteers and people employed along with adherence to safety protocols to ensure the protection of the participants who help in the gardens.

There are two innovative ways in which Michael and his full-time staff foster an inclusive work environment. Michael and his team provide physical and non-physical accommodations for staff and volunteers in the gardens. Physical accommodations include construction that often emphasizes

see Inclusive Work on page 23

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 (I/DD). 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 wellbeing of the people we serve.

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S:US

The Importance of Special Needs Trusts for Children with Autism

By Karen B. Mariscal, Esq.
Mariscal Special Needs Law

When my child with ASD and intellectual disability was young, I had no idea what tomorrow would bring, much less what would happen years from now, when I would no longer be there. My son's behaviors were anxiety-provoking enough without me having to lie awake at night thinking about the future. But I did anyway, and I was not alone.

One thing we can do to ease the anxiety and make sure our children are not only safe and secure but can live the best lives possible after we are gone is to prepare an estate plan that takes our children's special needs into account. Usually this means we need to create a supplemental needs trust, also known as a special needs trust (SNT), for our loved one, in addition to a will. Any share of the parents' estate that is allocated to their special child goes to the SNT, to be spent on the child as the trustee sees fit. Usually, an SNT is not funded until both parents pass away. Until then it is just a piece of paper.

By way of background, a trust is a legal arrangement that allows another person (the trustee) to be in charge of your child's money. A special needs trust is different from a regular trust in that the beneficiary - your child - cannot have any control over



the trust assets. How the trust money is spent is completely up to the trustee. Special needs trusts are "discretionary trusts," in that distributions are at the complete discretion of the trustee.

An SNT allows your child to have money when you are gone, and still have the public benefits that they may need. Money in the trust is not counted as their money. Some benefits such as Supplemental Security Income (SSI) require the child to not have more than \$2,000 in their own name.

Money in an SNT is not considered to be owned by the child, so with an SNT, the child has both the benefits that they need and extra money to live. Without an SNT, whatever you leave your child is likely to be eaten up by costs that otherwise would have been paid for by the state.

The SNT also ensures that the money will be handled by someone who is capable of managing the money and making sure it is spent the right way.

Appointing a trustee to manage your

child's money is one of the most important things you can do, but choosing the trustee for a child's special needs trust can be a difficult decision. The trustee will need to take over for you in terms of managing the child's finances, so if you are appointing a family member, it is best if the person not only loves the child, but also is good with money. An added complication is that you will want to name someone who might actually be around when the time comes, i.e., when both the child's parents have passed away and the trustee takes over. This can be accomplished by naming a contemporary, plus an alternate in the next generation, such as a niece or nephew.

The trustee is in charge of deciding how much money in the trust should be distributed to the child, and how often. In addition, the trustee's duties include overseeing investments, paying bills, keeping accounts, and preparing tax returns. Because the trust is meant to cover your child's lifetime, the job of trustee of a special needs trust could last for decades.

The main considerations when selecting a trustee are picking someone who is trustworthy, will stay involved, will seek help as needed, and can make sometimes difficult decisions. The trustee has a duty to manage the trust in the beneficiary's best interest. The trustee does not need legal or financial expertise but must have good judgment.

see *Special Needs Trusts* on [page 27](#)



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Autism, Online Offending, and Victimization

By Mary R. Cohen, PhD
and Reginald Candio, PsyD
Autism Specialists / Forensic Evaluation

Individuals on the autism spectrum are particularly vulnerable to committing online offenses, in many instances unwittingly. They are also victimized by online predators, financial scams, and extremist groups. Consequently, they are increasingly interacting with the criminal justice system as either offenders or victims. It is estimated that 25% of the autistic population aged 16 and older have had contact with the criminal justice system as either a victim or offender (Miller et al., 2021). Some autistic characteristics create a greater risk for online offending or of being victimized online. These include social isolation, trauma, lack of social awareness, difficulties discerning the intentions of others, insufficient sexuality education and support, immersion in fantasy, rigid thinking, and the need for community. Online safety awareness and education regarding legal consequences are critically needed to reverse these current trends.

Autism and Online Behavior

The online world is a unique space where conventional boundaries are often blurred and misunderstood. Online disinhibition is the tendency for people to feel less re-



strained in cyberspace and behave in a way they would never do in the real world (Suler, 2004). The ability to hide one's identity online causes a dissociation from online behavior. In essence, the online self is compartmentalized. This psychological effect is often observed in autistic individuals due to the large amounts of time they spend online. The propensity to engage in certain negative behaviors online without inhibition has produced a toxic and sometimes dangerous online environment for

many. This can result in harassing behaviors and sometimes illegal activities, such as making threats. Autistic individuals are operating in this environment without the social understanding and societal guardrails necessary for their personal safety. The uninhibited world of the internet and social media can create a perfect storm for those on the autism spectrum, which may result in either criminal offenses or victimization.

Many autistic individuals go online to seek the social acceptance that they cannot

find in their daily in-person interactions. The online world eliminates the need for real-time interactions and allows the person to respond in their own timeframe. It also does not demand the simultaneous processing of verbal and nonverbal social cues, which is so difficult for those on the spectrum. They can communicate in chat rooms and on social media easily without exposing their social awkwardness. As a result, the online world becomes almost their exclusive source of social contact. The online world is a fast, fluid situation; specific and unpredictable. It requires the ability to think flexibly and relies heavily on social pragmatic language. These are the very issues that individuals with autism find extremely challenging. We see that online situations are often misinterpreted by neurotypicals. Accordingly, this type of social contact is even more taxing for someone on the autism spectrum. They are extremely vulnerable to bullying, cyber scams, inappropriate sexual behavior, and even radicalization and cult recruitment.

Online Sexual Behavior

Autistic persons are sexually curious and may spend many hours viewing pornography to understand their own sexuality (Hénault, 2014). Many are drawn to the computer to explore their sexuality and have

see *Online Offending on page 27*



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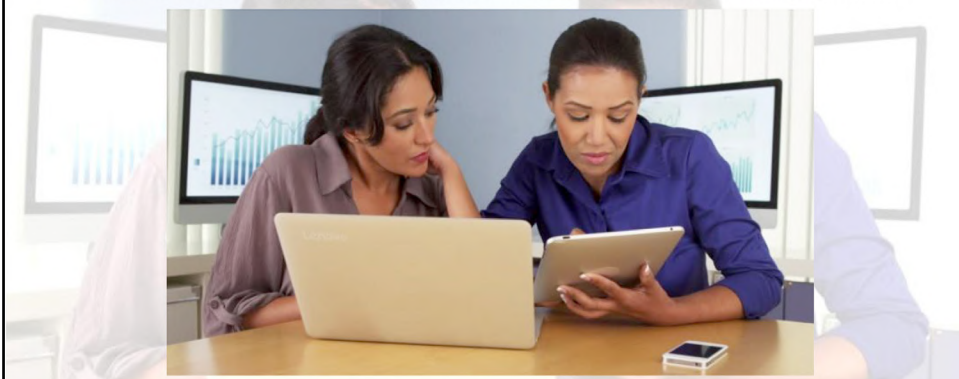
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An Autistic Woman's Success Story: Kaelynn Partlow, Therapist, Dog Trainer, and Star of the Hit Netflix Series "Love on the Spectrum"

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

Perhaps because of the stigma we are up against and how misunderstood we know we are, many in the autism spectrum community feel as though the entertainment industry has historically mis- and under-represented us. The autistic character of Raymond Babbitt from the popular Oscar-winning movie [Rain Man](#) has been acknowledged by many non-autistic individuals as being a primary source of their knowledge of autism, and yet, many autistics including me insist that he does not represent us. Many of the fans of the TV Series *The Big Bang Theory* and *Young Sheldon* have speculated whether [Sheldon Cooper](#) may be autistic, and autistic people I have heard from feel that he is, though he was never revealed as such on the show because the creators of the character willed it that way. As for Dr. Shawn Murphy, the autistic main character on the TV series *The Good Doctor*, [a panel of autistic adults assembled by Autism Ontario who reviewed the show](#) commented that actor Freddie Highmore's portrayal of Dr. Murphy came across as being a composite of his previous neurodivergent and neurotypical portray-



Kaelynn Partlow

als and that "we need people on the spectrum to play people on the spectrum."

Raymond Babbitt, Sheldon Cooper, and Dr. Shawn Murphy have arguably been the most prominent figures in the conversation around autistic screen characters in recent years. All three are fictional, all are played by non-autistic actors, and all three are men. Finally, the tide is beginning to turn.

Meet Kaelynn Partlow, star of the hit

Netflix docuseries [Love on the Spectrum](#), an autistic woman who plays the part of her genuine, true self. I had the privilege of meeting and interviewing Partlow and very quickly came to understand why the producers of *Love on the Spectrum* wanted her on the show. Her unique personality attributes, vulnerabilities, openness, and intelligence shine through on this beautiful, heart-warming reality series about autistic men and women who dive into the unpredictable world of dating, love, and romance, calling out society's misconceptions about them and how they want to live. And the show is resonating: three seasons to date, an 8.2 out of 10 IMDb rating, and 3 primetime Emmy awards including Outstanding Unstructured Reality Program.

No fictional characters, only real people. No neurotypical actors pretending to be neurodivergent. Autistic individuals being who they are while pushing the envelope with respect to how non-autistic individuals would likely expect them to conduct themselves. It's a truly wonderful thing to behold, and Partlow helps make it happen.

The stigma hanging over autistic and neurodivergent individuals in general stems from societal expectations around socialization, communication, and behavior which were not established with us in mind. As such, revealing one's authentic

autistic self is, in my view, an act of uncommon courage and a success story in itself. Partlow (and her *Love on the Spectrum* co-stars) has elevated the virtue of unmasking autism to a whole new level, living her truth as publicly as one possibly could. In doing so, she is both raising awareness and helping to cultivate greater acceptance of autism on a global scale. She uses her speaking engagements and social media platform to share who she is, educate the public about autism and neurodiversity, and discuss what it can be like to live with autism from the point of view of somebody who actually walks in these shoes. [Her TikTok page](#) has garnered more than 10 million likes and 380,000 followers as of this writing.

Kaelynn Partlow's success story does not end here. As a high school student at a non-profit autism services organization in South Carolina called the [Project Hope Foundation](#), she discovered her passion for working with kids, and as a therapist there, helps autistic kids develop self-acceptance, communication, and life skills. Project Hope positions her for success by matching her with kids who exhibit skills and challenges that are similar to her own. When that kind of synergy exists between an autistic therapist and her autistic clientele,

see Love on the Spectrum on page 26



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Rights and Challenges for Autistic People with Communication Disabilities in the Legal System

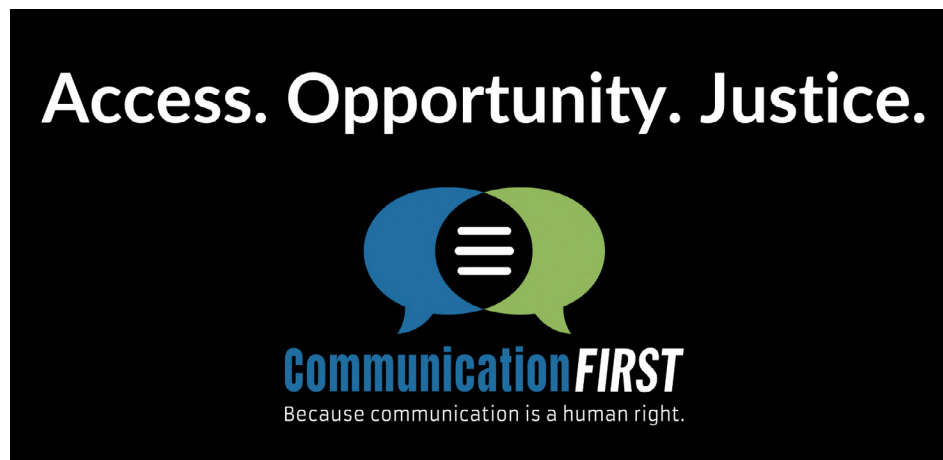
By CommunicationFIRST Staff

Police should be the last resort.... I shouldn't have to call the police if my son is having a meltdown. When I get up in the morning, I say, "Thank God he's not dead," and "Thank God I'm not dead."

- Kerima Çevik, activist and parent of a nonspeaking autistic son (Sokol, 2021)

Autistic people and their loved ones, like Kerima Çevik, often worry whether today, tomorrow, or the next will see unwanted contact with the legal system. Being autistic in public can be criminalized. Although our legal system is designed to develop, enforce, and secure civil rights for all people, too often that very system discriminates against, dismisses, or otherwise mistreats nonspeaking autistic people and others with communication disabilities.

One example is when law enforcement officers perceive autistic people to be "noncompliant" or under the influence of drugs or alcohol (Brown et al., 2022; CommunicationFIRST, 2023). Another is when autistic parents and other parents with disabilities are subjected to evaluations by mental health professionals and



denied custody of their children because of their disability (*Chapter 7: The Family Law System: Custody and Visitation*, 2015). Another is when judges terminate the rights of autistic adults by subjecting them to guardianship without considering less restrictive alternatives like supported decision making (Swadley, 2022; National Resource Center, 2023).

Nonspeaking autistic people, as well as autistic people who use both augmentative and alternative communication (AAC) and speech, experience additional hardships. Our speech-centric society is not yet accustomed to the various types of AAC that may be used by people with speech-related

disabilities. Alternative forms of communication might be viewed as suspicious or eccentric and impact the outcomes of interactions with people who use speech to communicate (Calton & Hall, 2021). For instance, an autistic person's efforts to communicate with a police officer who is unfamiliar with AAC or other types of autistic communication might lead to additional misunderstanding and result in the autistic person experiencing, at a minimum, frustration, anxiety, and sensory difficulties (Holloway et al., 2020). But autistic people's experiences with legal system professionals do not have to be this negative. By examining why these misunder-

standings occur, by equipping legal system professionals with greater familiarity with the various ways people with speech disabilities communicate, and by highlighting the communication rights nonspeaking autistic people have under United States law, we can help reduce the barriers to justice that are commonplace today.

Most of the societal barriers disabled people experience, including within our legal system, are rooted in ableism -discrimination and prejudice against people with disabilities (Friedman & Owen, 2017; Rajkumar, 2022). People with significant speech disabilities are routinely abused, segregated, and denied access to AAC (CommunicationFIRST et al., 2021; Patten, 2022; Zimmerman, 2022; Kapp, 2023). Beginning in preschool, nonspeaking autistic people are almost always placed in segregated classrooms away from nondisabled students, and sometimes are not even taught to read or write (Open Society Foundations, 2018). Thus begins what becomes for many a lifelong denial of human rights (CommunicationFIRST et al., 2021). Many nondisabled people assume that people with significant speech disabilities, in particular, are incapable of making decisions and therefore treat people with speech disabilities like young

see *Rights and Challenges on page 28*

Navigating the Legal Rights and Entitlements for Your Student with Autism

By Maria C. McGinley, MST, JD
Founder and Partner
McGinley Law Group, LLP

The Individuals with Disabilities Education Act (IDEA) is the federal law that governs the education of children with disabilities, including autism. Congress' purpose in passing IDEA 48 years ago was to open the school doors for children with disabilities and provide them "a free appropriate education" (FAPE). Over the years, the law has been reauthorized and the case law in the field of special education has sought to further solidify and improve educational opportunities for children with IEPs and special needs. For example, in *Endrew F. v. Douglas County School District*, 137 S. Ct. 988, the Supreme Court ruled that Individualized Education Plans (IEPs) must give students with disabilities more than a *de minimus*, or minimal, educational benefit.

Some of the most notable rights under IDEA include:

- Every child with a disability is entitled to a **Free Appropriate Public Education (FAPE)**. This includes special education programming, related services, supports, and an Individualized Education Plan (IEP), if eligible, that must be designed to meet a child's "unique needs and prepare them for further education, employment, and independent living."



- **The IEP** is a written plan, developed by an IEP team (which includes the student's parents), that includes a student's present levels of educational performance, annual goals and objectives, programming, services, accommodations/modifications, and more. An IEP should include the strengths of a particular child, any concerns of parent/student and the specific "academic, developmental, and functional needs" of the student.
- School districts need to conduct "**appropriate evaluations**" in all areas of suspected disability. Evaluations must

be conducted by trained evaluators, utilize sound materials and procedures, be administered on a non-discriminatory basis, and be geared toward planning for the child's education and future instruction. Evaluations *should* include recommendations regarding a child's eligibility and/or needs for special education services.

- The Supreme Court, in *Endrew F.*, affirmed that the vision and intent of IDEA is that children with disabilities will make **meaningful educational benefit and progress** in our education system,

achieve "appropriately ambitious" objectives, and "some benefit" is not enough.

- Under the IDEA, a student is guaranteed placement in the **Least Restrictive Environment (LRE)** possible. Therefore, an IEP team must explore appropriate alternatives to enable students to participate in the general education classroom.
- **Transition planning** is meant to consider and facilitate the student's move from school to post-school activities. The transition planning must:
 - start before the student turns 16 (or earlier depending on your state's regulations);
 - be individualized;
 - be based on the student's strengths, preferences, and interests; and
 - include opportunities to develop functional skills for work and community life.
- **Procedural safeguards** to help parents and students enforce their rights under federal law. Safeguards protect parental access to information and procedures allow for resolution of disagreements between parents and school districts. If disagreements arise, parents have the right

see *Legal Rights on page 18*

Preserving Educational Stability: Understanding the Role of Pendency in Tuition Reimbursement Cases for Students with Special Needs

By Susan Fingerle, Esq
and Tracey Spencer Walsh, Esq
Spencer Walsh Law, PLLC

Parents of children with special needs sometimes face a daunting challenge when it comes to securing appropriate educational services. Fortunately, many legal avenues exist to advocate for an appropriate education. One critical aspect that often goes unnoticed is the indispensable role of pendency in tuition reimbursement cases. In this opinion piece, we illuminate the significance of pendency and its potential to positively impact the education of special needs students.

Disputes between parents and school districts are an unfortunate and sometimes inevitable aspect of the education of students with special needs. The pendency provisions of Federal and State law provide a valuable benefit to students and families creating security and stability, especially during ongoing and sometimes long-term differences of opinion concerning the nature of a free appropriate public education and the services necessary to serve a student's unique needs.

Understanding Pendency

Pendency, known as "a stay-put provi-



sion" or "the maintenance of the current, or then current, educational placement," derives its authority from the Individuals with Disabilities Education Act (IDEA) (42 U.S.C. Section 1415 (j) Maintenance of current educational placement and Section 300.518 of the Code of Federal Regulations (Child's status during proceedings)). This vital legal concept ensures that, during disputes or legal proceedings

between parents and school districts, the child remains in the last agreed upon educational placement until a resolution is reached. The concept being that at some point in the past the parties agreed to the child's program and placement. The IDEA mandates that if the parents want the school to remain in the same program, the school district must provide or fund the program, services, and placement in that last agreed

upon IEP while the current dispute is resolved. While the dispute over the school district's proposed change in the program is ongoing, the child "stays put." Pendency is a child's statutory, automatic, and unconditional right to remain in the last agreed upon placement during the "pendency" of any litigation. The final, unappealed decision of an impartial hearing officer also creates pendency. Pendency serves as a safeguard, protecting the child's educational rights and providing stability and continuity in their education.

Securing Pendency: Intrinsic Benefits

The intrinsic benefits of securing pendency in tuition reimbursement cases are far-reaching and of utmost importance. Securing pendency allows children to continue receiving their current educational services while the legal process unfolds. This continuity is essential for children with special needs, as disruptions in their educational environment, program and services can significantly impact their progress and overall well-being.

By ensuring pendency, children are provided with stability, reducing the learning loss, stress, and anxiety that may arise from

see Pendency on page 30

Understanding and Resolving Conflict in Divorce Involving Autistic Children

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

Divorce is complicated enough, but when there is a child with autism or other disability involved, it takes things to another level. I should know. I unexpectedly faced divorce after 21 years of marriage, and it took incredible amounts of time, money, and emotional energy to get through the process, so I could effectively advocate for the needs of my kids on opposite ends of the autism spectrum. I did get a great result for my family, but I decided other families shouldn't have to recreate the wheel and go through the efforts that I did. So, I formed Special Family Transitions and became a Special Needs Divorce Coach to help other families through this overwhelming and complex process.

In my professional and personal experience, I have seen common themes for reasons for conflict in special needs divorce, which translates to additional expense and strife for these families, who already have so much on their plates.

First, parents may not agree on the child's diagnosis and the extent of their needs. This may be due to their different views, experiences, and involvement with the child, especially if one is the primary caregiver and the other parent does not have visibility to the challenges the child



may face when not in their presence.

Parents may be at different stages of the Grief Cycle, where perhaps a parent is stuck in the Denial phase, and has not moved through the Anger, Bargaining, Depression, or Acceptance phases. Until the parent finally acknowledges and fully accepts the child and their disability, coming to agreement and making plans for the child's current and future needs will be difficult.

Second, one parent may not be comfortable with the other parent's ability to address the autistic child's needs. If the

child has complex medical, behavioral, or psychological needs, one parent may worry that the other parent does not have the experience or knowledge to safely care for the child. A parent may worry about their autistic child's difficulty with transitions and adapting to altered routines. Parents may be concerned about different parenting styles and rules in each residence, which may cause difficulty transitioning back and forth between homes.

Third, parents may have issues communicating or sharing information. Even

though some parents may prefer not to communicate with their soon-to-be ex-spouse, it is important to find a method to provide updates about the children and important matters. It helps to keep emotion out of these communications, and respectfully and succinctly focus on facts, events, and inquiries related to the child. For various reasons in a divorce, written documentation via email or a parenting app is preferred over phone calls and text messages.

Fourth, some parents may feel the responsibilities of taking care of the child are not being shared equitably. This can include the amount of caregiving time and effort one parent is providing, taking care of the planning and decision making for the child, making plans for their future care, as well as financial contribution.

Fifth, custody and possession concerns cause great strife for many families. In determining how to allocate parenting time and possession schedules, "Standard Possession Orders," as they are called in some states, may not be ideal for children on the spectrum. It benefits all involved to be flexible and consider a schedule which accommodates the children's needs as well as the parents' work schedules. It is also helpful to minimize the number of transitions between homes per week for the child, since transitions can be difficult and may cause anxiety for children with autism.

Sixth, parents may not fully understand

see Resolving Conflict on page 34

Navigating Legal Challenges in Autism Healthcare: Ensuring Access to Services and Insurance Coverage

By Eileen M. Mendes,
Cathy Booth, CCC-SLP, BCBA, LABA,
Autism Care Partners,
and Ashley Williams, PhD, LABA, BCBA-D,
Learn Behavioral

Prevalence rates of autism are at an all-time high, and we know that early and intensive treatment produces the optimal outcomes for autistic individuals. According to the CDC, “most children (85%) identified with ASD had concerns about their development noted in the records by 3 years of age.” However, less than half (42%) received a developmental evaluation by 3 years of age, while 19% received evaluations between ages 3 and 4, and 39% of children received evaluations after the age of 4.

With many providers having waitlists of 12 to 18 months or more, access to qualified healthcare providers who can diagnose autism and access to skilled clinicians who can provide autism services within a reasonable amount of time are lacking and greatly reduce the opportunities for children to access timely intervention. Increasing timely access to services is paramount for individuals with autism.

While there are established standards for access to care; state standards vary widely, meaning that different states have different



criteria for determining whether individuals' access is adequate. For example, some states may require 1 primary care provider for every 100 individuals enrolled in a health plan whereas another state might require 1 primary care provider for every 2,500 individuals enrolled in a health plan. There may also be standards related to how much travel time or how far away a provider is from a patient (time and distance). For example, some states may have a 30 mile radius or 30 minute travel time for a

patient to see their provider to be considered adequate access. Network adequacy standards may also differ based on the type of healthcare provider. If after researching your state specific network adequacy standards you determine that your desired provider does not have adequate availability, you can contact your health plan to advise them that they do not have an adequate network of diagnosing or treating providers.

Several state and federal laws protect an individual's right to access to care. The fol-

lowing laws are most applicable for caregivers of children and adolescents with autism spectrum disorder:

- Early and Periodic Screening, Diagnostic and Treatment (EPSDT)
- Individuals with Disabilities Education Act (IDEA) Part C
- Individuals with Disabilities Education Act (IDEA) Part B
- Section 504 of the Rehabilitation Act of 1973
- Individual State Mandates
- Patient Protection and Affordable Care Act
- Mental Health Parity and Addiction Equity Act (MHPAEA)

Early and Periodic Screening,
Diagnostic and Treatment

Early and Periodic Screening, Diagnostic and Treatment Benefit (EPSDT) is a federal law requiring services under the Medicaid program for “categorically” or “medically needy” individuals under age 21. As

see *Autism Healthcare* on page 29

Autism and the Law: When Trouble Comes Our Way

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

“I may have the advantage of race and gender. I may be able to stave off a meltdown for a short period. I may try my hardest to comply and be non-threatening, but I'm only ever one misunderstanding or nervous officer away from death. And it may be, in any given encounter, that there's nothing I can do about it.”

- “Cassie” (personal communication)

Much has been written about training law enforcement officers to recognize and de-escalate situations involving people with mental health and cognitive/developmental disabilities. These situations can escalate to violence when non-autistic people, with little understanding, knowledge, or awareness of autistic differences, witness disturbing behaviors and call Emergency Services.

In the mid-2000s, I worked for Laura Sky, a documentary filmmaker in Toronto, Ontario, learning a lot about tragic encounters between people with mental illnesses and police. The premise of her documentary, *Crisis Call*, was, “Armed police should never be first responders to people experiencing a mental health crisis” (Sky). Too many people with



psychiatric issues and/or developmental disabilities behave in ways others don't comprehend. If police are called upon to intercede, the crisis may escalate - sometimes to the point of lethality.

“Since 2015, nearly a quarter of all people killed by police officers in America have had a known mental illness...One of the many examples: the [2020] shooting of a distraught 13-year-old boy with an autism spectrum disorder by Salt Lake City police after his mother called officers to report that her son was having ‘a mental breakdown’” (Treisman).

More Likely to be Victims

Like those facing a mental health crisis, Colleen M. Berryessa, 2014, (as cited in Chiacchia, 2014) reports, “Researchers agree that most individuals with high functioning ASD are law abiding citizens who are more likely to be victims of crimes than commit crimes, but they are still seven times more likely to intersect with the criminal justice system than individuals without ASD” (Berryessa, 2014).

Autistic children and adults frequently have co-morbid mental health issues. Au-

tistic traits may expose them to criminal charges due to perceived antisocial behavior, inability to pick up on social cues, and challenges with both verbal and nonverbal communication (Cohen, Dickerson & Forbes, 2014 cited in Chiacchia, 2014).

In nearly all situations, especially those involving a person in crisis, responding officers must evaluate the scene and make instant decisions. According to police officers I've personally heard address this issue, “You get very little information about the subject of a call from the dispatcher. You're going in blind, having to weigh each situation against your training, experience, and potential consequences. You're constantly making split second decisions.”

The decision-making process requires “A police officer...to describe a specific set of circumstances or facts that would lead any objectively reasonable law enforcement officer to suspect the individual is, or has been, engaged in a criminal activity” (“Reasonable Suspicion”).

Misinterpreted Traits

Gaze aversion, literal interpretation of language, mutism, reduced reciprocity, and flat affect are interpreted by a majority of neurotypicals as deceptive. Behaviors such as stimming, rocking and pacing are commonly associated with perceptions of dishonest behavior (“Criminal Justice and

see *Autism and the Law* on page 32

Enhancing Communication and Accessibility: Assistive Technology for Individuals with Autism

By Anne Reynolds
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Special Needs Lawyers

What do a wheelchair, closed captioning on a television screen, and a visual schedule all have in common? They are part of an extensive list of products or services that enable those with disabilities to access activities of daily living. Like a wheelchair, assistive technology can provide individuals with autism assistance in accessing activities of daily living. Assistive technology can bridge the gap that these individuals face in those areas and improve their ability to be independent and a fully integrated member of their community.

Assistive Technology and Autism

The American Psychiatric Association defines Autism Spectrum Disorder (ASD) as a complex developmental condition involving persistent challenges with social communication, restricted interests, and repetitive behavior. The National Institute on Deafness and Other Communication Disorders further defines ASD as a developmental disability that can cause significant social, communication, and behavior-



al challenges. The term “spectrum” refers to the wide range of symptoms, skills, and levels of impairment people with ASD may possess. Those who have experience in working with individuals with ASD or have loved ones with the disorder know all too well that the “spectrum” of deficits for these individuals can vary greatly.

One of the most prevalent impairments for people with ASD is the inability to communicate effectively. They often have

trouble developing language skills, interpreting nonverbal communication, and processing what others are saying to them. Assistive technology can be an invaluable tool to help facilitate communication for a person with limited communication skills.

Assistive Technology in Schools

The federal law enacted to protect students with disabilities, the Individuals

with Disabilities Education Act (IDEA), defines an assistive technology device as “any item, piece of equipment, or product system, whether acquired commercially off the shelf, modify, or customized, that is used to increase, maintain, or improve functional capabilities of a child with a disability.” The IDEA further states that on a case-by-case basis, the use of school-purchased assistive technology devices in a child’s home or in other settings is required if the child’s Individualized Education Program’s (IEP) Team determines that the child needs access to those devices in order to receive a free and appropriate education (FAPE) (Individuals with Disabilities Education Act, 2004). In addition to the IDEA, the Americans with Disabilities Act (ADA) and Section 504 of the Rehabilitation Act (Section 504) provide that students with disabilities are entitled to access places of public accommodations, including schools, and are entitled to a FAPE.

Under the IDEA, students with disabilities are entitled to an IEP which includes access to special education and related services. The purpose of the ADA is to ensure that people with disabilities are afforded the same rights and opportunities as everyone else, and a 504 Plan provides accommodations to permit students to access

see Assistive Technology on page 26

New Curriculum from page 5

and understood. To this end we’ve been successful; 88% of participants reported feeling extremely supported and included in our workshop. With this program, we want people on the autism spectrum to know that their desires do not have to be limited by society’s misconceptions about them; instead, they can live their lives as desired without judgment or fear.

In developing the curriculum, we started from the inside out. Because, in our opinion, loving others must be rooted in self-love, our program begins with an extended unit on love of self so participants can develop their self-love authentically. We work on building positive habits around mindset and mastering negative self-talk through positive affirmations, and we use tools to help participants explore all facets of themselves including their communication styles and their visions for their futures. The first unit culminates in participants sharing vision boards featuring images and phrases that inspire hope. We then move on to units focusing on relationship-building within friendships because being able to form and maintain friendships is a vital component of forming meaningful intimate relationships. We discussed the varied roles people play in our lives, and we explored concepts like reciprocity. We were also sure to discuss safety across the array of places where folks meet each other, both in real life and online. Finally, we explored “love languages,” aspects of sexuality, and expressing physical desires to a partner and we provided education on safe sex practices.



Victoria Pettiquoi-Morgan, LICSW-C

I AM is proud of its efforts towards creating an inclusive environment where all forms of human sexual expression can be accepted, respected, and understood. We firmly believe that everyone has the right to pursue meaningful relationships. We called the course Sex in DCity because we are unafraid to say the word “sex.” Sex is not a dirty word, and we need to be able to discuss sex and sexuality openly. Service providers and other stakeholders initially questioned whether it was necessary to call our program Sex in DCity, and we responded that if we are not free to use the word “sex,” then the program will not be as effective as possible. I AM believes everyone should have access to accurate information and resources when it comes to relationships and intimacy, and 77% of participants reported they are



Matthew Ratz, MEd

extremely likely to use the information and skills learned in the workshop in their personal lives.

I AM’s goal for its Sex in DCity curriculum is to make a positive difference in the lives of those living with autism spectrum disorders. Through the grant from OAR, we are able to make 200 copies of our curriculum guide available for free to organizations and individuals who would like to support adults with autism and I/DD in navigating their sexuality. We have set up the website iamsexindcity.org where interested parties can reserve their free copies.

We invite you to join us in our mission of creating an inclusive environment so that all can feel free to express themselves and form meaningful relationships. We want everyone, especially adults with autism, to

know that they do not have to be limited by misconceptions about them—they are capable of having fulfilling, meaningful relationships if they choose. We hope the Sex in DCity program will provide individuals with autism and I/DD with the knowledge and resources necessary for safe, meaningful intimate relationships. Together we can bring about positive change and make a difference.

Victoria Pettiquoi-Morgan is a Licensed Clinical Social Worker and Therapist who has been in the mental health field for over 18 years. Victoria provides therapeutic services in many capacities to families, children, adolescents, and couples. She is trained in several evidenced based treatment modalities and offers integrative mental health practices to meet the needs of the community through nontraditional approaches. Victoria’s professional journey of working with various government agencies at the State and County level engenders unique experience that supports her private practice; She is the owner and CEO of I Aspire to Be Me, LLC (I AM), a disability provider in Washington, DC, and the owner of PettiCare, LLC, a behavioral health support organization. She can be reached at vpmorgan@iaspiretobeme.org.

Matthew Ratz is an educator and is Executive Director of Passion for Learning, Inc. He served as the primary curriculum consultant for the Sex in DCity pilot program. He writes, speaks, and publishes frequently across an array of topics including mental health advocacy, autism education, college readiness, and the K-12 space. He can be reached at mjratz@gmail.com.

The Dangers of Engaging in Child Pornography (and How Education Can Prevent Heartbreak)

By Arlene Lechner, MEd
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You are enjoying your morning cup of coffee and planning your day. Your young adult son with Autism Spectrum Disorder (ASD) is online in his room. There's a forceful knock on the door. You open the door and find Federal Agents on your doorstep. They barge in to arrest your son and the rest is a difficult, emotional, frustrating, and expensive blur. What just happened? Your son was arrested for viewing and possession of child pornography on his computer.

Many young adults with ASD are socially isolated and turn to the internet to pass the time. Online communities are more accepting as they don't require the in-person stressors of reading social situations, facial expressions, understanding of group dynamics, self-regulation, dealing with social anxiety, and there's less worrying about what people will think of them. No one asks your age or cares how old you are. There's no need for small talk and they easily find groups with common interests. The feeling of having a friend and belong-



ing often leads to participation in an unsafe online community and overrides any sense of knowing right from wrong.

The online world is welcoming and dangerous. It's as if everyone is wearing a mask and you don't really know who you are talking to. People lie about who they are and those who are vulnerable, including people with ASD, often fall prey to online predators. While surfing online they may view child pornography with the misguided guidance of their new "friends."

An adult with ASD, who became en-

tangled in the criminal justice system, revealed that he joined an online community. He stated it was easy to chat with the other guys because he was readily accepted. He then engaged in the group chat about child pornography. It was the first time he was accepted without judgment and felt a sense of belonging. Looking back, he realized the people leading the chat took advantage of his vulnerability and desire to be part of a group. Unfortunately, he was arrested for possession of child pornography. Another son told his parents, "There's teacher porn,

librarian porn and nurse porn. How was I supposed to know that child pornography is illegal?" He was also arrested after a knock on the door.

"The internet can be a wonderful educational tool and it can also ruin your life," said Nick Dubin, a male with ASD who was arrested after unwittingly downloading child pornography on his computer. Nick and his family navigated the criminal justice system and wrote a book to help others avoid the same fate (Attwood, et al., 2014).

The lack of belonging to a peer group that is accepting of who they are and a lack of education about what pornography is legal, illegal and the "why" of the illegality is a significant problem for people with ASD. This is the root cause of too many arrests each year of males with ASD possessing, collecting, and viewing child pornography online without intended malice.

This is an ongoing issue. The lack of interpersonal relationships and social skills, challenges in initiating social exchanges, low self-esteem, naivete, loneliness, a need to please others even if the relationship is unhealthy leads to exploitation and crimes (Henault, 2006).

Viewing pornography in your bedroom is thought to be a private activity. However,

see Dangers on page 33

Strategies for Navigating College for Students with Autism

By Denise Gackenhimer Verzella, Esq, MA
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College is a transformative period in a young adult's life, offering a platform for growth, self-discovery, and academic achievement. However, for students on the autism spectrum, navigating the challenges of college life can be particularly overwhelming. College students with autism spectrum disorder (ASD) have a lower likelihood of completing their degree than either students with other disabilities or students in the general population (Jackson, 2018). Studies have shown that only 34.7% of young adults with ASD attend college (Shattuck, 2012). Of the group of students with ASD who attend college, only 38.8% will graduate (Cox, 2017). However, there are several steps students with ASD, their families, and schools can take to increase the likelihood of completing their degree.

Legal Overview

Local school districts often provide students with ASD an Individualized Education Program (IEP) to provide special education and related services. The Individuals with Disabilities in Education Act (IDEA) provides for these supports from age 3 through 21, or until the student grad-



uates from high school. However, IDEA does not apply to post-secondary institutions. Instead, students are provided with accommodations through a 504 Plan under the Americans with Disabilities Act (ADA) and Section 504 of the Rehabilitation Act (504). Unlike the IDEA, there is no mandatory process schools must undertake to identify students with disabilities and provide the appropriate services. Instead, the student must seek out and obtain the supports they may require to be successful in school. However, colleges that accept federal financial assistance are required to provide equal access for students with dis-

abilities provided the requested accommodations are reasonable, do not provide an undue administrative or financial burden on the institution, and do not alter the essential nature of the education (ADA & 504).

Applying to Schools

The transition to college starts while students are still in high school. The college application process can be long and difficult. Students with ASD have the added decision of whether they should disclose their disability during the application process. While colleges are prohibited by the ADA

and 504 from discriminating against a student due to a disability, college admissions are competitive, and it is understandable that students are concerned that the disclosure of a disability could negatively impact their application. Nonetheless, disclosing a disability may help an admissions officer understand an unusual pattern of grades or discrepancy in grades versus standardized test scores. Whatever decision a student makes is personal to that student, and there is no right or wrong approach.

Schools with Formal Programs for Students with Disabilities

Transition Programs - When researching schools, one option available to students with ASD are schools offering formal transition programs. These types of programs are designed to assist students with disabilities develop the requisite skills necessary for successful completion of college, including support with executive functioning, independent living and self-advocacy. One such program is [College Steps](#), which offers academic, social, and vocational support for students. Although College Steps does not offer a traditional college degree, it provides a transition for students who may require more support prior to enrolling in a degree-granting program. Many of these programs often include a residential component, as well as academic

see Navigating College on page 30

Autistics, Law Enforcement, the Law, and Unfortunate and Tragic Encounters

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

I am not an attorney, nor do I have any legal background. As such, I claim to have no knowledge of the law, and do not offer legal advice of any kind. What I am writing here is strictly my own opinion and impressions and is based entirely on personal experiences and stories I have heard from others in the autism community.

During the two decades since my diagnosis in late 2000, I have heard many stories about autistics and encounters with law enforcement, sometimes with unpleasant and even tragic results. Most of these have been second-hand recounting, but I have personally known members of the autism community who experienced such as well.

I will begin, however, with a small incident that happened to me many years ago.

A Minor but Memorable Encounter with the Police

Apart from being pulled over by traffic police on a few occasions, which mostly resulted in my being let go with just a warning (fortunately!), I recall only one incident where I encountered law enforcement. This long-forgotten incident, which happened when I was fifteen years old, came back to me (and quite vividly) several years ago after attending a conference workshop on autism and law enforcement.



Karl Wittig, PE

In the pursuit of my specialized interest in anything electrical or electronic, I would often walk through my New York City neighborhood in search of discarded televisions, radios, or other electronic devices that were put out as garbage and which I would bring home, take apart, repair, and get to work. One afternoon, while coming home carrying my most recent find (an old phonograph), I was approached by two men, one of whom showed me what I recognized as a police department badge. He asked me about what I was carrying, and I explained what it was and that I had found

it and was taking it home. “Looks suspicious,” he replied to me.

In my experience, policemen always wore uniforms and the only ones who wore regular clothes were detectives on TV investigating murders and other serious crimes – in other words, I was not familiar with the presence of plainclothes officers on street patrols, as had become the practice in New York at the time. I thus became concerned (probably from watching too much television) that these might really be dangerous criminals impersonating police officers and can remember feeling very scared. As they proceeded to question me, I explained that I was taking the item home, to see how it worked and try to fix it. They seemed somewhat dubious until they asked me where I was going to school, and I told them that I went to a science high school that was very well-known. At that point, they finally believed me and told me to go home, which I did (and immediately proceeded to disassemble my newest treasure!).

The reason this otherwise-forgettable incident resurfaced after so many years is that it involved so many of what I now recognize as autistic issues, which would have been completely unknown at the time. First, it involved an unusual and obsessive special interest (discarded electronics). Second, there was atypical, peculiar behavior on my part (looking through garbage). Third, I did not appreciate how my actions might be interpreted by others (particularly the police, who might have thought that I stole the item). Fourth, I was perplexed

when approached by the two officers and did not understand what was happening. Fifth, because of my apprehension (which police are trained to sense), they probably suspected that I was not being truthful. Finally, had I not been fortunate to attend a prestigious school, the policemen may well have pursued the matter further, and there is no telling what might have happened then.

When I think back to this experience, I also recall the many stories I have heard over the years about encounters between autistics and law enforcement, many of which did not end as happily as mine did.

Special Interest is a Powerful Motive

A famous case within the autism community involves an adult on the spectrum who had an obsessive interest in trains, particularly the New York City subway system and, at a very early age, learned how to operate a train. He went on to impersonate a conductor, even wearing a uniform, and then took over a train, while the real conductor was distracted, and drove it on its route. He did this many times and was always caught, serving a number of prison sentences as a result. Despite the consequences of his behavior, he was unable to control his compulsion. Such can be the power of an obsessive special interest over an autistic.

I appreciated this story because I too had a comparable interest in the subway system at around age 7, and learned every route in the entire system, to the point of knowing

see Tragic Encounters on page 21

Legal Rights from page 13

to request mediation or due process hearings with state-level education agencies, and beyond that may appeal the decision in state or federal court.

Parental Rights

In 2007, the Supreme Court issued a unanimous decision in *Winkelman v. Parma Cent. School Dist.*, 550 U.S. 516 (2007) affirming parental rights, underscoring the importance of parental involvement and the essential role parents play in ensuring that their child receives a FAPE, and concluding that parents have independent, enforceable rights.

Some of the most notable parental rights under IDEA include the fact that parents have the right to:

- Receive an explanation of all procedural safeguards,
- Confidentiality,
- Inspect/review their child’s educational records,
- Participate in meetings related to identification, evaluation, and placement of their child,
- Request an independent educational evaluation of their child,
- Receive parent counseling and training



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as a related service on their child’s IEP,

- Receive “prior written notice” on matters relating to the identification, evaluation, or placement of their child, and the provision of FAPE to their child,
- Provide or deny their consent before the school may take certain action with respect to their child,
- Disagree with decisions made by the school system on those issues, and
- Use the IDEA’s mechanisms for resolving disputes, complaints and appeals.

Some Other Legal Considerations

- The Americans with Disabilities Act (ADA) protects the civil rights of people with disabilities.
- Children with special needs may be eligible for accommodations under **Section 504** of the Rehabilitation Act of 1973.
- **Guardianship** may allow for a parent to continue having involvement with their child’s medical, financial or other aspects of their child’s lives. Before your child with autism turns 18 years of age, you should consider whether guardianship is an appropriate consideration for your family.
- **Estate planning** allows your family to plan for the future.
- You should see if your state and your **health insurance** have required coverage for autism-related treatments.

Tips for Parents

- Learn all you can about your child’s needs and their diagnoses.
- Ask a lot of questions. Listen to answers. Take notes.
- Get extremely organized – find a method for saving and organizing documents and information. Save documents, correspondence, and notes in real time.

- Become well-versed in the laws and regulations that govern special education.
- If concerns or issues arise, you can disagree without becoming disagreeable.
- Knowledge is power. Knowing what you don’t know is equally as powerful.
- Explore creative solutions if you are sensing an impasse.
- Get comfortable with the idea that you have an equal seat at the table and your child is relying on you to make good use of it.
- Get to know your child’s teachers and therapists. Keep open lines of communication. Ask for tips and strategies.
- Trust your gut. If something feels off, it very well may be. Voice concerns respectfully. If you feel like you need advice, you should identify an advocate or an attorney who can help guide you.

Individuals with autism and their families may face a variety of legal questions and issues. By being informed and proactive about your rights, entitlements, and the options available, you can help to protect your child and get them the resources, support, and services they need.

Maria C. McGinley, MST, JD, is Founder and Partner of McGinley Law Group, LLP. For more information, visit mlgsped.com.

The Invisible Struggle: Autism Diagnosis in Immigrant Families

By Veera Mookerjee, PhD, LMSW
 Founder and Director
 Resolveera - Serving Underserved
 Populations

According to Constance Baker Motley, the first Black woman elected to the New York State Senate in 1964, “something which we think is impossible now is not impossible in another decade.” About 11 years back when I was graduating as a Doctor of Social Work, I held similar thoughts for the vulnerable immigrant communities, especially those immigrant community members who were and are also caregivers for individuals on the Autism Spectrum. Over the past decade Autism cases had a significant rise in numbers. Per a CDC report in 2021, “1 in 54 children had been diagnosed with autism in 2016 compared to 1 in 150 in 2000.” Per a recent study “autism cases have tripled in the New York and New Jersey Metropolitan area from 2000 to 2016” (Shenaouda et al., 2023). An article in the New York Times on March 23rd, 2023, claimed that “in 2020, an estimated one in 36 8-year-olds had autism, up from one in 44 in 2018.” All the increases in autism cases have been reported from immigrant communities and communities of color. Hence, a vulnerable section of the population is even more vulnerable when it comes to a



disability diagnosis for the younger generation. In addition to this, during the previous administration, it should be noted that many immigrant families made the decision to forgo autism services for their documented citizen children because the parents were not documented.

In 2012, my thesis recommended options for needs assessments for the caregivers and identifying their problems in their own words, development of new accessible services, and professional development

through staff training. I am aware that, in NYC, a South Asian non-profit called [Autism Society Habilitation Organization \(ASHO\)](#) had conducted a needs assessment for the Bangladeshi immigrants who were caregivers to individuals with Autism, but even though the data was published and shared with local politicians, lack of funding prevented the program recommendation from hitting the runway. According to ASHO Executive Director, Rubaiya Rahman, unaddressed needs of the immigrant

population around ASD services will be a “Tsunami problem” in near future.

This article is being written with the aim of focusing on the challenges of immigrant community members when they face the stressors of a child being diagnosed, or even misdiagnosed, with an Autism Spectrum Disorder. The article will highlight the unaddressed needs in the form of late or missed diagnosis, of the lack of service efficacy and lack of adequate and accessible resources. In my career span of nearly 20 years, I have spent the past 11 years working for and with the immigrant population in New York State. As a Mental Health therapist and a private consultant, I have come across multiple examples suggesting immigration challenges around autism diagnosis. I will share case examples that focus on the unaddressed challenges that immigrant community members face in NY, which is a sanctuary state, and where, regardless of the immigration status of families, no child is left behind. However, due to medical and other professional malpractice, immigrant community members often find themselves at a loss.

To prepare for this article the author picked 3 families from diverse immigrant communities that have faced significant challenges with an autism diagnosis and from being in an immigrant community. One such parent mentioned earlier in this

see *Immigrant Families* on [page 31](#)

A Call for Reform of the Least Restrictive Environment

By Caitlin Sweetapple, EdD
 Director of Research
 Shrub Oak International School

Section 1412(a)(5) of the Individuals with Disabilities Act (IDEA) outlines regulations regarding the *least restrictive environment (LRE)*. The statute states:

To the maximum extent appropriate, children with disabilities, including children in public or private institutions or other care facilities, are educated with children who are not disabled, and special classes, separate schooling, or other removal of children with disabilities from the regular educational environment occurs only when the nature or severity of the disability of a child is such that education in regular classes with the use of supplementary aids and services cannot be achieved satisfactorily (IDEA, 2019).

I challenge you to think about what the “regular educational environment” provides for our autistic students. The term *restrictive* is used to describe the level of support a student receives from a programmatic perspective. In my professional experience, restrictive, as defined by IDEA, is sometimes most appropriate for autistic



Caitlin Sweetapple, EdD

students to master educational goals, make meaningful progress, and continue towards increased quality of life in a student’s post school-aged years.

It was noted over a decade ago that the language used by IDEA was vague and provided no direction to placement teams working with students with disabilities (Alquraini, 2013); however, changes have yet to be made to provide clear direction

to professionals. In my professional opinion, perceptual research is critical to understand how the LRE has impacted autistic students. To truly create effective change in policy, lawmakers must hear the voices of those who attend school in a least restrictive environment to understand the efficacy of this policy.

Though Section 1412(a)(5) of the IDEA is well intentioned, I argue the objectives are no longer relevant for our autistic students and students with disabilities in general. The statute is worded as if education is binary in nature, when informed professionals in autism education know diversification and individualization within special education is critical for autistic students to be successful in school. Simply put, our general educational system in the United States is not well prepared to educate autistic minds, and often, the restrictive environment is.

So, what’s next? Firstly, autistic voices should inform any educational policy. IDEA reform is needed, and quickly, utilizing the experiences of autistic students in the least restrictive environment. It’s critical to understand the impact educational environments have on autistic students’ trajectory post school-aged years to inform policy. Secondly, once initial reform is complete, school leaders should be trained in implementation to ensure un-

derstanding and consistency at placement meetings. Lastly, ongoing review of special education policy is imperative to ensure pertinent programming is implemented. The next steps do not come without challenges and perseverance, yet they are critical in the fight for educational justice for autistic students.

Dr. Caitlin Sweetapple is the Director of Research at [Shrub Oak International School \(SOIS\)](#), a private, coeducational, therapeutic day and boarding school for students ages 8-30 on the autism spectrum who face complex challenges. The mission of the research department at SOIS is to conduct and publish cutting edge, novel research in the field of autism education. For more information, please contact Dr. Sweetapple at csweetapple@shruboak.org.

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The Promise of Quality ABA: What Value-Based Care Means for Families

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As the prevalence of autism spectrum disorder (ASD) continues to rise, parents of children with autism face significant challenges in obtaining high-quality and appropriate care and services. Delays in diagnosis, waitlists for treatment, shortage of available providers, high staff turnover, and a lack of standardized outcomes are prevalent across the country. When one or more of these barriers exist, long-term progress is negatively affected (CDC, 2021).

One approach to addressing these challenges is value-based care (VBC). VBC emphasizes quality care over quantity of care and encourages cost-effective care management.

In this article, we explore:

- what VBC means for parents of children with autism;
- how VBC affects current providers;
- how VBC improves service quality; and
- how providers are measured based on outcomes.

What is Value-Based Care (VBC)?

In the current healthcare system, providers are often paid based on the number of services or service hours they provide, regardless of the quality of care they deliver. This fee-for-service model encourages high utilization because providers are financially incentivized to perform more procedures and services as more services translate into more revenue. This can lead to overuse of healthcare services, as providers may be motivated to perform unnecessary tests, procedures, or treat-



ments, even if they are not beneficial for the patient. Fee-for-service systems are designed to incentivize overuse of healthcare services leading to higher than necessary costs. VBC, on the other hand, pays providers based on the quality of services they provide as tied to patient outcomes. Typically, this is determined through various measures around cost-effectiveness and key quality indicators. In short, the conversation focuses on outcomes, not hours. By shifting the focus from volume to value, health plans and providers can bridge gaps in the treatment quality of Applied Behavior Analysis (ABA) services for autism.

How Does VBC Affect My Current Services and Provider?

VBC will significantly impact the services you receive for the better! The goal of VBC is for your providers to be reimbursed based on how well they provide services and how much their clients improve. This allows providers to focus less on maximizing the hours they spend with clients and more on what they are doing with the

hours they have.

Relatedly, over 60% of Board Certified Behavior Analysts (BCBA) and Board Certified Assistant Behavior Analysts (BCaBA) experience moderate to high levels of burnout due to exhaustion and loss of enthusiasm for work associated with the fee-for-service model (Plantiveau et al., 2018). By holding providers accountable to value, providers are better able to choose appropriate goals, tailor individual care, and observe measurable patient gains, giving them greater flexibility to deliver the right care at the right time (The Commonwealth Fund, 2023). As a result, providers can reconnect to their passion as healers, reclaim professional autonomy, and are empowered to maximize their clinical judgement (Tiesburg et al., 2020).

How Does VBC Affect the Quality of ABA Services?

Value-based care is applied in ABA therapy to increase access to care, reduce costs, and improve outcomes for children with autism. One way to apply VBC in ABA therapy is to prioritize early intervention.

Research has shown that early intervention can significantly improve outcomes for children with ASD, reducing the need for more intensive interventions later in life. By prioritizing early intervention, ABA therapy can be used to improve adaptive behavior, IQ (intelligence quotient) scores, and language skills, reducing the need for costly interventions into adulthood (Cucinotta et al., 2022).

Furthermore, coordination of care across treatment professionals reduces duplication of care and improves monitoring of medication effectiveness and behavioral side effects. Many individuals with ASD receive services from speech-language pathologists, occupational therapists, physical therapists, medication managers, and behavioral health providers. Coordinating care allows treatment professionals to carry over skills and goals across different settings which improves treatment outcomes by aiding in skill generalization and maintenance (Fulceri et al., 2023).

Throughout the treatment journey, consistently measuring progress also allows treatment professionals to predict long-term outcomes based on how the individual is progressing across all areas of their life. In so doing, treatment professionals can intervene early with additional case management, referrals, and resources where needed as significant barriers arise. This approach allows for each individual's overall healthcare to be managed according to their specific needs and with a focus on long-term outcomes.

How Will VBC Affect Parents?

Improved outcomes: By providing parent training in ABA techniques, parents can learn how to help their children engage in positive behaviors and reduce challenging behaviors. Such continuity of care across the child's day leads to improved communication skills, improved social skills, and fewer challenging behaviors as well as

see Value-Based Care on page 22

Power of the IEP from page 8

Having clarity and agreement within the IEP document is critical for not only ensuring that school districts are accountable for delivering needed services but also that the goals and services are understood by the parents.

Parents should remember that they are their child's biggest advocate. Parents should stay informed, document everything, and be persistent! While IEPs are legally binding documents, identifying that the school may be non-compliant with the IEP does not automatically mean the family has met burden of proof (traditional burden of proof falls on the parent to show that an IEP has been deficient in some way) in court for a due process hearing and that their child will receive compensatory education.

There are many constructive steps parents can take when they believe their child's IEP is not being following including:

- keeping factual and professional documentation of what is happening or not happening
- requesting an IEP meeting with the IEP team
- talking to school administrators
- finding an educational advocate or advocacy group
- filing a complaint with the Department of Education or with the Office of Civil Rights
- consulting with an attorney
- calling on local and state politicians to help

While not every step listed is necessarily needed, parents do have resources available to help them navigate IEP non-compliance issues.

It's important for parents to fully understand that the best outcomes for their child will come from collaborative team efforts. The IEP process does not need to be litigious for quality support and services to be implemented, and IEP issues can usually be resolved outside of the court room. Having a strong relationship with your child's school team and keeping lines of communication open and transparent will go a long way to developing a beneficial plan that all team members feel comfortable with.

IEP Improvement Opportunities

It would be beneficial for Board Certified Behavior Analysts to play an active role in the Child Study Team to support-placement of students to meet the goals of the child's IEP as well as to assist in determining fading protocols and processes documenting benchmarks that are achieved. They can assist in determining

clinical need for behavior support, social skill support or general support for learning readiness skills that may still be emerging for students. Applied Behavior Analysis goes beyond being a specific service for students clinically diagnosed with Autism. ABA is a science that helps effect meaningful behavior changes across domains for various types of learners. ABA also pairs well with counseling, physical therapy, and speech and occupational related services. At the end of the day, a cohesive treatment team is needed to guide the targeted progress for a student.

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“It’s Special” Podcast with Tracey Spencer Walsh, Esq. and Cecelia McCarton, MD

By Tracey Spencer Walsh, Esq.
Spencer Walsh Law, PLLC

Tracey Spencer Walsh is the Founder and Chief Litigation Strategist of [Spencer Walsh Law, PLLC](#) and is also the creator and host of the podcast, “It’s Special.” “It’s Special” takes a vast amount of information in the realm of special needs - sometimes too overwhelming to sift through on one’s own - and breaks it down into bite-size, easily understandable, and relatable pieces for all to enjoy.

Over her last 25 years in the legal industry, Tracey has learned the litigation ropes in New York City “big law” law firms, honed her skills, and found success in Federal Courts litigating IDEA cases in her own practice; assisting families with special needs children to get the education they need and deserve.

Her passion for Special Education Law stems from her own personal connection to the field, having family members with autism and ADHD, allowing her to truly understand the struggles families experience. Tracey has dedicated her career to sharpening her vast expertise and successfully representing hundreds of families with children with autism, ADHD, mental health challenges, and a variety of learning disabilities. For her, there is nothing better than making a difference in a child’s life and helping families in need.

Dr. Cecelia McCarton, a developmental pediatrician, was a featured guest on the “It’s Special” podcast. In 1998, Dr. McCarton founded the [McCarton Center for Developmental Pediatrics](#), a diagnostic and treatment center dedicated to childhood developmental disorders. She is also the Founder and Executive Director of [The McCarton Foundation for Children with Developmental Disabilities](#), The McCarton School for children with autism, and the Children’s Academy for children with speech and language delays. Dr. McCarton serves as a Diplomat of the

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to a child with autism - you
have been given a gift.”*
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American Board of Pediatrics (1988) and is a member of many professional societies, including the American Academy of Pediatrics, the Society for Behavioral Pediatrics, Society for Research in Child Development, the International Neuropsychology Society, and the American Academy for Cerebral Palsy and Developmental Medicine. A New York City native, Dr. McCarton received her BA from the college of New Rochelle and her Medical Degree from the Albert Einstein College of Medicine.

During Dr. McCarton’s episode of “It’s Special,” Dr. McCarton and Tracey discuss: The criticalness of early intervention for children with autism;

- How, culturally, people are more accepting of various paths to development and how that may push autism diagnoses under the radar;
- The growing recognition of the prevalence of autism along with the tension surrounding whether autism is being overly diagnosed;
- Why singing “Happy Birthday” may be a painful experience for a child with autism;
- The impact that the COVID-19 pandemic has had on children with special needs; and much more.

- How “dysregulated” behaviors can be a form of self-protection;

This episode of “It’s Special” illuminates how autism is a puzzle that has not yet been pieced together. But, despite all of the unknown that still surrounds the diagnosis of autism, Tracey and Dr. McCarton - two professionals exceptionally well-versed in the field of autism - discuss the ever-evolving autism diagnosis and the future of autism interventions.

For more information, please contact Tracey at itsspecialpodcast@gmail.com and visit www.itsspecialpodcast.com.

Tragic Encounters from page 18

all the rail tracks for those that I rode regularly. I have found that this is a very common interest for autistics who grow up in New York.

What is disturbing, however, is that, after years of ineffective legal representation, one of his attorneys attempted to use Asperger Syndrome as a mitigating factor, and the judge refused to accept it. At the time, there was little public awareness about the autism spectrum, and it was often not taken seriously.

This is certainly an example of the law lagging behind the current state of scientific and, in this case, neuropsychological knowledge. Comparable cases have involved a number of hackers (often on the spectrum) who cannot control their impulses to infiltrate computer systems and networks.

A Tragic but Common Story

One kind of incident that I have heard about on many occasions involves a young person on the autism spectrum being approached by “friends” who invite them to a party or social event, or simply say that

they want to be friends with them. As a condition, however, they are asked to deliver a package, the contents of which they need not be concerned with (or else are misrepresented), to a specified location. Needless to say, the package contains illegal drugs or other contraband.

If the autistic is caught by police while delivering the package, they will be arrested and charged with a very serious crime that can result in years of imprisonment. If unable to prove that they had no knowledge of the contents (which is often difficult to do, since there can be a legal presumption of intent), they are usually convicted, or forced to plea-bargain, and sometimes sentenced to a harsh prison term. Many autistics, who cannot understand the social dynamics of the prison environment, let alone deal with them, will not be able to survive such an experience.

What I find remarkable about these stories is that, in nearly every case, the inducement is the prospect of friendship or social inclusion and not of financial gain as would usually be in such a situation. Also, the perpetrators readily identify victims that are susceptible to this, even though they do not know that they are on the au-

tism spectrum and, for that matter, may not have even heard of autism (this would certainly have been the case until recently). Still, they are somehow able to recognize those who can be so exploited.

This is another example of the law lagging behind the current state of knowledge about the autism spectrum, its challenges, and its deficits.

Another Tragic But Common Story

The ubiquitousness of the internet, along with proliferation of websites displaying just about any kind of dubious content, created conditions which have resulted in a disturbing number of autistics being prosecuted for serious crimes. Websites concerning terrorism, explosives, weapons, criminal activities, etc. are now commonplace and can attract the attention of autistics who, for whatever reason, develop an interest in such things, even though they have no intention of doing any actual harm. Some of the most tragic cases, however, involve illicit pornography.

Autistics famously have difficulty finding friendships and social inclusion, let alone romantic and sexual relationships.

Consequently, they can easily develop an excessive fascination with pornography that goes beyond the typical interest of early adolescents. Since the advent of the internet made every kind of pornography readily available on one’s computer screen, it can easily be accessed with nothing more than a few keystrokes.

The possession of certain types of pornography, particularly those involving underage subjects, has been made illegal by the U.S. Congress. At the time these laws were passed, pornography was distributed via physical media (print, film, video, etc.) and, as such, its acquisition required deliberate effort on the part of the individual (e.g., physically purchasing or ordering). Distribution over the internet was not common (if it even existed) at the time, so the laws did not take it into account.

Not long afterwards, however, online distribution became the predominant means of consuming pornography, illicit and otherwise. An autistic person with an interest in such could easily view and even download any such material. If they came across an illicit website, they would treat

see *Tragic Encounters* on page 24

Value-Based Care from page 20

Reduced costs: By providing parent training in ABA techniques, parents learn how to implement behavior modification techniques at home. This reduces the need for expensive in-person ABA therapy sessions and can lead to cost savings for families and the healthcare system while maintaining positive treatment outcomes.

Patient-centered care: Value-based care emphasizes the importance of patient-centered care, which involves empowering patients and their families to be active participants in their care. By receiving parent training utilizing ABA techniques, parents learn how to be active participants in their child's therapy and can work collaboratively with healthcare providers to achieve the best possible outcomes for their child. Furthermore, VBC enables parents to obtain resources and advocacy such as for individualized education programs (IEPs), financial and public health resources, respite care, and other services. This holistic care approach has been demonstrated to improve care and outcomes for children, especially those in underserved and under-resourced communities.

What Will My Provider Be Measured On?

BCBAs who provide ABA services may be measured on several outcomes for value-based care contracts. These outcomes typically focus on improving patient outcomes while reducing costs.

Patient outcomes: Improvements in com-



Dana D'Ambrosio, MS, BCBA, LBA

munication skills, social skills, and reductions in problem behaviors are measured using standardized assessment tools or through direct observation of the patient's behavior as reported by the provider.

Cost savings: Reduction of healthcare costs associated with treating patients is achieved through interventions that reduce the need for costly medical interventions or improve the patient's ability to function in their daily life.

Treatment adherence: Measuring the ability of BCBAs to adhere to evidence-based ABA treatment plans that have been shown to be effective in improving patient outcomes is achieved through regular monitoring of treatment progress and the BCBAs adjustment of treatment plans as needed.

Patient satisfaction: Patient and family surveys or direct feedback enable measurement of patient and family satisfaction with the ABA services, access to care and overall care experience.

VBC enables providers to focus more on delivering high quality treatment, improving outcomes, reducing care costs, and prioritizing empowerment of patients and families. With appropriate measures in place, VBC is the future model for payment of ABA services.

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Melmark Interview from page 6

We're seeing that across the United States and I think, certainly pre-pandemic, we saw these staffing trends where the workforce was increasingly becoming smaller and smaller. If you think about the demographic of the United States, we have so many people aging who will actually require people from the care community to take care of them. The bucket of people coming into college is dramatically smaller. Some of us knew this demographic data before the pandemic that we're going to hit six to eight years of very difficult demographics in terms of people graduating from college to work in the care industry. I think one of the things we're concerned about is that we don't value our care employees.

During the pandemic across the United States, we heard that the care workers were all heroes. But we work across states, and they didn't seem to be heroes when the budgets came out. They are some of the lowest paid employees in the United States. You can make more making coffee at Dunkin Donuts or Wawa than you do working in a direct care position. Again, I think it comes back to an advocacy community and working towards getting better funding. For us, it means trying to make our administration as lean as possible to make sure as much funding goes to point of care salaries. In addition to that, we do a significant amount

of fundraising, quite frankly, and pay our staff more than what the state pays us. In one of our states, we have a gap of every dollar of services we provide, we lose seven to eight cents on the dollar because we pay our staff more. And we refuse to not do that because we want the quality of care. In the short staffing, we've built such strong infrastructure with direct personnel supervision, then another level above that, all of those staff fall into direct care roles when we're short staffed. If we did not have those roles, there is no way we could sustain the organization's quality. And in addition to which, because turnover continues to be so high in this area, those people are also our trainers. So, they're doing side-by-side training at the point of care, and that's helping us maintain our quality of service.

David: This is an issue everyone is facing, and it sounds like you're doing a lot to really support your staff. It is clear that you are an important voice beyond Melmark and you are leading the charge for change across the country for legislative action. What are the challenges you are facing in your role as a legislative advocate?

Rita: I think the understanding of the wide spectrum of autism services in terms of how we compare, for example, in the care community where everybody is competing for staff, childcare, elder care, school in-

structional assistance, those kinds of things – we're competing. But Melmark serves a higher acuity population that really needs technical supports to get their best outcomes. We actually had a legislative panel in Pennsylvania last week. And one of the set of senators said, "Well, childcare workers have the same issue." And I responded, "Oh, no, no, no. Serving a 16-year-old who's struggling with toileting, maybe aggression, self-injury, and communication, is not the same as managing a six-year-old who's having a temper tantrum." And the skillset needed of that staff has to be different, and that's not disrespecting child children who have childcare. But I think the reality is, there is a difference in different levels in the care community, and we need to recognize that better. We're trying to train or teach legislators that the population we serve is often hidden because they do have such high support needs. It's not someone who's going to be on TV playing the piano. It's not someone who's going to be at the very high end of an individual with autism or an autistic individual. So we have to then retrain and ask them to come tour Melmark facilities - come see our individuals and talk to their families. It's really about educating the nature of the spectrum. And I think sometimes for those individuals who cannot speak, voices are getting lost. I think that often their families or their guardians are elbow to elbow with them making sure

they're okay every single day, and they almost have fatigue about advocacy because they're just trying to get through the next day. I think the challenge for us is the education of the wide range and needs of individuals and what the workforce also has to reflect that range and those needs.

David: Absolutely. How about we switch gears and talk about COVID. You mentioned earlier that you successfully led Melmark through the COVID pandemic by maintaining the delivery of services while prioritizing the safety of both your clients and staff. Where does your drive and resiliency come from?

Rita: That's a good question because I would say COVID tested me both personally and professionally in ways I could never have imagined. On March 14th, 2020, the governors announced the pandemic procedures and closing of many, many businesses. My mother died of COVID, and I was on the job about an hour after I buried her, begging staff to stay on the job. Even during the weeks leading up to COVID, I knew I couldn't give my family the time I needed to give them because I was responsible for almost 1,000 individuals with very vulnerable issues and that we were going to quickly have to pivot from a long-term care

see Melmark Interview on page 33

Inclusive Work from page 9

accessibility like high garden beds, use of electric or small hand tools which are lighter in weight than gas-powered or larger gardening tools, and job carving to assure assignments match the physical capacity and strengths of the participant. In addition, urban farmers assist with virtual or in-person training workshops or perform tasks requiring less dexterity. Non-physical accommodations include job coaching (as an accommodation allowing gardeners to fully engage in competitive employment, whether with job task analysis or modification, or training through cues, prompts, modeling, self-instruction or additional methods); and advocacy around S:US' policy (such as providing language supports, delivering in-person or virtual corporate training and policy communications, liaising with administrative support departments and/or Human Resources to overcome technical barriers in completing timesheets, adjusting personnel information, addressing payroll issues, obtaining employment records, or other related areas where extra support is needed). Each participant with a disability, whether an employee or a volunteer, is provided with job carving so that their responsibilities match their capacities and goals to grow as a gardener, or tailoring so that their strengths are in line with the tasks that are needed to be completed.

Valerie, a person supported by S:US' day habilitation program in Brooklyn, NY and who has an intellectual/developmental disability (I/DD), began as an Urban Farms volunteer and now works as an urban farmer. Valerie loves helping to grow vegetables and also cleans garden beds, prunes dead branches, adds mulch to trees to protect them from storms, helps make tables and benches, and works at an S:US Urban Farms booth at a local farmer's market. Due to having sore knees and using a rollator to assist her in walking, Valerie cannot bend a lot and stand for an extended period of time. Part of her job carving includes mobility supports allowing her to sit when needed, reducing, or limiting her bending, and working with raised garden beds. Valerie shared "...I like everything about my job except I don't like weeding because it's tough on my knees. But I like all the other parts. Working in the gardens motivates me; it keeps my spirits up, keeps me calm, and gives me ease because I am outside in nature." Through her work with S:US' Urban Farms, Valerie embodies biophilia, a desire or tendency to commune with nature. According to authors Bjørn Grinde and Grete Grindal Patil in the article "Biophilia: Does Visual Contact with Nature Impact on Health and Well-Being?" studies have shown that "...Nature can be beneficial for human health and well-being... More specifically, contact with Nature has been reported to have psychological benefits by reducing stress, improving attention by having a positive effect on mental restoration, and by coping with attention deficits."⁴ Michael Hollis and his urban farms team provide staff and volunteers with opportunities to connect with nature regularly, which strengthens a sense of biophilia, decreases stress, and cultivates a holistic work environment.

Angelo, a person supported by S:US' day habilitation program in Brooklyn, NY and who has a disability, works with S:US' Urban Farms one day per week. Because he has challenges with his short-term



Urban farmer Noel (left) uses a power tool to build a raised bed with the help of a volunteer

memory caused by his disability, Angelo works between 2-2 ½ hours per shift and is accompanied by his Job Coach, Andrea. The job is tailored to Angelo's needs by maintaining a shorter shift, including Andrea working alongside him in the garden to provide verbal prompts when he forgets something, plus breaking his tasks down into smaller steps to promote ease. Angelo comes from a long line of gardeners since his father, uncle, and grandfather cultivated their backyards and he helped them grow tomatoes, cucumbers, basil, and mint. Angelo shared, "...I like being outside in the garden with the sun and the wind. I don't have a lot of patience so it helps me to work for a short period and I like that we (Andrea and I) do the work together. I like the job." Wilfredo Ila, S:US' Urban Farms Coordinator, reminds staff to weave in compassion, provide breaks, and change the conversation topic when needed due to Angelo's low level of patience, to provide support and help him achieve his gardening tasks. All of these steps exemplify job tailoring for Angelo which helps him be productive, remain focused, and relaxed while working.

For Wilfredo, who is both an S:US' Urban Farms Coordinator and, at times, a Job Coach, it is important to him to provide a rich, engaging work experience for the farmers and volunteers; it is more about the experience they have when working in the gardens than how many pounds of produce or honey they help cultivate. Wilfredo and his colleagues always treat all of the gardeners, whether they are staff or volunteers and no matter what abilities they may have, with respect and kindness and provide good training with an emphasis on safety for them to follow security protocols. Some farmers use power tools to help build or repair garden beds while others care for the beehives to cultivate honey. All of the gardeners are proud of their work and this is more than a job to them. Wilfredo explained, "The key is how we impact their lives and how they change and grow. We give them training to enable them to have new experiences, develop as gardeners, and more importantly as people. They are proud of their work and it gives them a purpose and meaning to keep going."

S:US' Urban Farms would like people with disabilities to develop transferable skills to hone their ability to articulate their wants and needs, not only regarding

their job tasks in the garden but also in all areas of their lives in order to become stronger self-advocates. S:US' day habilitation services also partner with the urban farms team and job coaches in working together to prepare people with I/DD who desire to work, obtain a job, and maintain employment. Skills such as punctuality, building and writing a resume, and reviewing appropriate attire to look professional for job interviews are all taught, along with practicing and building upon communication techniques to foster connection once employed.

Rauly started as a volunteer at S:US' Urban Farms seven years ago, attends an S:US day habilitation program in the Bronx, NY, primarily speaks Spanish, and has an I/DD. From growing up on a farm in the Dominican Republic, he honed his love of the natural world. Over time, he has participated in trainings, has grown enormously in his farming skills, operates power tools and equipment, works well with the other volunteers, and likes to take on new challenges to deepen his skills. According to his job coach, Rauly is very independent and intelligent. He has grown in his English language skills too, and due to training provided by both his job coach and his day hab staff, has learned to travel independently to other boroughs for his job. As Rauly shared, "Work has been a challenge and I meet the challenges. I fell in love with garden beds – to build and repair them – and carpentry; I get to know the soil and I love it. There are different types of soil and it is good to know which ones are good for which crops to help them grow. Now I even grow my own herbs and vegetables at home in my own garden bed. I love nature. It helps me feel so happy and free, it releases stress and helps me feel calm or calmer when I am in the gardens doing this work." His Job Coach Wilfredo shared, "Before working in the gardens, Rauly never thought of traveling alone in his community or in New York City via the subway. The training that we provide has been so impactful on his life. Now he travels alone comfortably and has grown in his confidence and English language skills."

The positive impact of being in the gardens is a common theme in Rauly's experience along with other gardeners and volunteers. The environmental psychologist Judith Heerwagen, who has studied workplaces remarked, "Biophilia is just

exploding... People are happier when they are in a natural environment."⁵ Studies have shown that movement in nature has been "...associated with decreases in tension, confusion, anger, and depression, and a perceived increase in energy and feelings of positive engagement."⁶ Working alone, with a job coach or among a team, the gardens provide a holistic environment for staff and volunteers which promote a sense of calm, health and wellbeing.

In 2011, Noel, who lives with an I/DD, began as a volunteer of S:US' Urban Farms in the backyard of his home in Brooklyn, NY, managed by S:US. He then expanded to volunteer at other program sites. One of Noel's strengths is that he is physically strong and he likes to take on new challenges. With time and extensive training, Noel helps deliver wood and soil to newer gardens and supports building new garden beds since he is adept at using power tools through training that he received from the urban farms team. Noel shared, "My work takes energy to put together the (garden) beds, but it is relaxing and comfortable to me. I like it. I am proud of my work. I have learned how to grow so many vegetables and herbs. In the off-season, I help with the workshops, teaching healthy eating and cooking to the tenants at other homes. I also help train the volunteers on garden tools and caring for the garden. It is good. I like my job coach Wilfredo – he's kind, cool, and helpful. He helps me fix broken beds and learn new skills." For Noel and his co-workers, S:US' Urban Farms has had a positive impact on developing their skills as gardeners and empowered them to take on new challenges and grow. It is through the practices of job carving and tailoring, along with the accommodations to employ people with disabilities, that have made the gardens such an inclusive, impactful, and beneficial place to work and volunteer.

Another place of employment for people with disabilities is Domestic Personal Helpers (DPH) where Jesse and Robert, two people with an I/DD who are supported by S:US, are employed. In 2014, DPH, which was originally called Ditmas Park Helpers, was founded to provide snow and ice removal services, but soon expanded to offer more property maintenance and tri-state moving services. DPH offers various residential and commercial services, including but not limited to: home and business cleaning; decluttering and organizing; painting; clean-up and trash services; electronics recycling; junk removal; snow and ice removal; moving and delivery; furniture assembly; and other tasks as needed. The company hires skilled and experienced staff that are friendly and reliable. Jesse works mostly alone in outdoor maintenance one day per week in Queens, but sometimes works with a team. He rakes the grass to remove trash, sweeps sidewalks and pavements to keep them clean, and picks up garbage. He has a job coach, Ulysses, who makes sure that he has all of the supplies needed to do his tasks, helps him maintain his focus while working, and assists him with his schedule, payroll, timesheet, and work commute. Jesse shared, "I like my job coach Ulysses. He's great, helps me stay focused and organized, which I like. I like my job. DPH gives me the tasks and I do them. My mom taught me to always be a leader for other people so I am always a leader, a model, on

see Inclusive Work on page 24

Inclusive Work from page 23

my job. I do this in my job. I want to be good at it.” Robert, another person supported by S:US who has an I/DD also works at DPH at the same location in Queens. For two days per week, he sweeps and cleans sidewalks and pavements and assists co-workers in their use of heavy equipment such as leaf blowers or lawn mowers. Robert expressed, “I like my job. They give me the tasks and I get them done. I get along well with my co-workers, we laugh a lot together. I worked all the time during the COVID-19 pandemic because I am devoted to my job. My job coach Ulysses helps me with my commute for work, with my budget for my metro-card, and also helps me pay my bills. He has also assisted me in traveling more independently by using the MTA app and learning my way around the city.” Ulysses is a supportive asset to both Jesse and Robert, helping them with staying focused while working, making certain they have needed supplies to do their jobs, assisting them with their commutes, and helping them with budgeting. DPH fosters an inclusive work environment by hiring people with disabilities and making accommodations for them and their job coaches.

Cleaning with Meaning NY is another cleaning service based in New York City that employs people with disabilities. It is different from their competitors in four ways: they provide two cleaners for the price that their competitors charge for one cleaner; they use only top-quality cleaning products and supplies; they are fully bonded and insured; and they are a nonprofit organization and hire staff who have disabilities including I/DD. Their staff receive extensive training in both cleaning and customer service, and they support their staff in thriving and succeeding at their jobs. They believe that it has a positive benefit to employ staff with disabilities because it changes their lives.

Justin and Darren are two people with an I/DD who attend an S:US day habilitation program in the Bronx, NY and both work for Cleaning with Meaning at different lo-



Lori Lerner, LMSW, RYT-200 hr.

cations. For three years, Justin has worked two days per week helping to clean office space in the Bronx, NY with his job coach Deidre. Justin shared, “I like my job, it’s fun and I wouldn’t change anything. Deidre is kind, cool, listens well to me, and is respectful to me. When I can’t do something or don’t know something, she helps me learn it or shows me a new tool or method to clean in a hard-to-reach place. She’s so helpful.” For three years now, Darren has worked cleaning a commercial space once a week with his job coach Michael. Darren sweeps and mops floors, cleans tables, takes out the garbage, and works well with his co-workers. Darren shared, “My job is tailored to my strengths. I can lift heavy things like (cases of) water bottles and Gatorade – I’m good at it and it’s easy for me. I worked in cleaning at a different job and I have a good memory. My coach Michael supports me well, gets me the cleaning supplies I need, and makes sure that I do a good job. I like my job and I like to earn money.” For both Justin and Darren, they value working and the support that they receive from their co-workers and job coaches, which helps ensure their success in their jobs.

With insight gained from interviewing people with disabilities, staff, and job coaches, it is clear that a holistic work environment filled with the qualities of kindness, compassion, and respect, plus supportive job coaches that meet the individual needs of each person that they assist, supports the goal of employees with disabilities and I/DD to be successful in the workforce. Working outside in nature also provides a deeper connection to plant and animal life, and the experience of biophilia has a beneficial effect for staff and volunteers who work in S:US’ Urban Farms. Job coaches support people with disabilities to stay on task, maintain focus and concentration, complete their responsibilities with success, and advocate for themselves when they need help or assistance. In addition to the benefits of a job coach, the practices of job tailoring and job carving go even further, to promote engagement in the workplace by tapping into the rich resources of each employee’s strengths which allow them to become adept in new skills and areas, and shine in their job responsibilities. It is the progressive practices of S:US’ Urban Farms Director Michael Hollis and his team and other organizations that employ people with I/DD to hone their skills, connect to their job and co-workers, and find meaning and purpose while doing their job. The author Michael Carroll writes in his book *Awake at Work: 35 Practical Buddhist Principles for Discovering Clarity and Balance in the Midst of Work’s Chaos*:

“We can engage our jobs sanely and openly without giving up on success or disregarding our feelings or ambitions. What is required is surprisingly ordinary: simply to be *who we are where we are*, to subtly shift from *getting somewhere fast* to *being somewhere completely*. By taking such an approach, we discover not only a larger view of work but also a basic truth about being human: by genuinely being ourselves in the present moment, we naturally become alert, open, and unusually skillful.”⁷

A holistic work environment is essential in supporting people with varying

strengths, abilities, and disabilities in order to maintain employment, achieve work goals, embody authenticity, and commit to their purpose to complete meaningful work.

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Tragic Encounters from page 21

it just as they would a more conventional site. Because such sites are regularly monitored by federal, state, and local law enforcement, the autistic could easily find themselves arrested and their computer seized by police or federal agents in their own homes.

What is tragic about many of these cases is that the autistic who is arrested, and faces very serious charges with extremely severe penalties, was viewing this material strictly out of interest and curiosity; they are neither pedophiles nor predators of any kind (which typical consumers of such often are) and do not present a threat to anyone. They never even realized that they were doing anything wrong, let alone how serious it was.

This is yet another example of the law lagging behind current knowledge about autism. It is also an example of the law needing to catch up with the current state

of technology. My understanding is that the latter has long been the case in the history of the law: legislation is often written that does not anticipate subsequent developments. As technology advances, cases arise that were not anticipated at the time of the legislation, and miscarriages of justice can thus occur. This has been true for much of the modern scientific and technological age and is especially pronounced during periods of rapid technical development and change – the current digital, computer, and internet age certainly qualifies as such.

Autistics, Jurisprudence, and the Law

Having no education or other background in the law, my knowledge of and experience with such does not extend much beyond serving on jury duty a few times. During a jury trial, after the two sides present their cases in a courtroom, the judge “charges” the jury with instructions on what the law is, and how they are to

deliberate and arrive at a verdict. They are then sent to the jury room for deliberation.

In a criminal case that I served on, a few of the judge’s instructions made an impression on me. Years later, after my autism diagnosis, I reconsidered these in light of my new knowledge. In a criminal proceeding, the standard for convicting a defendant is that the prosecution proves its case “beyond a reasonable doubt.” The judge emphasized that this referred to what a reasonable person could assume, and not mathematical certainty. Having a strong math background, I found this very interesting – it meant that an innocent defendant could be convicted if the evidence was sufficiently convincing. This may work in the typical world, but in the autism community we know that, where autistics are concerned, things are anything but ordinary. Consequently, a case involving an autistic defendant can easily be misunderstood by a jury, which could then render an erroneous verdict.

Another element of the jury charge was that, in evaluating the credibility of a witness giving testimony, their demeanor should be a primary criterion. I was always perplexed by this but, after my diagnosis, became very disturbed by it. Autistics, who often have issues presenting themselves regarding body language, facial expression, and tone of voice can easily give a different impression than they intend to. An autistic person giving testimony in a case can be seriously misinterpreted by the jury and even by the court. If testimony is given by autistic criminal defendants taking the stand on behalf of themselves, the possibilities are nothing short of frightening.

Legislation, the legal system, even the law itself, need to catch up with much of what has been learned about the autism spectrum, its differences, and its challenges.

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Advocating from page 1

with “masking,” a term defined as, “hiding or disguising oneself in order to better fit in.” (National Autistic Society-NAS, 2022) Second, the accused autistic individual’s disrupted routine by law enforcement is inevitable. This disruption, to most accused people who are typically developing is alarming, but to an autistic individual the aftereffects are often felt over the long-term. Lastly, autistic individuals do not do well with novelty or new environments and new people. Law enforcement purposely harnesses the power of surprise in arresting accused individuals. This is often to make the process less dangerous for everyone involved, but for an autistic individual, this can create exaggerated reactions and effects. Unsupported social communication for an autistic individual is at best disheartening and disconcerting, but in the worst-case scenario can be a violation of an autistic individual’s civil rights. Civil rights violations are many times addressed in legal cases after the fact because autistic individuals do not spontaneously understand communication, especially under duress. However, high functioning autistics (HFA) do report that they can understand many social concepts but do not understand social concepts until processing the social interaction after the event, with one of their trusted persons.

Another pre-trial concern for autistic individuals is a pronounced history of social failure. Many autistic individuals have easily identified developmental histories of social failure dating back to preschool or earlier. Very shortly after an autistic child is introduced to the outside world or community, an identified set of abnormal, odd, or idiosyncratic behaviors can be noted by caregivers and peers outside the family. These noted differences frequently lead to the diagnostic process.

Upon receiving a formal diagnosis of an autism spectrum disorder (ASD),⁵ which the US Center for Disease Control’s 2020



Tyler T. Whitney, PsyD

surveillance suggests is 1 in 36 children, and which diagnosis is commonly made by age 8 in the US, begins documentation of the autistic individual’s recognizable atypical development pattern. Atypical development is often accompanied by alienation, rejection, ridicule, and in many cases constant teasing or “bullying” by the autistic child’s peers. Differentiating teasing and bullying can be recognized as, “teasing can be a type of communication, a social exchange, either positive or negative, but bullying is meant to hurt.”⁶

This pattern of social failure starting at a very young age leaves many accused autistic individuals not equipped to handle the direct and aggressive stance of law enforcement during an arrest or the ensuing investigation, the need to answer questions quickly in rapid succession, or the lack of familiar people present to support them in the US criminal justice system. Autistic individuals are prone to extreme detachment or fight or flight responses when they cannot manage their environment.

The vast difference between a young child with autism being ill equipped to handle social interactions and an accused autistic individual in the US criminal justice system is clearly observable. An autistic young child will break down crying or throwing a fit. This behavior signals to the caregiver to intervene. In the US criminal justice system, an autistic adolescent, young adult, or adult does not have anyone to intervene, despite underdeveloped or missing coping skills. Intense exchanges and aggressive tactics by law enforcement, attorneys, and the courts can quickly become abusive.

As a forensic/clinical psychologist for more than 20 years working in the United States criminal justice system in both state and federal courts, I recognize that high stakes criminal cases are often handled in spite of individuals with autism. Other recent autism research is reaching this conclusion as well: “Autistic individuals are encountering the criminal justice system as victims, offenders, and witnesses at high rates.”⁷ While recent research is focusing on policy change and system wide change, there are also individual changes that can be implemented. For example, while criminal justice system professionals recognize that neither state or federal justice systems currently have programs specifically designed to meet the needs of individuals with autism, it may be appropriate to give more training to law enforcement about identification of autism spectrum disorders. It may also be wise for prosecutors and judges to consider the impact of an individual’s autism on their thinking and actions related to a crime prior to issuing a warrant, indicting an accused individual, or arresting the accused. Ultimately, it benefits the US criminal justice system to understand each individual’s autism uniquely and consider their unique traits and behavior from an autism perspective instead of moving forward with the legal process, arresting, detaining, and more often than not, traumatizing an individual with autism, simply on

the neurotypical face value of their behavior. I hope this overview impresses others to support more research and reform in the United States criminal justice system.

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Guardianship from page 1

representative payees can help safeguard a financial future and manage benefits, while advance directives or power of attorney can assist with healthcare.⁶ At the least restrictive side, person-centered planning supportive decision-making promotes the maximum potential for self-determination.

Supported decision-making puts the person with a disability in control, allowing them to sign an agreement authorizing people they trust to assist them with making their own decisions. As of November 2022, 17 states and the District of Columbia have supported decision-making laws on the books, with other states trending towards those bills as well.⁷ Regardless of how much we rely on others in our daily lives, we all utilize some form of supported decision-making. Sometimes, I have difficulty with certain life decisions or want to bounce things off of my parents or friends, and I listen to their advice before deciding what’s best for me. Some of us feel more comfortable if a parent or partner comes with us to a doctor’s appointment to help voice our concerns. That is what is at the heart of supported decision-making: being able to lean on the people we choose to help us live our best lives on our own terms, and for the legal system to recognize that.



Guardianship might be the option that works best for some, but it certainly isn’t the one that works best for all. Autistic people and their families deserve to have options and carefully consider what is best – and be included in those major decisions whenever possible.

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of four books that guide neurodivergent people through professional and personal challenges. She is a consultant to top corporations and nonprofits that seek her guidance in creating a diverse workplace and a sought-after commentator on disability rights. The first openly autistic lawyer in Florida, Moss’ books include “Great Minds Think Differently: Neurodiversity for Lawyers and Other Professionals” and

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Assistive Technology from page 16

their education. Under either an IEP or a 504 Plan, students with ASD may be entitled to assistive technology. School districts have an obligation to assess children in all areas of suspected disabilities. Therefore, if a student with autism has difficulty accessing their education, assessments can be provided to determine what programs, services, and assistive technology can be useful for the student. School districts can provide assistive technology evaluations either in-district or via an outside agency to determine what type of assistive technology may benefit the student.

No-Tech, Low-Tech, and High-Tech Assistive Technology

There are three categories of assistive technology that can be provided to disabled individuals. No-tech is usually free to low-cost and requires little to no training. It can be something as simple as a pencil grip or slanted workspace. Low-tech assistive technology may have some cost associated with it and may require training; devices such as headphones or a modified keyboard would be considered low-tech options. High-tech assistive technology is the most sophisticated and is usually costly and requires extensive training. Devices such as an augmentative and alternative communication device (AAC) or specialized software would be considered high-tech.

A Closer Look: Augmentative and Alternative Communication Devices

The American Speech-Language-Hearing Association (ASHA) defines, Augmentative and Alternative Communication as "all the ways that someone communicates besides talking" (American Speech-Language-Hearing Association, n.d.). For those with communication impairments, including those with ASD, AAC devices can enable them to communicate functionally with the world around them. Within AAC there can be low and high-tech options. The Picture Exchange Communication System (PECS) is the presentation of



Anne Reynolds

everyday activities on pictures or cards. Higher technology options can include actual devices, such as an iPad loaded with specific software that can generate speech and be customized. This can enable an individual to participate in conversations, ask and answer questions, and to have the ability to socialize without having to speak verbally. Speech and language therapists often are the professionals that are most familiar with the utilization of these devices and should be a part of the evaluation, implementation, and training process, either through private therapy or within a school system.

ASHA notes that there are common concerns when deciding to use an AAC device. Concerns such as "Is my child too young to use a device?" or "Will using an AAC device will prevent my child from learning to talk?" are common and both are typically misconceptions about these devices. According to ASHA, children younger than 3 can learn to use a device, and AAC devices do not slow down communication skills; they actually can help in the production of speech and are used in tandem with verbal communication. Finally, people of all ages can use an AAC device to communicate,

not just children (American Speech-Language-Hearing Association, n.d.).

The Best Types of Assistive Technology for Individuals with ASD

When deciding what is the right type of assistive technology to use with children, adolescents, and adults with autism, the first place to start is by evaluating the educational and functional needs of that person. Evaluations such as speech and language, occupational therapy, physical therapy, assistive technology, and assistive and augmentative communication can be done privately, through a local education authority (such as a public school), or through a government agency. These evaluations can determine what the needs of the individual are, and what services and devices can support those needs.

Some of the most common assistive technology that those with autism access are visual boards which display routines, daily living skills, and schedules, sign language, PECS, AAC devices, stress balls, manipulatives, weighted blankets, and social stories and scripts which enable individuals to link visual information and strategies to improve social situations.

How to Obtain Assistive Technology

If you have a school-aged child between the ages of 3-21, you can request that your local school district evaluate your child. If it is determined that a student needs a program or service, either an IEP or Section 504 Plan can be developed. If you have or are an older individual with ASD, you can contact your state government to access support, including evaluations, therapies, and general assistance.

Impact of Assistive Technology on Individuals with ASD

In a 2018 study on the impact of assistive technology on individuals with autism, the authors found in a longitudinal study of the impact of assistive technology and ASD that the use of assistive technology demonstrated a positive increase in speech, social communication, and motor skills (Bollin, A., VanderMolen, J., & Bierwagen, T., 2018, p. 122). The authors noted

that in all the studies they reviewed on assistive technology and ASD, there was an "increase in abilities of children" (Bollin, A., et al., 2018, p. 122).

In sum, with the use of assistive technology, individuals with ASD can increase their ability to access services, communicate functionally, gain independence in navigating the world around them, and live a more fulfilling life.

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Love on the Spectrum from page 12

great things happen. Partlow's overarching philosophy with respect to her therapy work: "Lead with your humanity when providing human services."

Many autistic self-advocates including me, particularly those of us who have had to endure challenging if not traumatic behavioral therapy experiences, frequently cite the need for greater communication and understanding between the clinical and neurodiversity communities. It's refreshing to know that this is standard operating procedure at Project Hope, and Partlow is central to this effort. She teaches Project Hope's therapists about what autism is, drawing from her own lived experiences as an autistic, as it should be.

Partlow's efforts toward her colleagues are noteworthy in that knowledge of autism is essential if clinicians are to work effectively with their autistic clients. Other autistics I have come to know, as well as myself, know this to be true based on our own clinical experiences. If a thorough



Sam Farmer

understanding of autism is not there, then more harm is done than good. Partlow helps the Project Hope therapists build the relevant skills, screens the materials used to train new hires, and the written feedback

she provides is incorporated into the organization's training program.

All too often, autistic individuals struggle to compensate for their challenges, in part because the accommodations and supports we need in order to be at our best are not always there. Partlow found a way to address this issue by leveraging her dog training skills while training Finnegan, her black Labrador, to be her own service dog.

Finn, as he is often called, does what Partlow needs him to do for her. He is a source of stability in her life. He assists her in ways that help her cope with executive functioning challenges, including organization and time management, by retrieving certain items on command, responding to alarms, and incentivizing her to get out and do things with him which she otherwise would not do. Furthermore, Finn has received training in crowd buffering, which helps provide Partlow with personal space in congested environments. This training protects her from sensory overload, a vulnerability she

would otherwise have. What a dog, and what an impressive accomplishment by his trainer and owner!

Kaelynn Partlow's story is truly inspirational. Her story is a narrative of exceptional achievement in the face of challenge and adversity. My greatest hope for Kaelynn is that her therapy and teaching efforts continue to increase awareness, understanding, and acceptance of autism in society and inspire more success stories among those with whom she works; very realistic goals, considering what she has already accomplished.

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

Online Offending from page 11

no real sexual experience or knowledge. They may have limited peer relationships. A significant number have been exposed to pornography at a young age (10 years +). This exposure often portrays young children in a highly sexual way and the distinction between age appropriate and underage females and males is intentionally blurred (Mahoney, 2009). This may result in a preference for images of minors even as they become older. If the emotional maturity of the person is delayed by several years, their viewing may focus on that age group, which feels less threatening. Much of what they may be viewing online is fetishistic and outside the realm of conventional sexual behavior. Pornographic sites often prompt users to click on sites that are increasingly more violent, disturbing or that involve children. This may develop into online sexual addictions. Several have reported an addictive sequence of compulsive viewing, which led to a need for novel stimuli in increasing amounts to achieve sexual satisfaction. Autistic individuals may also seek out highly novel sexual content out of curiosity. It is therefore critical to provide sexuality education to those on the autism spectrum and discuss the highly addictive qualities of pornography.

Sexual Victimization Online

Lack of sexual experience and social naiveté combined with intense loneliness creates a perfect storm for those on the spectrum becoming victimized by sexual predators. Autistic young people are often easily deceived and manipulated by online pedophiles seeking pictures and videos. Clinicians have heard many of their clients discuss sending explicit photos online or allowing themselves to be videoed in sexual scenarios. Clearly, this is not just happening to those on the spectrum and is an issue that must be addressed with all adolescents and young adults. Sexting and sexual exploration online are common among teenagers (Madigan et al., 2018). The primary concern is the increased risk of those with autism to be the object of online sexual solicitation (Wells & Mitchell, 2013). Those with autism are at risk due



Mary R. Cohen, PhD

to their inability to detect deception or discern the motivations of these predatory individuals. They may not have the social maturity or knowledge of the boundaries of appropriate sexual behavior and may be operating with “social scripts” they learn in chatrooms or texting. Many do not fully understand the social implications of their imitative language.

Collecting / Completing the Collection

For many ASD individuals, their activities revolve around a specific interest: finding collecting, and “completing the collection.” This completion is necessary and results in the amassing of large amounts of images or other materials at times through file-sharing software. File sharing can result in large dumps of computer files to a receiver’s computer while it is left on overnight. Many illegal items may be embedded in these files and the receiver is unaware of the content. Besides being avid collectors, autistic individuals may also be adept at obtaining copyrighted materials and circumventing security controls.

Online Radicalization

Individuals on the autism spectrum are particularly at risk for joining cult-like organizations and radicalized groups. As these groups have proliferated online, the instances of radicalization are increasing. They are seeking a community where



Reginald Candio, PsyD

they will be accepted and are drawn to rigid ideologies that match their “black and white” thinking style. Many have decreased social contact and can be easily drawn into groups that encourage isolation from others. Those on the autism spectrum like the structure and routine that is associated with group affiliation. Some autistic individuals are highly impressionable and do not understand the motives or agendas of the group (Allely, 2022). They are seeking group acceptance and may be easily manipulated by group members. Due to their social naiveté, individuals on the spectrum are used as pawns by those who deceive them into thinking they are trusted allies. It is common to see ASD individuals “set up” by those more socially savvy to carry out risky or illegal actions on their behalf.

Parents for Peace, a public health organization that empowers families, friends, and communities to prevent radicalization, has reported an increase in cases involving individuals on the autism spectrum. They have observed that autistic individuals exhibit great fluidity in the ideologies they subscribe to from right-wing to left-wing extremism. Autistic individuals seem mainly drawn to the structure, rigid thinking style and the sense of belonging that these groups provide. Trauma also appears to be a significant factor in online radicalization. Autistic individuals have frequently experienced bullying and feel they have no locus of control.

Through their affiliation with a radical group, they hope to achieve a sense of control of their environment. Unfortunately, they can be further victimized by members of these groups. Therefore, education, understanding, and involvement of family members are essential to preventing online radicalization.

Dr. Mary Cohen is the Director of ASD Forensics and can be contacted at www.asdforensics.com.

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Special Needs Trusts from page 10

If you don't know anyone who meets these qualifications, you can look into hiring an independent trustee. This can be an individual or an institution, such as a bank or trust company, a professional trustee, an investment advisor or manager, an investment advisor, an accountant, or a lawyer. In addition to being independent, a professional trustee will usually have experience and expertise in managing trusts. If you aren't comfortable with having a stranger manage the trust, you may want to choose a family member and a professional trustee as co-trustees. The downside to hiring an independent trustee is that the trustee will charge a fee, which is usually a percentage of the trust, but this is generally well worth the benefits that a professional trustee provides.

If your child is a minor, or is over age 18 but not competent, you also will need to name a guardian for the child in your



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will. I am often asked whether the trustee and the guardian should be the same

person. You can do that and make it easier for the guardian to access the money your child needs without having to ask someone else for the funds. Alternatively, you can pick someone else: for example, one family member is more nurturing and can be the guardian, and the other more financially savvy and can be the trustee. Or you may want to keep both sides of the family involved, so you name the mother's relative as the trustee, and the father's relative as the guardian, or vice versa.

Whoever you choose as trustee, it is important to reevaluate your choice every few years. The person who is right today may not be right tomorrow. Your attorney can help you determine who is the best trustee for you.

How much money the parents need to leave to the special child is different in every case. If you don't have what you think is enough, consider purchasing life insurance to fund the trust. A second-to-die

(also known as a survivorship) policy often works well in these situations and is less expensive than a regular life insurance policy because the policy doesn't pay out until both parents pass away. A good insurance broker should be able to advise you about your options.

My son is now 30 years old. His behaviors are much better and usually he is a calm, happy young man. The estate plan with a special needs trust that we put in place 10 years ago is still our plan today, and my husband and I know that we have done what we can to make sure our son will have what he needs once we are gone. It may feel like one more thing to add to your already jam-packed life, but it is worth it for the protection it will provide your child in the years to come.

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Rights and Challenges from page 13

children regardless of their age. If our educational system were more inclusive, autism would be stigmatized less, and non-disabled people would learn from an early age about human neurodiversity and how to co-exist and accept autistic people for who they are.

It is no surprise that many autistic people, especially those who are multiply marginalized (e.g., people of color, women, or gender-nonconforming people), [mistrust police and others within the legal system](#). If one hasn't been around nonspeaking autistic people much, they will carry preconceived notions and misunderstandings due to stereotypes. This is the recipe for negative encounters (Parry & Huff, 2022). CommunicationFIRST Policy Director [Bob Williams](#) has stated, "Oppression takes place when we are not heard and are not seen." By fully including autistic people and others who have speech disabilities in society from a young age, including at school, nondisabled people will gain a better understanding of how to communicate in diverse ways and with diverse groups of people. Over time, people in the legal system - police, attorneys, and judges - will gain greater cultural competence in interacting with people with significant speech-related disabilities.

Title II of the [Americans with Disabilities Act, or the ADA](#), is a federal law that every autistic person and their loved ones should know about ("Introduction to the Americans With Disabilities Act," 2023). Title II says that people with disabilities have the right to equal access to state and local public services. That means that they have the right to accommodations that may be needed to allow them to have the same level of access and services as someone else without disabilities. For example, nonspeaking autistic victims and witnesses have the [right to testify](#) with any reasonable accommodations that might be needed to make sure they have the same opportunity to testify as a nondisabled victim or witness does ("Child Victims With Disabilities: A Guide for Prosecutors," 2022). The ADA has a special focus on ensuring access to effective communication. In interactions with state and local public entities, including schools, courts, and law enforcement, people with communication disabilities have the right to understand what is being said to them, and the right to be understood when they communicate. If a person needs communication "[auxiliary aids and services](#)" to understand and be understood, with few exceptions, they have the right to request and receive those accommodations (Mid-Atlantic ADA Center, 2017).

People with developmental disabilities, including autism, are [seven times more likely](#) to encounter police than people without disabilities (Larson, 2021). Police officers should know how to recognize when someone has a communication disability and how to comply with the ADA to try to bridge any communication gap with the other person. In May 2023, the U.S. Department of Justice (DOJ) filed a [State-](#)

[ment of Interest](#) in *Lou v. Lopinto*, a lawsuit filed by parents of an autistic teenager who died while officers in Jefferson Parish, Louisiana, were responding to a sensory episode the child was having (Clarke et al., 2023). The lawsuit claimed that officers violated the ADA by discriminating against the teenager's disabilities. In its Statement of Interest, the DOJ confirmed that law enforcement agencies can violate the ADA by failing to provide people with disabilities an equal opportunity to benefit from their services during emergency calls, and that "exigent circumstances" should not provide an excuse for failing to do so. In that situation, the officers should have reasonably accommodated the teenager's disability while interacting with the teenager, and before restraining him. State and local public entities may be able to avoid such tragic outcomes by taking deliberate steps to find a way to effectively communicate with the nonspeaking autistic person. That may mean consulting with the person's loved one, disability support professional, or other service provider to learn what the person may be communicating when they act a certain way, how best to communicate ideas with the person, and how the person needs to be accommodated more generally.

Other professionals in the state and local legal system also need to be aware of and comply with disability rights laws. Court personnel and judges who encounter people with speech-related disabilities, whether they are attorneys, jurors, witnesses, litigants, family members, spectators, or otherwise, must provide [reasonable accommodations](#) to ensure equal access to the court system for those people (*Guide to Judiciary Policy, Vol. 5, Ch. 2 § 255.10*, n.d.). Every state has a federally mandated, independently operated [Protection & Advocacy System](#) that aims to empower people with disabilities and advocate on their behalf (*Protecting Rights and Preventing Abuse of People With Disabilities*, 2023). If you are an autistic person who believes that your rights were violated, you have the option of [reaching out to your state's Protection & Advocacy System](#) for support or filing a complaint with the U.S. Department of Justice's [Civil Rights Division](#) (*NDRN Member Agencies*, n.d.; *File a Complaint*, n.d.).

CommunicationFIRST recently received seed funding to develop several toolkits on the communication rights of people with significant speech-related disabilities in the legal system. Be sure to [sign up for updates](#) (at the bottom of the home page of our website) or email us at info@communicationfirst.org for more information (*CommunicationFIRST*, n.d.).

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Autism Spectrum News
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Autism Healthcare from page 15

described in Federal rules, states' Medicaid plans are required to ensure that health concerns are screened for, diagnosed, and treated early before these concerns become more complex [and treatment more costly].

The EPSDT benefit requires Medicaid to "cover any service that is necessary to *treat or ameliorate* a defect, physical and mental illness, or a condition identified by a screen, regardless of whether the service or item is otherwise included in the state's Medicaid plan." Services under EPSDT must be sufficient in **amount, duration, or scope** to reasonably achieve their purpose [emphasis added]. The amount, duration, or scope of EPSDT services to recipients may not be denied or reduced solely because of the diagnosis, type of illness, or condition.

IDEA Part C

Under the Individuals with Disabilities Education Act (IDEA) - Part C, children with developmental delays and disabilities and their families are eligible for Early Intervention services and supports up to the age of three. Services covered under Early Intervention are tailored to meet the child's individual needs, are documented in an Individualized Family Service Plan (IFSP), and may include:

- Assistive technology (devices a child might need)
- Audiology or hearing services
- Speech and language services
- Counseling and training for a family
- Medical services
- Nursing services
- Nutrition services
- Occupational therapy
- Physical therapy
- Psychological services

IDEA Part B

The [stated purpose of the IDEA](#) is:

- to ensure that all children with disabilities have available to them a free appropriate public education that emphasizes special education and related services designed to meet their unique needs and prepare them for further education, employment, and independent living;
- to ensure that the rights of children with disabilities and parents of such children are protected; and to assess and ensure the effectiveness of efforts to educate children with disabilities.
- to ensure that educators and parents have the necessary tools to improve educational results for children with disabilities by supporting system improvement activities; coordinated research and personnel preparation; coordinated techni-



Eileen M. Mendes

cal assistance, dissemination, and support; and technology development and media services.

Services for school-aged children with developmental disabilities (3 through 21 years of age) are provided free of charge through the public school system. Among the services covered under IDEA are special education; related services such as physical, occupational, and speech therapy; and supplementary aids and services, such as adaptive equipment or special communication systems.

Before Part B services start, an Individualized Education Plan (IEP) is developed for children 3 through 21 years of age who qualify for special education services from school districts. An IEP is similar to an IFSP, but more focused on the child's goals rather than on the family's goals; however family input is still an important component. Goals may address communication, increasing social skills, or reducing behaviors that interfere with learning.

Under both IDEA Parts B and C, parents are provided with a Notice of Procedural Safeguards, which provides a full explanation of their rights covered under IDEA and provides information on the provisions in special education law that enables parents to be involved in educational decisions about their child.

[Compulsory age for school enrollment](#) is between 5 and 8 depending on each state. It is important to note that an IEP will be developed to address skills that are educational or academic in nature, whereas services funded through a health plan will focus on medically necessary intervention. While some overlap in goals between the two plans may occur, the plans and services are distinctly separate. Making the decision to enroll your child in school at the age of three or waiting until compulsory aged should be based on your child's individual strengths, needs, and progress with their current treatment providers.

Section 504 of the Rehabilitation Act of 1973

The Section 504 regulations require a school district to provide a "free appropriate public education" (FAPE) to each qualified student with a disability who is in the school district's jurisdiction, regardless of the nature or severity of the disability. According to the US Department of Education, Section 504 requires schools to provide students with disabilities appropriate educational services designed to meet



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their individual needs to the same extent as the needs of students without disabilities are met. An appropriate education for a student with a disability under the Section 504 regulations could consist of education in regular classrooms, education in regular classes with supplementary services, and/or special education and related services. In general, the goal of Section 504 is to accommodate students with disabilities in general education classrooms without discrimination. These accommodations should be documented in a plan, known as a 504 plan or Individual Accommodation Plan (IAP).

The goal of an IAP or 504 plan is to ensure a student has equitable access to a learning environment whereas an IEP focuses on educational benefits and often includes direct services such as ABA, speech, or occupational therapy. Both the IEP and the 504 are federally mandated services provided free of charge to students in public schools. Both require annual meetings to review and update the plan and families/guardians are required to be invited and included in all planning decisions. Parents may also invite outside service providers, advocates, attorneys, or anyone else they would like to have attend the meetings. Both plans require three year "recertifications" to assess continuing need for services.

Examples of accommodations under Section 504 may include environmental modifications such as sensory breaks, visual schedules, or use of noise canceling headphones.

Individual State Mandates

Coverage of Applied Behavior Analysis services through commercial health plans is mandated in all 50 states. The laws regarding coverage vary by state, and some may have limits, including age caps; however, advocates continue to work to strengthen, update, and amend state mandates with limits on access to treatment. State mandates do not relieve the public schools from their obligation to provide a free and appropriate education under IDEA Part B once the child is enrolled. It is important to note that state mandates do not include self-funded plans, as those are regulated by federal law, specifically the Employee Retirement Income Security Act (ERISA).

Affordable Care Act (ACA)

Under the Affordable Care Act, most health insurance plans are no longer per-



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mitted to deny, limit, exclude or charge more for coverage to anyone based on a pre-existing condition, including autism and related conditions. Additionally, plans must cover all essential health benefits, including coverage of those treatments needed for children and adults with autism. The ACA also prohibits discrimination on the basis of race, color, national origin, age, disability, or sex (including pregnancy, sexual orientation, gender identity, and sex characteristics) in covered health programs or activities. So, if your health plan changes after your child is diagnosed with autism, your new health plan cannot deny or limit coverage and you cannot pay more for your policy as a result.

Mental Health Parity Addiction and Equity Act (MHPAEA)

MHPAEA ensures that health plans treat mental health and substance use disorders the same way that they treat other health issues. This means insurers cannot have additional limitations, higher costs, lower coverage for mental health benefits, including treatment of autism. MHPAEA requires group health plans and insurers that offer mental health and substance use disorder benefits to provide coverage that is comparable to their coverage for general medical and surgical (medical/surgical) care. Limitations on mental health and substance use disorder benefits (such as copayments, visit limits, and preauthorization requirements) must generally be comparable with those for medical/surgical benefits. What this means for your family is that copays cannot be higher for your autism service provider than they are for other providers. If there are limits to how many hours of treatment they will cover, they should have similar limits in place on medical visits and treatments for chronic medical conditions such as diabetes or dialysis.

Given the rapidly increasing prevalence rates of ASD and what we know about barriers to access and early intensive treatment for best outcomes, it is important for families to know about laws that protect an individual's rights and options to timely access to care.

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Pendency from page 14

potential disruptions in their education. The knowledge that they will continue to receive familiar services and support can have a profoundly positive impact on meaningful educational progress and well-being. Without pendency, children with special needs face the risk of temporary and long-term interruptions or withholding of appropriate educational services during legal proceedings. Such interruptions could lead to significant gaps in their education, impeding their progress and hindering their ability to reach their full potential.

Tuition reimbursement cases most often involve parents seeking reimbursement for placing their child in a private school or specialized program that appropriately meets their child's unique educational needs after the school district failed to do so. Securing pendency allows children to remain in the last agreed upon educational placement while a subsequent due process case progresses, ensuring that the child receives necessary and appropriate services without imposing undue financial burden on the parents. During the subsequent litigation, the student is entitled to remain in the pendency program until the later matter is resolved.



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Navigating the Process

To secure pendency in tuition reimbursement cases, several crucial steps must be followed.

Parents must initiate due process proceedings by filing a complaint with the appropriate state or local agency. This formal complaint should outline concerns, explain



Tracey Spencer Walsh, Esq

the inadequacy of the programs, services and school placement proposed by the district, propose the solution sought, and request an impartial hearing.

Parents must clearly express in the complaint that they are seeking pendency or the maintenance of their child's current educational placement during the legal proceedings. Detailed information about

the child's last agreed upon placement and the services they are receiving should be included in the complaint.

Seeking guidance from knowledgeable special education lawyers is highly recommended. These professionals can navigate the complex legal process, ensuring that parents' rights are protected and effectively advocating for the child.

Conclusion

Securing pendency in tuition reimbursement cases is essential for preserving uninterrupted access to appropriate educational services for children with special needs. By understanding the significance of pendency and following the necessary steps to secure it, parents provide their children with stability, continuity of education, and protection during the legal process. Collaborating with special education lawyers empowers parents to effectively advocate for an inclusive education system that addresses the unique needs of the child with special needs. Let us work together towards a future where no child is left behind in their pursuit of quality education.

For more information about Spencer Walsh Law, PLLC, visit www.spencerwalshlaw.com.

Navigating College from page 17

support and counseling, such as [The College of New Jersey's Career and Community Studies program](#).

Degree Granting Programs - Other schools offer formal support programs within their traditional degree-granting programs. Websites such as MyAutism.org and HereOnTheSpectrum.com provide information about a variety of colleges that have robust programs geared toward students with ASD. The exact components vary by institution, but they often include academic support, counseling, peer mentoring, specialized housing, and social activities. Some of these programs do have an additional cost associated with them.

Disability Services Departments

In addition to specific programs for students with ASD, almost every college has a disabilities services office. Students with ASD should obtain information about the types of disability accommodations available to students, and how they can access them. Some schools require students to register with the disabilities services office prior to starting classes, and each subsequent semester or academic year. They may also require updated medical or educational documentation.

Students should make an appointment with the disabilities services office to discuss their needs soon after receiving an acceptance, and prior to accepting an admission offer. Students should be prepared to ask questions about the services provided, how to obtain them, and if any additional documentation is required. Questions can include:

- What accommodations do you offer?
- How do you qualify for them?
- What assistive technology devices do you provide?



Denise Gackenheimer Verzella, Esq, MA

- Is there a transition summer or program that is available to students with disabilities?
- Is there a cost for any of the services provided by your office?
- What is the four-year graduation rate for students with disabilities? How does it compare to the general student population?
- Does the office provide assistance if a professor does not comply with a student's accommodation plan?

In addition to direct questions, a lot can be learned about an institution's attitude toward students with disabilities, including ASD, by general observation. Is the disability services office appropriately staffed? Is the office in an area accessible to students? Is the office pleasant and well-maintained? There is a significant difference between a school that is simply providing the minimum legal requirements versus one that is supportive and welcoming of all types of students, including those with ASD.

Accommodations

While the specific accommodations avail-

able may vary by institution and student, these are some of the most common that are available to students with disabilities.

Extended Time for Exams - The availability of extra time on exams allows the student time to process what the questions are asking and respond in a way that permits them to provide complete answers that showcase their knowledge. In addition, the extended time may also help alleviate stress and anxiety often experienced by students with ASD during exams. This can be combined with an alternative testing site to allow students to take tests in low distraction environments.

Note-Taking Assistance - Providing professor notes, outlines from lectures, or having another student take notes allows students to focus on the material being taught in class instead of struggling to take notes.

Preferential Seating - Allowing a student with ASD to select a seat that minimizes distractions and sensory overload permits them to better focus on the material presented in class.

Counseling Services - Most colleges offer some form of counseling services to their students. Counseling focused on the stressors associated with college and navigating interpersonal relationships can be particularly beneficial.

Housing/Residential Life - Whether it is a single room or a room in a quiet dorm, the selection of housing cannot be overlooked as a key aspect of success in college. Having a space that is quiet and private can allow students who need to decompress and regroup with the privacy required.

When considering what accommodations a student may want to request, a good starting point is reviewing their IEP accommodations section from high school. This section will contain a list of the accommodations provided by the local school district

which may be useful in determining what accommodations they want to request.

Family Support

The most important part of any support system for students with disabilities is their family. In addition to providing financial and emotional support, there are several practical steps parents can take to assist their child. First, the student can provide a Federal Education Rights and Privacy Act (FERPA) waiver for the parents. This will allow the parents to communicate with administrators, staff, and faculty on behalf of their child so they can assist if there are any issues with things like financial aid, registration, housing etc. Next, the student may execute a power of attorney permitting their parents to take action on their behalf with banks, insurance companies, landlords, etc. Neither the FERPA waiver nor the power of attorney take away any rights or responsibilities of the student. They simply add another person who can act on their behalf.

Conclusion

Attending college is pivotal for many young adults. For students with ASD, this step may be more difficult than for a non-disabled student. However, there are academic programs that can support students who seek to attend, and complete, their college education. The level of assistance provided may vary by school, so it is important that students and their families research prospective schools and make an informed decision.

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see [Navigating College on page 32](#)

Immigrant Families from page 19

article is a parent advocate and a very active community leader.

Rubaiya Rahman founded ASHO, a non-profit organization dedicated to developing habilitation services for young adults with autism and creating a safe and supportive space for aging parents who are caregivers. Being an immigrant and a parent of a young adult with Autism, Ms. Rahman has faced significant issues, cultural bias, and lack of services while navigating the resources and understanding the legal options, being a lawyer herself. Professionals in Rubaiya's country of origin had already recommended that she seek support from the "western world" that was advanced in working with a child already diagnosed with autism. When Rubaiya landed in the USA, she was a law student and trying to understand the process of navigating the available resources. While she was here at her child's Early Intervention stage, to perceive Autism and what it means to her child and family was a challenge. Speaking to her child's pediatrician was helpful, as there she was able to follow the basic developmental milestone checklist, and was informed about getting the child evaluated and about enrolling in early intervention services. But what if the pediatrician misled the patient's family and ignored the virtue of medical ethics?

Unlike Rubaiya, DM (name changed per request) was not fortunate enough to find services for her child. DM is a legally documented immigrant, while her family members are permanent residents. By the age of 5 years, DM's child was showing issues related to socio-environmental and behavioral skills. The school labeled it as anxiety as the child would stop communicating with anyone in school, and soon, the child was also getting speech services as per her IEP goals. DM always advocated for her child and thought that the child's speech delay was causing the anxiety, hence leading to their showing anxiety in public. However, DM was never able to relax her red flags, and at every visit kept mentioning concerns that landed on the deaf ears of the pediatrician. Being from the same country of origin, the pediatrician crossed the thin line of biomedical ethics and, while negating DM's concerns about her child, lied that Autism is now simply a common label for children around age 5 and that nothing is wrong with the child. The pediatrician further commented that "immigrant kids are easily labeled as Autistic kids and DM would not want her child to be a part of that data." DM was unable to get a referral to get her child evaluated for her atypical behavior in social settings and lack of communication skills. She did not want to take steps against the provider as she had fears of retaliation from the provider and feared it may lead to some legal concerns for herself and family. The 5-year-old now had an IEP for speech delay and was getting mental health services for anxiety and selective mutism.

Post COVID-19 pandemic when the child returned to school, the child was verbal but now had issues with peers because the child had no social skills. While the vocabulary had increased, the child lacked finesse and repeatedly the school would complain to DM about their being rude and frustrated with teachers and peers. Soon the child was labelled for making racist comments in school and the situation seemed to be going out of DM's control. DM had to change the pediatri-



Veera Mookerjee, PhD, LMSW

cian to be able to move ahead, and so she did. She was finally able to get her child evaluated and now her suspicions were validated, as the child was diagnosed with ASD but a delay of 4 years had already passed because an early evaluation was discouraged by a culturally competent provider who forgot his biomedical ethics and denied the patient's parent/caregiver autonomy. While DM mentions that it was a relief to get the diagnosis, the delay led to bigger challenges in navigating the appropriate services. As soon as the child got the ASD diagnosis, the mental health clinic that was providing services backed out, terminating all services, by stating that the clinic is not equipped to serve individuals with Autism. Though resources were placed at the time of termination, the child currently has no formal mental health services, and DM is still trying to get the OPWDD to schedule an evaluation date via the county office. Prior to the diagnosis, the child was getting mental health services and DM was getting culturally competent parenting support and her child was getting weekly counseling focusing on daily social skills and better functioning that was helpful.

What if the child had been diagnosed at the right age? But with autism being a common diagnosis with behavior such as flapping hands and repeated activities, what if the evaluation was wrong? Often immigrant families face misdiagnosis due to stereotypical thinking and active professional assumption. To top it off, community members and relatives blame it on the non-immigrant society for labeling vulnerable immigrant children, especially children of color. One such case narrative is as follows.

RG (name changed as per request), a mother of two, raised concerns about her younger child's delay in speech and social skills. She was immediately referred to Early Intervention, and soon an evaluation was made stating that her child is on the spectrum, followed by about 10 hours of therapy services being started for the child that included OT, PT, and ABA therapy. Five hours of speech therapy were also added. Another strong mother, RG recalls when a so-called culturally competent speech therapist walked into her house and even before the official diagnosis was in, she diagnosed the child and told RG that her child is "severely autistic" and no speech can bring any language to him. The speech therapist never returned following

RG's request to the service coordinator. The ABA therapist who was from a different immigrant community was there to help the family. While the countries were different the culture was close for both the ABA therapist and RG. RG was able to share her concerns with the ABA therapist and, with quality services, the ABA therapist started pushing for a re-evaluation. To the ABA therapist who was an expert in ASD cases, RG's child showed other delays but none of those advocated for an ASD. Meanwhile the community member would call RG and blame her for "thinking too much" and often told her "these people have a habit of calling our boys crazy, you do not get your child evaluated as they will never let him grow up to be normal." While RG advocated for her child, a new speech therapist started to provide services and, similar to the ABA therapist, found manageable speech and feeding delays and requested for a re-evaluation similar to what the ABA therapist had requested. Re-evaluation negated the ASD diagnosis and explained the child had oral motor developmental delay and with speech and feeding therapy the child would be able to function better. The frustration was due to the lack of expressive language. RG reports that her child now sings and eats by himself. He is on his school soccer team and he "talks." RG has now relocated out of NY. However, even now after all these years, RG still struggles to get timely services for her child because at every administrative and bureaucratic level she has to prove that she is a naturalized citizen and is eligible for certain services to be approved earlier unlike for new immigrants who need to wait for clearance and approvals.

The cases do not do justice to the plethora of challenges faced by immigrant communities with or without the halo of immigration law. These challenges range from cultural bias to self-imposed lower community esteem to hesitation and of course lack of much needed services. Providers misleading consumers, crossing much needed ethical boundaries and creating insecurity are challenges for many immigrant community members who are hesitant and fear retaliation. Many community members often find the system complicated; it could be due to language or due to the long waits that often lead to impatience and lack of interest in services, or both. Also, the stress due to legal status cannot be ignored.

While we, on a daily basis, discuss and share information about Diversity, Equity, and Inclusion, I have yet to see a significant change in addressing the autism needs of the immigrant population. These community members and caregivers are looking for culturally competent service providers who provide the right kind of services, and neither make statements based on assumptions nor practice out of their professional scope. Challenges in immigrant communities are often laced with language barriers, culture shock and lack of perception about diagnoses and their prognoses. While many typical American families are open to sending their young adults to group homes, and create a foundation/trust for the care of their child with autism, various immigrant families by virtue of their principles do not have this concept of sending their children away to group homes. They may feel somewhat more comfortable if there are residential spaces where similar community members

reside so that when aging parents come to see their children, they also get an existing parent support group. Lack of English proficiency and hesitation to ask questions or advocate for services are common issues with some major immigrant communities that are also the fastest growing communities, especially in NYC. Being aggressive and seeking answers is not considered positive behavior in certain immigrant communities and sending children with physical or mental challenges to group homes is taken as lack of care and love. It is hard for many immigrant community parents to part from their young adults with a diagnosis, and to place them in a group home is not a regular caregiving practice. Of course, developing a trust and a foundation is often impossible for immigrant community members who work multiple jobs to make ends meet and strive for financial security.

As a professional in the field for nearly 20 years and working with immigrant communities, it is very easy for the author to identify the issues and list them. The real work comes when the issues are listed and need to be resolved through affordable recommendations. To address the challenges, it is important that professionals understand the caregivers' perception of the diagnosis and use appropriate language to build trust and rapport so that services and knowledge can be adequately transferred. Cultural competency can be used for service efficacy and must not be misused for crossing professional boundaries and the scope of practice by the provider. Immigrant community members should not experience isolation due to a diagnosis but should get supports that would take away their hesitation to advocate for their children, and for themselves, without the fear of retaliation. Often families migrate to seek better life outcomes for their families. These expectations of life should be taken care of when addressing Diversity, Equity, and Inclusion, because this also includes ableism and ensuring appropriate outcomes for a significant representative of our future.

When we think of legal issues and immigrant communities, we automatically start thinking about visa status, permanent residencies, naturalization and the scope of services and benefits with each level of immigration status. As correctly mentioned by one of the parents quoted in this article, Rubaiya Rahman, who is also a lawyer and works closely with the community, first it is important to acknowledge that the community has these unaddressed needs; services are required in a timely manner and made accessible to the community regardless of the immigration status of the children. Professionals should be legally answerable for practicing outside their scope of licensure and be mandated to follow patient/caregiver autonomy if the patient is a minor. Culturally competent legal advisors should be available for parents to discuss the future for their children so that life's planning can be made smoothly and appropriate to the needs of the individuals with diagnoses. Only then can we design an effective and legally sound service plan for the individuals with an ASD diagnosis.

Veera Mookerjee, PhD, LMSW, is Founder and Director of Resolveera - Serving Underserved Populations. Dr. Mookerjee is also Westchester Division Director for the National Association for Social Workers (NASW) - New York State Chapter.

Autism and the Law from page 15

Mental Health, Disability | EurekaAlert!”). In an Ontario study of 284 youth and adults with autism conducted over a period of 18-months by the Centre for Addiction and Mental Health (CAMH), 16 percent of the study participants reported interactions with police. In one-third of the incidents, adverse police action increased the autistic person's agitation, worsening the situation. The study's author, clinician-scientist Yona Lunsky, suggests, "If police maybe don't recognize or understand that there's autism there, they don't have the right sensitivity to respond" (Boisvert).

Terrifying Encounters

Ryley Bauman, 16, who is non-verbal and functions at the level of a seven-year-old, was playing in a park behind his grandparents' house when he was apprehended by officers who believed he was on drugs. Spending time in a holding cell traumatized him. Ryley now clings to his parents and, according to his father, has been robbed of his hard-won independence (Snowdon).

In March 2021, an 11-year-old autistic boy, highly sensitive to touch, was arrested for poking a classmate with a pencil, after the other student wrote on him with a marker. Bodycam footage showed officers grabbing him, pushing him against a desk, ignoring his screams that they were hurting him, and putting him in the back of a patrol car. Left alone in the car for two hours, the terrified pre-teen repeatedly banged his head on the plexiglass, badly bruising his arms and forehead, requiring hospitalization (King).

What Causes Aggression in Autism?

While no one is 100 percent certain, numerous factors have been linked to autistic "rage" and aggression, including information and sensory processing impairments, insomnia, impaired communication (Sarris) plus medical/metabolic disorders such as pain, seizures, GI issues, medication side effects, low blood sugar, vitamin/mineral deficiencies, hormone imbalances, anxiety, OCD, and more (Panol).

Anger is Common in Autism

Obsessions combined with negative emotions often turn into anger rumination. Reliving stressors and the difficulty expressing emotions in ways others understand can lead to outbursts of irritability, anxiety, and anger. Anxious, frightened people tend



Annie Kent, MA

to seek out ways of managing or alleviating their negative emotions. Sometimes in ways that may not conform to social norms.

People with autism have few defenses and are vulnerable to bullying, intolerance, and negative behavior from others. Unfortunately, many of the things that upset those of us on the Spectrum may seem petty to our [neuro]typical peers. Warning signs of aggression include:

- Fear, anxiety
- Unwillingness to leave, or enter a room or residence
- Sweating, shaking
- Self-abusive behavior
- Covering eyes or ears
- Pacing, hand flapping, rocking
- Lashing out

Language

We use many terms to define autism: e.g., anxiety, executive functioning, bullying, social ineptitude, and sensory sensitivities. But we seldom talk about *frustration*. Frustrations accumulate. They stem in part from our cognitive rigidity, plus the fact that the NT world feels like an alien culture. We're misunderstood, struggle to make friends, and often fail to reach our potential - which can lead to un-or under-employment and homelessness. We're outsiders and many of us are lonely.

Autists do behave badly at times. But, according to Lunsky, the big problem is, "If police maybe don't recognize or understand that there's autism there, they don't have the right sensitivity to respond... [P]olice need to be on the lookout for behaviours like repeating commands, avoiding eye contact or not responding to an officer's questions" (Boisvert).

Working Together Toward Solutions

Better and more extensive police training on recognizing traits and behaviors signifying a person may have autism is vital. Being the subject of a police enquiry is frightening for anybody. And common "police tactics such as ramping up instructions, moving closer or even making physical contact can quickly backfire," (Boisvert) escalating an incident to dangerous, even lethal, levels.

Cognitive Behavioral Therapy can help the autistic person better understand their own behaviors and teach them more productive coping skills. Police officers can receive training. And parents/guardians or caregivers of autistic children and adults can help by discussing, planning, and preparing for situations where law enforcement officers may be summoned.

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

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Autism Spectrum News Fall 2023 Issue

"Supporting Parents, Caregivers, and Family Members" Deadline: August 30, 2023

Contact dminot@mhnews.org for details on advertising and/or submitting an article

Navigating College from page 30

the Director of Student Services for a New York area law school where she was responsible for providing accommodations for law students with documented disabilities.

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Dangers from page 17

anything viewed online is public, even when viewed in a private space. All Internet Service Providers are required by law to provide information on viewers looking at child pornography. Any time a person views child pornography, law enforcement is notified potentially leading to a knock at the door. It is important to educate individuals of all ages to understand child pornography is illegal and, if viewed or accidentally clicked on, to immediately close the laptop, turn off the device and let a safe person know.

It is surprisingly easy to access pornography online and for free. Child pornography images are readily available through virtually every Internet technology, including social networking websites, file-sharing sites, photo-sharing sites, gaming devices, and even mobile apps (2020 [Child Pornography \(justice.gov\)](https://www.justice.gov/criminal-ceos/child-pornography#:~:text=Child%20pornography%20is%20a%20form,less%20than%2018%20years%20old)). The ease of accessibility may lead to viewing and/or downloading of the material

Individuals with ASD need the education to understand child pornography is illegal and why. A person with ASD may see a child smiling in a picture or video and think the child is happy and not understand that children under the age of 18 cannot provide consent according to the law and are victims of sexual abuse. Some states

**Arlene Lechner, MED**

consider the age of consent to be younger than 18 years old, but when child pornography is concerned, any depiction of a minor under the age of 18 engaging in sexually explicit conduct is unlawful ([What Legally Makes It Child Pornography? - HG.org](https://www.hg.org/legal-articles/what-legally-makes-it-child-pornography/)).

“People on the autism spectrum are notoriously law-abiding rule followers, but if they don’t know a rule, they don’t follow it,” said Dr. Lynda Geller, a clinical psychologist specializing in the unique

**Melissa Hochberg, MED**

challenges of individuals with ASD. This highlights the need for people with ASD to receive this education.

There is an urgent need for education on online safety and child pornography. Parents and carers are often reluctant to talk about these topics. The education must be comprehensive and explicit, utilizing visuals, discussions, scenarios, and must be made available and accessible for everyone with Autism Spectrum Disorder. This

education is offered by Ease and can be accessed at www.EaseEducates.org.

Take the time to educate your children and prevent the heartbreak of a knock at the door.

Additional Resources for Parents

- [Defend Young Minds](#)
- [NetSmartz](#)

To learn more about Ease Empowerment, Advocacy & Sexuality Education, LLC, please contact Arlene Lechner, Med, and Melissa Hochberg, Med, at EaseEducates@gmail.com and visit www.EaseEducates.org.

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Melmark Interview from page 22

system to a medical system. I have never been so grateful for picking a public health degree from Boston University in my life, and I will sing their praises forever. When I started to meet with the state legislators or some of the governor’s team, people were saying, “It’s going to be over in three weeks.” And I thought, “Oh no it’s not.” I was able to pull out my textbooks from 20 years ago and say this is what a morning is going to look like as you transition children into early intervention or into school. You have 68 exposures, immediately within two hours.

You asked me about where my resilience comes from. I like to consider myself a behind-the-scenes fixer. Doing these interviews are very difficult for me - I prefer to work behind the scenes. I’m a grinder. If you’re familiar with hockey, I’d be the player in the corner, figuring out solutions. I knew right away what we needed and I called in my siblings - I have 13 siblings, some of them are who are at high levels in healthcare - and said, “I need PPE, I need this, how can I get it?” I told my CFO that we’re going to wire funds to China to get PPE and he thought I was out of my mind. And we got them through a supplier who supplied NASCAR in Charlotte, North Carolina, because they used them in the pits and NASCAR wasn’t going to be running. I pulled out everything I’d done for 42 years. I had no problem going across the street to my neighbors who worked in the pharmaceutical industry. It was a very difficult period of time for Melmark, but we had full PPE for every staff before we ever had a case of COVID. We had on-site testing by April 7th of 2020 before some hospitals did.

But during that period of time, I had lost my mother to COVID, my sister died weeks later of cancer, and I was working 20 hours a day. I had a friend at McLean Hospital and said to them, “I’m not sure I’m going to survive being CEO of a multi-

state organization during a pandemic.” Also, a couple of my own children were struggling. The work stoppage during the pandemic meant that their careers, which are athletically-based, suddenly stopped a career that had been very difficult for them get to that point professionally, in terms of athletics. We had so many issues going on. I went from an empty nest syndrome to five children being at my home, including a student from Canada. So, I reached out and I got a professional coach. This was the first time that I’ve ever seriously had a mentor. This professional coach is still my coach today and we worked on establishing some balance, telling myself that you’re not going to fix COVID.

We had leadership teams at Melmark that stepped up across three states. We had done a lot of work since our 2017 strategic plan. We have incredible training systems that I would tell you are probably state of the art in the United States, and we pivoted. We used those same training systems to develop medical care. We developed COVID-positive units. Nursing taught us how to do things. We did testing, we became clinic-based, we got approval for clinics to do on-site testing, and we did it fast.

While we looked very resilient and we bounced, I would say a leadership team worked every single day during a COVID meeting in the morning, talking about cases and we ended every meeting with a bad dad joke from Sean Quigley, our COO. We tried to keep balanced and lighthearted about it, and in November of 2022, we had another surge where we lost about 20% of our workforce and I thought, “We are never going to ever see the end of this.” It was devastating. It was right before Thanksgiving. Staff could never get a break and we did it again. And then we went through that and here we are today.

I think very often when people talk about these care systems, we don’t really talk about the leadership teams who, at great personal cost, kept these organizations

open. And even I can hardly talk about it because it’s so emotional for me. I think my point of making it so detailed is to remember those people across the United States who took care of our most vulnerable individuals in nursing homes and very, very disabled individuals in long-term care programs. We’ve kind of forgotten them in the next legislative budget process. As inflation has gone up 14%, many states have given zero increases to long-term care services. That’s a problem.

David: Yes it is. It sounds like you used all the resources you had and got creative and, with your tremendous staff, Melmark made it through COVID successfully, even given such a terrible situation. As we come to the end of our conversation, can you share what inspires and motivates you to persevere through challenges and achieve your high standards of excellence?

Rita: Absolutely. I think as a young clinician, I was a good clinician, but self-injury, aggression, those kind of things really always broke my heart every single day. And then I saw clinicians and educators and folks like our Chief Clinical Officer, Frank Bird or Helena McGuire, our head of the Massachusetts divisions, do work that was incredible. And I always felt that I’m not as skilled in that area, but I can build systems of care and will beg anyone for money for disabled individuals. I will do anything to get the right care for individuals with disabilities so that those clinicians and educators should do their work.

So, the inspiration for me is every meeting that we lead with mission moments that talk about our core commitments and some successes. Every time I hear about what our staff has done to improve the lives of individuals, I can’t imagine that I was ever going to be that good, right, in terms of that kind of work. And then I’m inspired by the staff that do it. You know, we met recently with our founding team in Stoughton,

Massachusetts, for our new day school and the skill level at a fairly young age, married with the mission of Melmark - I can’t wait to see what they can do. It’s inspiring. They’re going to bring the next generation of Melmark to a whole new set of individuals just like our staff in the Carolinas. I think about if it was my son or daughter, or my brother or sister, and they needed care, are we good enough? I think that inspires me to work very, very hard. And quite frankly, I think our leadership team across the three states is unmatched. They’re just so committed to the mission and the core commitments. And then they just happen to have incredible technical expertise. So, what inspires me every single day is our work and the outcomes that our incredible staff achieve.

David: You know, I have visited Melmark, New England, toured the facility, and met some of your wonderful staff and I think “inspiration” is a great word. You just feel it from their energy and camaraderie, and as you said, it’s the staff that really do the hard work to keep operations going.

Rita: There is no question. The care point of contact is exceptional, and it’s the thing that matters the most. Absolutely.

David: Rita, I want to thank you so much for your time. It’s been such a pleasure to speak with you to learn more about Melmark and your role as a leader and advocate for people living with autism and developmental disabilities.

Rita: Thank you, David!

David: To those watching, for more information about Melmark, please visit Melmark.org. And be sure to also visit AutismSpectrumNews.org and browse our free online library to find information you can trust and get connected to quality resources in the community, just like Melmark!

Mesa, Arizona: Leading the Way as an Inclusive and Accessible Travel Destination

By Alison Brooks, CATP
Vice President
Destination Experience and Advocacy
Visit Mesa

Mesa, Arizona has emerged as a groundbreaking destination, setting new standards for inclusivity and accessibility. With the prestigious title of being the first-ever Autism Certified City in the United States, designated by the International Board of Credentialing and Continuing Education Standards (IBCCES), Mesa has established itself as a pioneer in creating a welcoming environment for individuals on the autism spectrum.

The efforts behind this remarkable achievement were led by [Visit Mesa](#), the city's official destination marketing organization. Recognizing the unique challenges faced by travelers with autism spectrum disorder (ASD), particularly for families, Visit Mesa initiated a comprehensive program to encourage local hospitality businesses to participate in specialized autism training. The training was specifically designed to equip executives and front-facing service staff with the knowledge and skills needed to better understand ASD and effectively cater to the needs of ASD travelers.

The response from the community has been extraordinary, with nearly 5,000 individuals in Mesa committing to or completing the autism certification. This impressive number reflects the city's deep-rooted commitment to ensuring that individuals with autism and their families feel supported and valued throughout their visit to Mesa.

To further assist travelers with autism, Visit Mesa provides the Autism Travel Guide, a valuable resource available for download on their website, [AutismTravelMesa.com](#). This guide serves as a comprehensive reference point for families and individuals with autism, providing them with a complete list of Certified Autism



Centers in Mesa. By offering this guide, Visit Mesa ensures that families and individuals can confidently plan their trips, knowing that they will receive the necessary support and understanding throughout their visit.

Building on their commitment to inclusivity, Mesa has embraced the [Hidden Disabilities Sunflower Program](#). Originating in the United Kingdom, this globally recognized initiative aims to provide additional support and assistance to travelers with hidden disabilities. By wearing a distinctive lanyard, individuals can discreetly indicate to service representatives in the hospitality industry that they may require extra attention or assistance during their journey. Visit Mesa believes that the implementation of the Hidden Disabilities Sunflower Program is a significant step in extending support to all visitors with disabilities, particularly those on the autism spectrum. "The Hidden Disabilities Sunflower Program is a wonderful way to support all visitors who have disabilities that are not easily seen, particularly for those

on the spectrum," states Alison Brooks, Vice President, Destination Experience and Advocacy at Visit Mesa.

Furthermore, Mesa has taken significant strides to enhance accessibility for individuals with visual impairments. The city now offers [Aira](#), an on-demand visual interpretation service that caters to the needs of visually impaired visitors. Prior to their arrival, travelers can download the Aira app on their smartphones and gain access to trained Aira agents who can provide assistance with trip planning. Once within the city limits of Mesa, visitors can utilize this service to navigate public buildings, attractions, restaurants, hotels, and more. The availability of Aira, free and unlimited for use while planning a trip to Mesa or exploring local attractions, demonstrates Mesa's commitment to ensuring that all visitors, regardless of visual impairments, can fully enjoy and experience everything the city has to offer.

In a strategic partnership, Visit Mesa has joined forces with [Wheel the World](#), a third-party booking engine specializing in

accommodations and attractions for people of all abilities. This innovative platform connects visitors to facilities that best suit their individual accessibility needs, ensuring a seamless and enjoyable travel experience. In addition to facilitating bookings, Wheel the World also offers comprehensive and detailed accessibility information, allowing travelers to make informed choices that align with their specific requirements.

To complement these initiatives, Visit Mesa has made comprehensive information readily available on their website to cater to travelers of all abilities. The website showcases virtual tours of many hotels, attractions, and restaurants, providing a unique accessible perspective that includes features such as parking lots, restrooms, and ADA rooms in hotels. This detailed accessibility information empowers travelers to make informed decisions about their accommodations and plan their itineraries accordingly.

The commitment to creating an inclusive and accessible destination extends beyond these individual programs and initiatives. It is ingrained in the culture of Mesa, as evidenced by the city's ongoing mission to ensure that Mesa, Arizona is regarded as one of the most accessible travel destinations in the nation. Visit Mesa continues to work diligently to expand and enhance their accessibility initiatives, seeking out new ways to accommodate the needs of all travelers. By prioritizing the unique needs of individuals with autism and hidden disabilities, Mesa has not only enhanced the travel experience for those visitors but has also set a shining example for other communities to follow. With each step taken towards accessibility, Mesa brings us closer to a future where travel is truly inclusive, allowing everyone to explore the world and create lasting memories.

Alison Brooks, CATP, is Vice President of Destination Experience and Advocacy at Visit Mesa. For more information, visit [www.AccessibleMesa.com](#).

Resolving Conflict from page 14

or agree on the financial needs for a child with a disability. It is important to understand current expenses and costs to support the child, including therapies, private schools, special diets, medical costs, supplements, as well as basic living costs. Sometimes when one parent is the breadwinner or handles the finances, or if one parent is the caregiver and handles the child's special needs and services, the other parent may not be aware or have visibility to the child's expenses and funds needed to address their needs. It is important to not just develop a plan for current expenses, but to also plan for future needs, since many children on the spectrum may not be able to be fully independent adults.

Once both parents have a handle on the costs needed to raise and provide developmental opportunities for a disabled child, the next challenge is how to fund those needs as part of the divorce. Funding can be in the form of child support, setting mon-



Mary Ann Hughes, MBA

ey aside in third party trusts or other accounts, as well as agreed to contributions

to schools, therapies, or programs. Parents should discuss who will fund and provide health insurance coverage for the child. It is important to set up life insurance to fund the child's needs if something happens to one or both parents, but it is advisable that the beneficiary of the life insurance policy should be a third party trust, and not the disabled child, so the child can maintain eligibility for government benefits. Some states or agreements allow for extended or indefinite child support past age of emancipation, but to maintain eligibility for government benefits past age 18, ongoing child support can be paid into a first party supplemental needs trust. Financial and legal considerations can become complex, so working with professionals knowledgeable in special needs planning is helpful. Working through the financial planning and payments to support a child on the spectrum can be one of the most overwhelming and conflict-producing aspects of a special needs divorce.

So what should divorcing parents do to limit conflict and work towards what is

in the best interest of a child on the spectrum in a divorce? To make the divorce more child-centric, consider the child's diagnosis and needs, jointly develop a plan to meet and fund the child's current and future needs, discuss how each parent will spend time with the child to minimize changes in the child's routine, and respectfully communicate with each other. Not only will working jointly and agreeing on these aspects of taking care of the child during and after divorce save time, money, and effort, but it will also provide a better and healthier co-parenting environment to help the child develop and thrive.

Mary Ann Hughes, MBA, is a Special Needs Certified Divorce Coach and is Founder of Special Family Transitions LLC. For more information and resources on special needs divorce, please visit [SpecialFamilyTransitions.com](#) and follow us on [Facebook](#), [Instagram](#), and [YouTube](#). You can also reach Mary Ann at mary-ann@specialfamilytransitions.com.

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