

# AUTISM SPECTRUM NEWS

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INFORMATION, ADVOCACY, AND COMMUNITY RESOURCES

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## Staying Safe with Autism

### Bullying and Youth with Disabilities and Special Health Needs

By StopBullying.gov

Children with disabilities - such as physical, developmental, intellectual, emotional, and sensory disabilities - are at an increased risk of being bullied. Any number of factors - physical vulnerability, social skill challenges, or intolerant environments - may increase the risk. Research suggests that some children with disabilities may bully others as well.

Kids with special health needs, such as [epilepsy](#) or food allergies, also may be at higher risk of being bullied. Bullying can include making fun of kids because of their allergies or exposing them to the things they are allergic to. In these cases, bullying is not just serious, it can mean life or death.

#### Creating a Safe Environment for Youth with Disabilities

Special considerations are needed when addressing bullying in youth with disabili-



ties. There are resources to help kids with disabilities who are bullied or who bully others. Youth with disabilities often have

Individualized Education Programs (IEPs) or Section 504 plans that can be useful in crafting specialized approaches for pre-

venting and responding to bullying. These plans can provide additional services that may be necessary. Additionally, [civil rights laws](#) protect students with disabilities against harassment.

#### Creating a Safe Environment for Youth with Special Health Needs

Youth with special health needs - such as diabetes requiring insulin regulation, food allergies, or youth with epilepsy - may require accommodations at school. In these cases they do not require an Individualized Education Program or Section 504 plan. However, schools can protect students with special health needs from bullying and related dangers. If a child with special health needs has a medical reaction, teachers should address the medical situation first before responding to the bullying. Educating kids and teachers about students' special health needs and the dangers associated with certain actions and exposures

*see [Bullying on page 20](#)*

## The Link Between Autism and Suicide Risk

By Marina Sarris  
Interactive Autism Network  
Kennedy Krieger Institute

Mr. A, a middle-aged chemist, came to a Baltimore emergency room after a suicide attempt. He said he was "thoroughly depressed." He had been fired after throwing a chair at his boss, not his first outburst at work. Doctors admitted him to the hospital, where they became suspicious of his rigidity, social awkwardness, and trouble making eye contact. After talking to his parents about his childhood, hospital psychiatrists settled on an unexpected diagnosis. In addition to psychiatric and alcohol abuse problems, Mr. A. had autism spectrum disorder, they said.<sup>1</sup>

Researchers and doctors alike are focusing on a link between autism and suicidal thoughts, plans, or actions. Suicide is the second leading cause of death for teenagers and young adults in the United States and abroad.<sup>2-5</sup> In the U.S. alone, almost 6,000 youth died by suicide in 2015; many, many

others thought about it, or tried to end their own lives.<sup>6</sup>

A growing number of scientists want to know more about how this public health crisis affects people with autism spectrum disorder (ASD). Studies show that people with autism are at higher risk for suicidal thoughts, plans, or actions than the general public, although how much higher varies widely among the studies.<sup>5,7-14</sup> The evidence that suicide is a critical issue in autism is "increasingly strong," two researchers concluded after analyzing 13 studies about it.<sup>12</sup>

"It's shocking and sad," said Alycia Halladay, PhD, of the Autism Science Foundation, in a 2018 podcast, "Sobering Statistics on Suicide."

#### Risk Factors for Suicide in ASD

What's behind these sobering statistics? Some of the risk factors for suicide in the general population occur more frequently in people with autism, although scientists do not know for sure if these factors have the same influence in ASD.<sup>12</sup> For example:

- Children with autism are bullied at a much higher rate than their unaffected brothers and sisters.<sup>15</sup> Research shows that both bullies and their victims have a higher risk of suicidal thoughts and attempts.<sup>16</sup>
- People with autism have higher rates of underemployment or unemployment than the general population.<sup>17-19</sup>
- Youth and adults with autism have higher rates of depression and social isolation than others.<sup>14,20-22</sup>

A 2015 study of adults with autism in Northern California, for instance, found they had double the rate of depression and anxiety, and eight times the rate of bipolar disorder, than adults who do not have autism. They also were five times more likely to try to kill themselves. To put that in perspective, about 1 in 56 people with autism attempted suicide, compared to 1 in 313 other adults, according to that study by Kaiser Permanente.<sup>14</sup> A different study found that the risk of death by

suicide was seven times higher in people with autism than in the general population in Sweden.<sup>13</sup>

Research on suicide in autism is still in its relatively early stages. Some studies are either small - which is not ideal for making broad conclusions - or focused only on adults or people with Asperger's Syndrome, according to researchers who study youth with more severe forms of the disorder.<sup>23</sup> Asperger's refers to autism spectrum disorder in people who did not have significant speech and learning delays in childhood.

#### Scouring Through Medical Records

Some studies stand out for their size or thoroughness, especially those using national registries or medical records.

In Sweden, researchers identified 54,000 people with autism using records from 1987 through 2013, and compared them to similar people who did not have autism. (Scientists often use a comparison, or control,

*see [Suicide Risk on page 18](#)*

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**“Autism and the Transition to Adulthood”**

Deadline: December 4, 2018

Spring 2019 Issue

**“Improving Communication Skills”**

Deadline: March 1, 2019

Summer 2019 Issue

**“Supporting Older Adults with Autism”**

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For over 10 years, *Autism Spectrum News* (ASN) has been providing a trusted source of science-based autism information, education, and quality resources in the community.

ASN is a nonprofit quarterly publication with an annual readership of over 100,000 in print and online made up of individuals with autism spectrum disorders, families and caregivers, educators, treatment professionals and service provider organizations across the country. ASN is an evidence-based publication with an [Editorial Board](#) that reviews all content in each issue to ensure that all information is safe and proven-effective.

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## A Responsive, New Wave of Real Estate Options for Adults with Autism and for Special Populations

By Desireé Kameka  
Madison House Autism Foundation  
and Denise D. Resnik  
First Place AZ

Exciting new models for supportive housing are emerging, changing the landscape and raising the bar on dreams and expectations for the neurodiverse population. Far too many young adults are graduating from high school to the couch. They are socially isolated, unemployed or underemployed, and disconnected from the community (Roux, Rast, Rava, Anderson, & Shattuck, 2015). Compounding the urgency of the situation are the nearly one million adults with intellectual and/or developmental disabilities (IDD) living with a caregiver over age 60 (Braddock et al., 2017).

People with IDD or brain injuries, seniors and veterans all represent groups in need of additional assistance and support options to live as independently as possible and to thrive in their community. Group homes are not meeting the demand and are no longer the only residential option for adults with autism and others with IDD. Across the country, pioneering leaders and parents are working with local communities to create more options. Elements of a viable marketplace that develops housing inspired by this population are forming and the delivery of marketplace options cannot happen soon enough.

### An Innovative Example: First Place-Phoenix

Using the knowledge gathered in 20 years of research, support from the Urban Land Institute and the expertise of more than 100 collaborators, [First Place-Phoenix](#) represents a new residential prototype and allows greater life choice based on individual needs and interests.

Set in the heart of the urban region, the \$15.4 million, 81,000-square-foot First Place-Phoenix property offers three primary components:

- Neurodiverse residents of the 55 First Place Apartments enjoy a suite of services and amenities, with all the benefits of community-connected living: transportation, healthcare, employment, continuing education and recreation.



Desireé Kameka

- Participants enrolled in the two-year First Place Transition Academy, operated by SARRC, benefit from the two-year Learn4Independence™ curriculum of 32 semester-length courses focused on independent living skills, helping them integrate into the fabric of the community as citizens, neighbors, employees and friends.
- The First Place Global Leadership Institute is a catalyst for advancing replicable options - a center where families, people with autism and thought leaders collaborate on housing solutions through training, education, research and public policy. The Institute is focused on 10 priority areas shaping where we go next with more housing and community options for special populations.

As a first new property, First Place-Phoenix is a pioneering property representing new ideas and innovation. It also illustrates several of the design goals and guidelines cited in *Opening Doors* (found in Exhibit A on [page 23](#)), based on economic sensibilities and the segment served.

First Place is designed for those with support needs and some form of functional communication. They have a desire to live more independently and participate more fully as part of the greater community through employment, lifelong education, health and wellness, recreation and interests of their choosing. Set in the heart of Phoenix, First Place is within walking distance of light rail and public transit, in close proximity to supportive, welcoming neighbors.

Technology is prevalent throughout the property, aiding in the security and safety of residents. It encompasses an electronic keycard system, a resident information and communications platform, entertainment and recreational options, and various educational workshops, trainings and meetings. It was a conscious choice not to automate all home features allowing residents to walk into their homes and simply push buttons to turn on lights, raise blinds and adjust the thermostat. Our intention



Denise D. Resnik

was not to make life so automated that it could preclude someone from honing their independent living skills before transitioning to their next place after First Place.

*NOTE: First Place-Phoenix is not a group home or a licensed congregate care or assisted living facility. The property is not designed for those with self-injurious or aggressive behaviors.*

### Research Informing Important Elements for Building Community

The first study focusing on the residential concerns of adults with autism and related disorders was published in 2009. It was produced to advance the development of replicable residential models offering quality, affordable housing options within the fabric of their communities. [Opening Doors: A Discussion of Residential Options for Adults Living with Autism and Related Disorders](#) (2009) was a collaborative project by the Urban Land Institute Arizona, Southwest Autism Research & Resource Center (SARRC), Arizona State University's Stardust Center for Affordable Homes and the Family, and the ASU Herberger Institute School for Design and the Arts. The study explored market demand and concerns, financial frameworks, residential models, and home design.

Opening Doors was a catalyst for the launch of the [Autism Housing Network \(AHN\)](#), a project of the Madison House Autism Foundation, in response to barriers identified in the study. AHN is the only online platform that offers a hub of housing information and connects a network of innovators with home seekers, project starters and existing residential options. The AHN Housing Directory uses a set of filters to describe different options, and the [AHN's Virtual Tour of Housing and Support Models](#) video series describes 18 different models, both traditional and emerging. While AHN is an excellent starting resource to begin to define the market, research is not yet available to share on what it takes to build an inclusive, successful, move-in-ready environment.

In the broader community development research, the [Knight Foundation](#) wanted to find out what attracts people to the place they live and described 10 top domains driving community attachment in its Soul of the Community report (2010). Interestingly in the 26 communities they studied, three specific elements rose repeatedly to the top: Social Offerings (places for people to meet each other and the feeling that people care about each other), Openness (how welcoming the community is to different types of people), and Aesthetics (the physical beauty of the community including the availability of parks and green spaces).

Using data from what impacts community outcomes in the neurotypical and neurodiverse population, we must create more supportive housing opportunities for the diverse market segment of special populations—both in the number of supportive housing units and through a range of home and service options. What we call these different housing options with different service delivery systems for people with high-, moderate- and low-support needs is still vague.

### A One-Size-Fits-All Approach Won't Work – Identifying What Does

Whether their home is for a season or a lifetime, members of special populations should be given the opportunity to benefit from a full array of choices. IDD-inspired amenities and supports may include assistive technology, transportation options, sensory-friendly and accessible design, skill-building programs, community support navigators, planned social activities and more.

Currently, we are unable to measure outcomes of these newer, emerging models. National databases that collect outcome data, such as the National Core Indicators, do not accommodate non-Medicaid-funded options or track different types of housing in consumer-controlled models. With this evolution of housing and support systems, as well as ever-increasing demand, we must define the marketplace of residential options for neurodiverse populations by creating the foundational nomenclature for different housing and service delivery models, and track outcomes through quality of life indicators. We must better equip public, private, philanthropic and nonprofit sectors—individually and collaboratively. So, what is that next place? How is it structured—operationally, financially, culturally? How does the marketplace define and recognize what works for residents after they leave First Place? There is no “one size fits all” solution. Not everyone is right for every property. Do we try to create a prototype for everyone or nothing for all? Or do we develop options that respect diversity in our population and offer more choices, just like the general marketplace does?

Consider that we are today with housing for special populations where senior housing started some 50 years ago. Then consider all the choices those seniors can access from the opportunity to “repurpose”

see *Real Estate* on [page 23](#)

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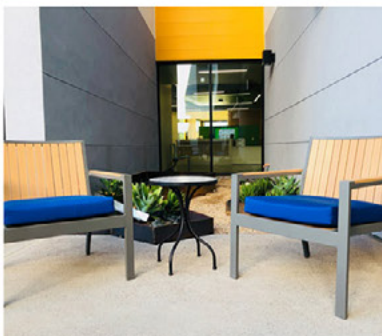
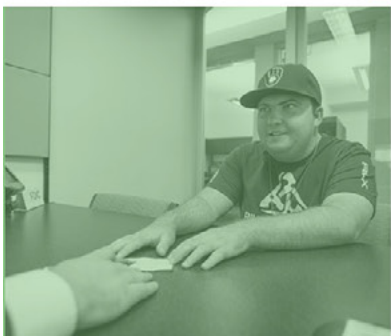
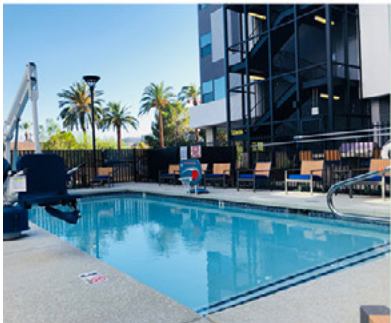
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## Two Sides to the Safety Equation: Bridging the Gap Between Police and Individuals with ASD

By Emily Iland, MA, ET  
Autism Advocate and Consultant

*Given the heightened risk that individuals with autism face when they have contact with the police, this article highlights two valuable safety programs that bridge the gap between police and those with autism to build mutual understanding and improve outcomes in a police encounter.*

Media outlets draw attention to situations where things have gone seriously wrong between police and community members. As the number of individuals with Autism Spectrum Disorder (ASD) continues to grow, and more children than ever become adults, they may be at greater risk for a police encounter compared to the general population (Sobsey, 1994). When all parties are unprepared for such an encounter, the outcomes may be unsafe or even disastrous.

### Training the Police

The obvious solution is to train the police to recognize and respond to people with ASD. The Experience Autism® Program was created specifically for this purpose. This empathy-based program offers



Emily Iland, MA, ET

simulation activities that help officers understand the communication, information processing, behavior, and fine motor difficulties common to autism.

It's often difficult for officers to correctly identify an "invisible" disability. Experience Autism® simulations help officers identify the pattern of differences that constitute autism and distinguish it from

mental illness or substance abuse. Officers learn how the features of autism can affect someone during an interaction. Most importantly, officers discover for themselves how to accommodate an individual with ASD during police encounters, whether the person has wandered, needs help, or is a suspect.

An independent researcher studied the effectiveness of Experience Autism® during three training events, with a robust total sample size of 195 officers (Medina del Rio, 2018). Results showed significant increases in officers' **knowledge** of core features of ASD, **confidence** to interact with persons with ASD, and perceived **practicality** of providing accommodations. Officers also viewed the training as **relevant** to their work. This makes Experience Autism® the only independently-validated, evidence-based police training in the country. Experience Autism® is available to communities across the nation.

### Training Youth and Adults with ASD

The story does not end there. Training the police is *not* enough. Features of autism may interfere with the ability to understand and follow commands as expected. Individuals with disabilities may unwittingly escalate an ordinary police encounter when they are not prepared and don't know what to do.

News stories highlight specific behaviors that can lead to escalation for anyone: running or fighting with an officer, reaching in their own pocket/waistband or reaching for an officer's equipment. BE SAFE The Movie was created to reframe these problematic behaviors into four positive ones: 1) Stay where you are when you meet the police; 2) Do exactly what the police tell you to do; 3) Make sure the police can see your empty hands; and 4) Keep your hands to yourself (don't touch police equipment).

BE SAFE is a video modeling DVD that shows viewers what to expect and do in everyday police encounters ranging from inadvertently breaking the law, to a traffic stop, to being mistaken for a suspect. Actors with autism and related disabilities interact with real officers to model safe behavior. Viewers become familiar with police procedures, commands and a critical safety vocabulary of more than 100 words.

Video modeling has an extensive evidence base for teaching social skills (Reichow & Volkmar, 2010). In addition, BE SAFE is enhanced with evidence-based and promising practices to improve comprehension (Iland, 2011). These include priming or "frontloading" key concepts and vocabulary; use of visual supports; interviews to help with perspective-taking

see *Safety on page 24*

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85% of alumni are employed in at least one job

89% of alumni are satisfied with their social lives  
64% of alumni spend time with friends at least once per week

## Online Dating and Neurodiversity

By Leslie A. Sickels, LCSW  
Clinical Social Worker  
Spectrum Services

Much has been written about the basic safety considerations of online dating, yet little research has been conducted to understand the nuanced difficulties that may be present for individuals on the autism spectrum who date online. A survey by Roth and Gillis (2015) found the most commonly reported online dating concern for individuals on the spectrum was related to safety. Safety associated with online dating typically refers to prescribed guidelines such as “meet in a public place” and “do not disclose personal information,” but there are additional difficulties that may be present for neurodiverse individuals. These more specific safety concerns may result from lack of experience in relationships, difficulty understanding social conventions, or perpetuating negative social experiences. Technology and written communication make connecting online increasingly accessible and appealing, and more neurodiverse individuals turn to online dating to form romantic connections. While this may facilitate easier opportunities for initial connection, it may also pose specific risks and dangers. This article aims to offer additional information about the landscape of online dating for individ-



Leslie A. Sickels, LCSW

uals on the spectrum, and to better support those who wish to successfully and safely connect online.

### Past Experiences

Individuals on the spectrum tend to have fewer romantic relationships that begin later in life than their neurotypical counterparts (Attwood, Hénault, & Dubin, 2014). While the onset of puberty and interest in

relationships occur at the same time as their peers, embarking on dating is often delayed for neurodiverse individuals (Hénault, 2006). This translates into less experience in dating, interpersonal relationships, and understanding the progression of relationships. Dating skills are primarily learned through experience, exposure, or psychoeducation. If an individual has not gained in vivo relationship skills through friendships or past dating experiences, it is imperative that therapists or parents provide psychoeducation on the social conventions of dating. While this supports healthy relationship development of any kind, it also decreases the risk of a neurodiverse individual misunderstanding the social contexts of online interactions. In addition to better understanding standard relationship development, previous experiences or psychoeducation may also make individuals on the spectrum less vulnerable to negative intent online. By strengthening this understanding and supporting skill development, individuals on the spectrum will better decode the nuances and meanings of profiles and written messaging from others.

Another important component of psychoeducation related to online dating is boundary setting, including saying “no” to unwanted interactions. Since individuals on the spectrum typically have fewer positive social connections throughout life, they may hold the perspective that they need to make connections with any-

one who shows interest in them. By being taught about consent, boundaries, and self-worth as it relates to dating, neurodiverse individuals can be more empowered to disengage from people online who they are not truly interested in pursuing. This may become problematic when an individual on the spectrum receives less replies and subsequently feels the need to communicate with anyone who responds, regardless of interest or fit. Psychoeducation around interests, attraction, and desirable qualities of partners can help equip individuals on the spectrum to know what they are looking for before they embark in online dating.

### Deciphering Profiles

In the online dating world, there are many covert communication styles that signify everything from sexual proclivities, to personal disclosures, to expectations for the progression of a relationship. Many of these messages are subliminal and meant to signify something specific to interested readers. When social context and limited experience cloud the way an individual on the spectrum is interpreting these profiles, it could lead to unwanted involvement or exposure to individuals or situations.

In a similar regard, deciphering “fake profiles” can be especially challenging for individuals on the spectrum. Deciphering a

see *Dating on page 20*



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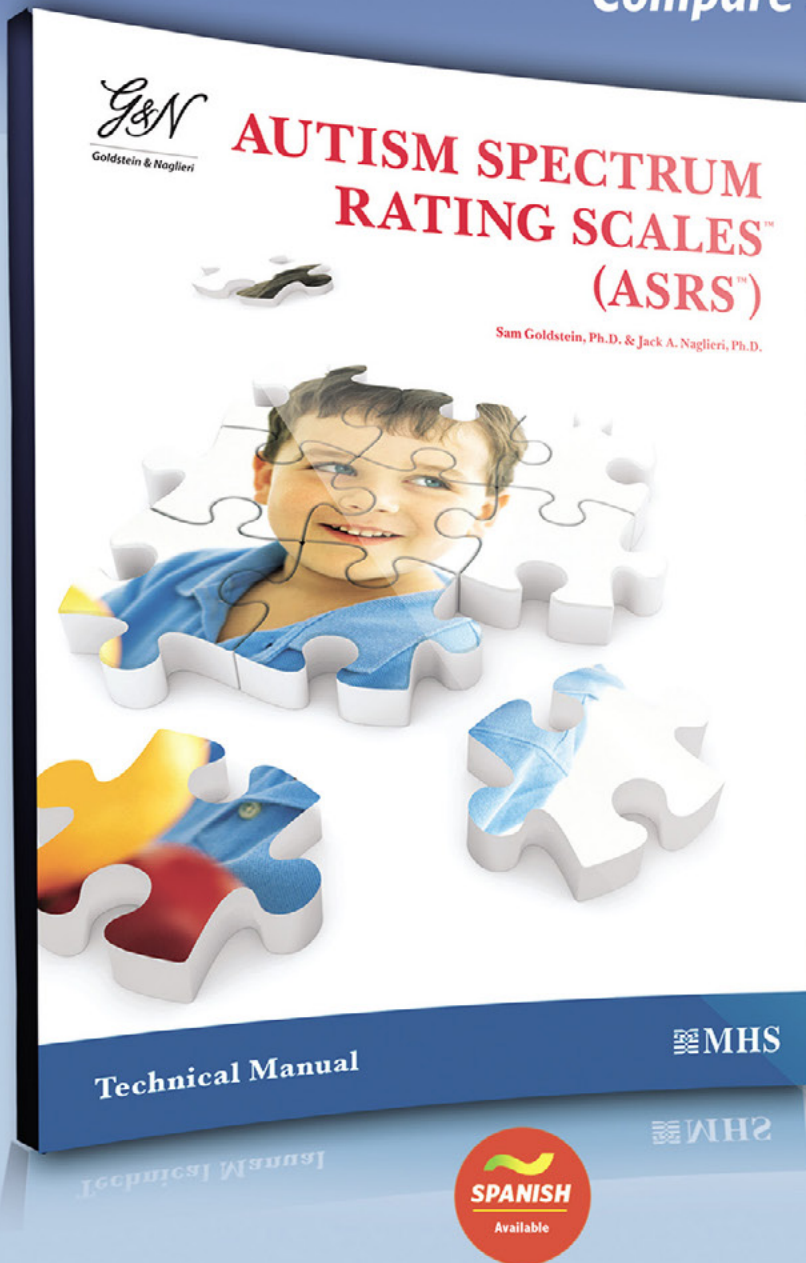

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## Literacy Supports for Learners with Autism

By Mary Kate Ross, MS, SYC  
and Lauren Tucker, EdD  
Southern CT State University

In her article *How People with Autism Think*, Temple Grandin (1995), a high-functioning person with autism, describes her visual method of thinking. Grandin retrieves words through visualizations and movies within her mind. This type of thinking takes time to process, often making abstract thoughts challenging.

Grandin's explanation correlates with research towards the evidence-based practice of utilizing visual supports to help individuals with autism. Hayes, Hirano, Marcu, Monibi, Nguyen, and Yeganyan (2010) define visual supports as "cognitive tools to enable learning and the production of language." They further explain that these supports include "words, images, and tangible items to represent both concrete and abstract real-world concepts" and aid in learning and language production. Visual supports are a part of an individual's communication system that allows them to hold attention, reduce anxiety, make abstract thoughts concrete, and better express one's thoughts (Rao and Gagie, 2006). They may include real objects, photographs, line drawings, words, and static/dynamic and interactive displays (Meadan et al., 2011).



Reading Difficulties  
for Learners with Autism

The National Reading Panel (NRP) (2000) is an organization that assesses different approaches to reading instruction. It identified five areas of reading: phonemic awareness, phonics, fluency, vocabulary, and comprehension. Dolores Durkin stated that comprehension is the "essence of reading," therefore it will be the focus of this article.

The NRP describes reading as an active process that engages individuals in problem solving and various thinking processes. They emphasize that reading comprehension is the gestalt to reading, and therefore, a challenge for learners with autism due to impairments in theory of mind and central coherence.

Elisabeth Hill and Uta Frith explain the core cognitive features for individuals with autism. Theory of mind is the understanding of another person's knowledge,

beliefs, and intentions. Typically, those with autism have an impairment in theory of mind, making it difficult to view things from different perspectives. Central coherence is the ability to draw together various pieces of information in order to construct meaning. Individuals with autism have an impairment in central coherence with tendencies to focus on smaller details, rather than the "bigger picture." Impairments in theory of mind and central coherence impact reading for those with autism, particularly reading comprehension.

The NRP detailed reading comprehension development for typical learners. However, having a weak theory of mind and central coherence pose a barrier for learners with autism. A reading profile consisting of advanced word recognition and weak comprehension is identified throughout the research on literacy development in children with autism. (Turner, Remington, & Hill, 2017; Braun, Austin, & Ledbetter-Cho, 2017; Knight & Sartn, 2014; Nation, Clarke, Wright, & Williams, 2006).

The following are examples that link to current research regarding reading difficulties of learners with autism:

- Difficulty with semantic knowledge (Brown, Oram-Cardy, & Johnson, 2012)

Example: answering wh- questions related

see *Literacy on page 25*



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## Adults with Autism Face a Unique Set of Dangers and Hazards

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

The dangers and hazards of the world that are faced by autistic children and adolescents are very well known, and much has been said and written about them. Autistic adults, however, all too often face a variety of threats not frequently encountered by neurotypicals. I will be discussing these from the perspective of an adult autistic who has been susceptible to them during the course of his life and, as such, is able to recognize the dangers they can present to other autistics (I am not an autism professional – these are strictly my personal views). I will also draw upon the many stories that I have heard over the years of my involvement with the autism community.

This issue, for me at least, is typified by a story I have heard at many autism gatherings, on numerous occasions, and in various forms. It usually goes something like this: a young person on the spectrum is approached by strangers (perhaps acquaintances from their schools or communities) who present an attractive offer. In exchange for delivering a package (usually of unspecified content) to a particular location, they are invited to a party or gathering with the prospect of meeting people, making friends, and even finding romantic



Karl Wittig, P.E.

partners. Of course, the autistic does not realize that the package contains illicit drugs or other contraband, the legal consequences for being caught with being very severe.

A few things immediately strike me about these stories whenever I hear them. First, the perpetrators of such schemes are somehow able to recognize autistics as being susceptible to them (in particular, their obliviousness to both the deliberate deception and its potential consequences), even

though they most likely have never even heard of the autism spectrum, let alone realize that their prospective targets are on it. Second, they know to use the possibility of finding friends as an inducement, as opposed to the usual offer of financial reward for taking the risks incurred from engaging in illegal activities. As such, neurotypicals, who are much less likely to fall for such a scam, will not be subjected to it nearly as often as are autistics, who tragically fall for it all too often. This is a prime example of dangers that specifically affect autistics as a group which, as such, needs to be emphatically warned about so that they learn to recognize and, hopefully, not become victims of. Family members and friends, as well as teachers and professionals, who have autistics in their lives also need to be made aware of such hazards and become vigilant for them.

### Deception and Exploitation

The main reason autistics are so much more susceptible to such schemes is their inability to recognize that the perpetrators are intentionally deceiving them and do not have their best interests in mind. This may very well be due to the impaired theory-of-mind (i.e., ability to see things from the perspective of another individual) that autistics are known to have. Although this notion is not well received or even accepted by many in autism community, mainly

because it has been grossly extrapolated to imply that autistics are incapable of empathy (a view which has been largely discredited), it is far less of a stretch to conclude that such a deficit may actually be responsible for their well-known challenges in recognizing deception on the part of another person. This needs to be further investigated, as it could help better understand this serious hazard that autistics so frequently encounter and thereby help them to not fall victim to it.

Whatever the reason for these deficits, autistics need to be taught, as much as possible, that there are people in this world who will deceive and take advantage of them given the opportunity, and how to recognize such situations when they arise. Although the earlier example was used for its extreme consequences, there are many other situations where the same considerations apply. These can involve taking financial advantage of an unsuspecting victim or, as often happens with autistics, persuading them to do something that will embarrass them for the entertainment of others. For an autistic with known special interests or abilities, these can serve as inducements to lure them into disadvantageous or dangerous activities as well; such interests can be used the same way that the prospect of friendship is. If the autistic is academically talented, or has abilities

see *Dangers on page 22*

## This is what success looks like...



## This is what an adult living with autism looks like!

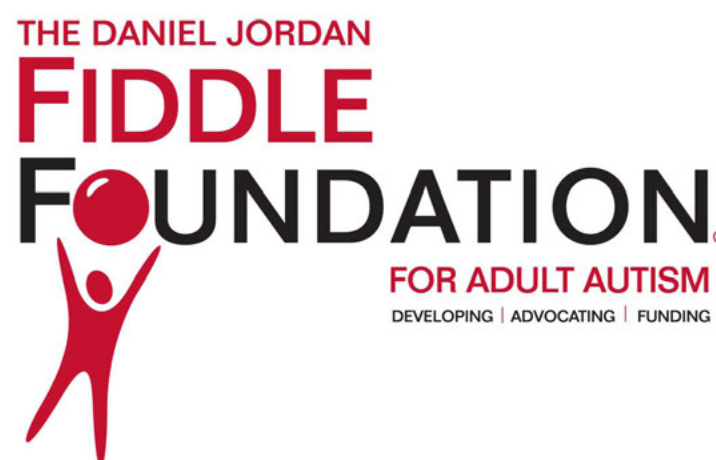
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## Autism Plus Wandering

By Beth Arky  
Child Mind Institute

When Liane Kupferberg Carter's son Mickey began "escaping," as she calls it, around age 2, "he was greased lightning," she says. "I couldn't take my eyes off him for an instant or he'd disappear - in malls, supermarkets, or in any public space."

As her son got older, things weren't any better at home. "He figured out how to unlock the front door and take off, so we had to install an extra deadbolt lock," says Carter, a Westchester County-based journalist and advocate. "We put it out of reach - or what we thought was out of reach - all the way up at the top of the door. Then he figured out he could stand on a chair to reach the lock, so we also installed a loud chime to alert us any time the door opened."

Back then, Carter had no idea that Mickey, now 19 and diagnosed with an autism spectrum disorder (ASD), was demonstrating a behavior common among those on the spectrum, who have an impaired sense of danger. Called wandering or elopement - aka bolting - it is terrifying to parents and other caregivers at best, tragic at worst. Spurred by the increasingly frequent stories of lost children being found dead, often drowned in ponds and creeks close to their homes, the autism community has



made wandering an urgent priority.

But up until recently, there was only anecdotal evidence of the behavior. Now, preliminary results from the [first major study on wandering](#), conducted online by the Interactive Autism Network (IAN), provide advocates the hard data they've needed to take action.

### Data on Wandering

According to the responses from more than 800 parents, roughly 50 percent of children between the ages of 4 and 10 with

an ASD wander at some point, four times more than their unaffected siblings. The behavior peaks at 4, but almost 30 percent of kids with an ASD between the ages of 7 and 10 are still eloping, eight times more than their unaffected brothers and sisters.

Nearly half of the respondents said a child had been missing long enough to cause significant safety concerns, with 32 percent calling the police. Two out of three reported their wandering child had a "close call" with a traffic injury, while almost a third said their child had a "close call" with drowning. Another alarming statistic: 35 percent of

families with wanderers reported their child is "never" or "rarely" able to communicate his name, address or phone number, either verbally or by writing or typing.

But extremely verbal "high functioning" children are a flight risk, too, because they may also have accompanying diagnoses such as language processing issues or anxiety, which can make it difficult for them to convey personal information in an understandable, appropriate way to first responders and others who might help them. Or they may just be so fixated on whatever's interesting them, they don't answer to their name.

### Highly Stressful for Parents

Consider the case of Nadia Bloom, an 11-year-old with Asperger's who disappeared while riding her bike, only to be found waist-deep in an alligator-infested Florida swampland. Incredibly, she suffered only from bug bites and dehydration. Jeff Bloom, Nadia's father, told reporters, "Our daughter is a nature lover. She went on a bike ride and stopped and went off to take some pictures."

It's no wonder that more than half of parents reported that wandering is the most (or among the most) stressful ASD behavior, ahead of self-injury, rigidity, aggression, and meltdowns. Meanwhile, 62 percent

see [Wandering on page 21](#)



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# Analyzing Health Informatics to Ensure Safety and Wellness

By Andrew Shlesinger, MSW, LICSW  
Director of Clinical Technology  
Melmark New England

As the amount of data recorded in classrooms continues to expand, so, too, does the opportunity for individual, organizational, and systemic improvements informed by that data. One area of increasing focus is the collection and analysis of health and wellness data, collectively known as *health informatics*. This article will give insights into how the modern service organization can leverage health informatics data like sleep, weight, well-body checks, and unusual incident tracking into real and meaningful improvements in student safety and wellness.

## Common Measures of Health and Wellness

Sleep, weight, diet, well-body checks and unusual incident tracking are several common measures of health and wellness. Our organization, for example, has developed database applications for each of these critical measures, including an application to record sleep quality throughout the night, weight and height on a weekly and monthly basis, well-body checks twice daily and real-time unusual incident tracking. These applications allow for real-time



Andrew Shlesinger, MSW, LICSW

reporting, charting, emailing, alerting and graphing of the data, making analysis timely and convenient.

*Sleep* - Research carried out at Melmark has shown sleep quality, measured by variables such as time to sleep onset, total continuous hours of sleep, and total hours of sleep, impacts both academic and behavioral performance the following day. Sleep quality data, therefore, can be used

to inform better treatment by tailoring the next day's academic and clinical work. For example, if the data shows a client is likely to have more clinical behaviors following a night with less than four hours of continuous sleep, the behavior plan can be written to address that condition separately, possibly calling for a greater frequency of reminders, increased vigilance upon antecedents, or increased break opportunities. Academically this data can guide the frequency of lesson delivery, the types of lessons taught, and frequency of breaks, as just a few examples.

Comprehensive sleep data is also critical for sharing with the client's health care team. Doctors, psychiatry providers, prescribers, and nurses highly value this data, which is often a key variable for informing treatment decisions.

*Weight and Diet* - Weight is another key factor in health and wellness. Keeping a close eye on the height and weight of all your clients will give you and your medical providers insight to guide the individual's medical plans, meal plans, and exercise routines. We have developed a database which calculates Body Mass Index (BMI) from regular height and weight measurements and uses that data to build a profile at one-, three-, and six-month intervals. This data, in turn, is used to automatically inform health care staff of cases that meet criteria for excessive weight gain or loss

over those intervals, in real-time, so effective change can be made before the issue becomes critical.

*Well-Body Checks* - The ubiquitous "well-body check," where staff check over the body of the individual for any marks, bruises, scratches, etc., is most often carried out by marking up an outline image of the front and back of a body on paper forms. The major issues with this method is the data is onerous to analyze across dozens of forms, and the data is duplicative because marks on the morning form, for example, are often re-recorded over and over, form by form, until the issue resolves.

Collecting this data into a database eliminates both of these issues by keeping the data in one location and never duplicating a report from check to check. Melmark uses a database application that allows the user to record his or data on a display of the typical body outline. The data marked on the form goes into a database for real-time reporting and analysis. In this way, a profile can be formed regarding each individual's well-body health which is used to inform measurable improvements for the individual. A self-injurious individual, for example, may have hundreds of self-injurious behaviors a day recorded to what seems like random parts of the body. A trend analysis of well-body data over months, how

see *Analyzing Health* page 26

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## NY State Assemblyman Angelo Santabarbara's Personal Mission of Advocacy on Behalf of New Yorkers with Disabilities

By Assemblyman Angelo Santabarbara  
Chair of the NY State Assembly's Sub-Committee on Autism Spectrum Disorders

**L**ife is almost never a straight path. If you try to make a plan, you will sometimes head in a direction you never could have imagined. For me, the journey has not been simple, and it has not always gone as I expected.

My parents are both Italian immigrants. They left their homes in the Province of Caserta in the Campania region of Italy to come to New York almost 50 years ago and I was the first in my family to be born here. After graduating high school, I joined the US Army and served in the reserves for 8 years. Later, I graduated from the University at Albany and went on to work as a Professional Engineer. During that time my wife, Jennifer, and I got married and started a family with our first child, a beautiful baby boy, Michael. We were a new family. We just bought our first home and were beginning our lives together. Then one day, everything changed. It's a day that I will never forget. I remember the words in my head repeating over and over again. My wife saying, "Ang, there's something wrong with Michael. He's not talking."

As a young father, I was told that my 3-year-old son, Michael, had autism. It



**Assemblyman Angelo Santabarbara in the NY State Assembly Chamber with his 16-year-old son Michael, who lives with the challenges of autism**

was a scary diagnosis for a new father and I didn't know what the future would hold. It's a day that I re-live every time new parents come into my office after receiving a similar diagnosis. Years later, it has led me to some of the most rewarding and important work that I could ever be doing. In the New York State Assembly, I now serve

as chair of the Sub-Committee on Autism Spectrum Disorders where I have the privilege of working with amazing advocates on key issues facing those with developmental disabilities. As a state legislator, much of my work has been focused on providing those with developmental disabilities a voice in our state legislature.

The numbers are alarming. The latest report released just this year by the U.S. Centers for Disease Control showed that about 1 in 59 children in the US are now being diagnosed with autism, up from 1 in 68 in 2012 and the numbers have doubled in less than 20 years. Autism is now the fastest-growing developmental disability in the country. It's a crisis that needs immediate attention.

### Autism Action Plan for NY State

With more than 3.5 million Americans living with an Autism Spectrum Disorder, time was running out and people were being left behind. It was time to take on the challenges and in my first term in office I introduced my Autism Action NY initiative in the New York State Assembly. It's a plan that takes on the challenges thousands of families affected by autism are facing each day. It's about participation, removing the barriers to communication and helping everyone understand. It's a plan that's about people, acceptance and inclusion, potential and independence. It's the plan I created for those who need a voice in our state legislature so that everyone has the opportunity to become the best they can be, with no one left out and no one left behind. It's my

see *Stantabarbara on page 26*

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## Reducing Disparities in Early Identification of ASD

By **Jill Harris, PhD**  
**Director of Research Development  
 and Coordinator of Autism Services  
 Children's Specialized Hospital**

**E**arly identification of autism spectrum disorder (ASD) expedites access to appropriate intervention and leads to improved functional outcomes (Dawson et al., 2010). Yet, despite concerns of possible ASD often noted by 18 months, the median age of diagnosis in the United States continues to hover around age four (Baio et al., 2018).

There are significant income, racial, and ethnic disparities in the early identification of autism. For example, Latino children receive a diagnosis of ASD later than white non-Latino children (Magaña et al., 2013; Mandell et al., 2002), are more likely to receive an alternate diagnosis such as a language disorder (Mandell et al., 2009), and when diagnosed, are more likely to have severe symptoms than white non-Latino children (Mandell et al., 2009; Palmer et al., 2010). Within the Latino population, disparities are especially pronounced for those with low English proficiency (Zuckerman et al., 2017). Reasons for these disparities have not been well-researched and are likely influenced by multiple factors including culture, ASD knowledge, social support, literacy issues, maternal education and number of sources



**Jill Harris, PhD**

of knowledge about ASD, and mistrust of health care providers. This suggests that it is important that primary providers solicit and understand parent concerns as this may help the decision-making process regarding types of evaluation and intervention needed.

While the American Academy of Pediatrics recommends screening all children for autism at 18 and 24 months using a validated autism screening tool, many children

are not screened. Reasons that pediatricians may not screen for ASD include lack of time, limited reimbursement, workflow challenges, and inability to track and monitor referrals. Even when autism screening tools are used, these tools may not be universally effective among different racial, ethnic or cultural groups (Khowaja et al., 2015) or screening may only be offered in English. This may result in missed opportunities to identify young children at developmental risk, delaying enrollment in early intervention and having a potentially negative impact on child outcome.

Even when ASD has been diagnosed, minority or low-income children often have difficulty accessing services. For example, Zuckerman (2014) found that Latino parents of young children already diagnosed with ASD reported that providers sometimes dismissed parents' concerns. This, coupled with a diagnostic process which was viewed as cumbersome, led many parents to normalize child behaviors, deny that a problem existed, and lose trust in the medical system.

Clinicians and researchers at Children's Specialized Hospital have attempted to reduce income, language and racial or ethnic disparities in ASD diagnosis in various ways. This includes creation of new ASD screening tools with reduced literacy demands (Janvier et al., 2018). Janvier and colleagues created a tool, the Developmental Check In (DCI) that is primarily picto-

rial with limited wording and found it to be effective in identifying ASD within an underserved population of young children at risk for ASD. Currently, the DCI is being tested within a general population of young underserved children.

Other innovative efforts from Children's Specialized Hospital to improve early access to diagnosis include reducing transportation, insurance and financial barriers by locating free developmental screening clinics within underserved communities (Harris & Norton, 2016). Research on this model found that although almost all children screened in the community-based clinics had a regular source of healthcare, 51% were found to be developmentally at risk and most reportedly had not previously been referred for evaluation.

Reducing disparities related to early identification of ASD must include improving access to services once an ASD diagnosis is made. Research and clinical practice needs to focus on best practices in training healthcare and other service providers to better communicate with families of young children in order to foster effective partnerships. Providing care within a medical home model is one method to address this issue. The medical home approach embraces family centered care and promotes care coordination across the various providers and settings involved with

*see Identification on page 26*

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## Won't You Be My Neighbor? Unique People Services Creating Community Connections

By Donna Davis  
Writer/Consultant  
Unique People Services

On a sunny day in August, on a typical tree lined suburban street in Queens, NY, a knock opens a neighbor's door. "Are you coming?" asked a client of Unique People Services (UPS). UPS was holding an open house to introduce the community to their newest neighbors: six women with varying degrees of developmental and intellectual disabilities. Before the event, UPS reached out the neighbors with invitations. They invited community residents, elected officials, and the local police community relations officer. The whole point of the event was to evoke neighbor and community engagement for the purpose of inclusion and the safety of both the UPS residents and their neighbors.

Founded in 1991 and headed by Executive Director Yvette B. Andre, Unique People Services, Inc. (UPS) is a New York-based nonprofit 501(c)3 that provides supportive housing and medical case management services to individuals and families living with mental health challenges, developmental disabilities and HIV/AIDS. Their mission is to serve—holistically and without judgment—those who may have



Donna Davis

been denied compassionate and considerate treatment elsewhere due to their race, religion, gender, sexual orientation, developmental level, health status, criminal or substance abuse history.

As a society, we are aware of the myriad of support for children on the autism spectrum, but the same degree of support doesn't always exist for the adults on the

spectrum. This population of incredibly talented and kind-hearted adults are sometimes faced with the challenge of feeling safe and included in their new communities. To help these individuals, Unique People Services is committed to creating opportunities, which introduce individuals to their neighbors.

"The foundation of our approach is to fill in the gaps of understanding when it comes to individuals with disabilities. We understand that there is a social stigma that surrounds the population. These opinions only harbor misunderstandings that further underlines a view of them as different and potentially dangerous. As a result, misconceptions and stereotypes arise. But once you interact and become familiar with them, only then do the fears begin to disappear," stated Sherri Lindo, Program Director of the residence where the open house was held. UPS periodically has the individuals make cards introducing themselves to local businesses and community centers of influence. Inclusion is possible, but it does come with its challenges, especially when it comes to misunderstanding from the overall community and law enforcement.

Sadly, and all too often, we hear in the news of heartbreaking events that have occurred because of the lack of proper community introductions. Interacting with law enforcement, because of a lack of commu-

nication and understanding, has at times tragically resulted in death.

The Ruderman Family Foundation released a [white paper](#) on media coverage of law enforcement use of force and disability. The white paper stated that individuals with disabilities comprise one-third to one-half of all people killed by law enforcement officers. In the same publication, they cited a report published by The Guardian titled "The Counted," which includes a database of people killed by police totaling 1,101 as of December 21, 2015. The Washington Post has also compiled a similar database of individuals shot (focusing on firearms as opposed to all fatalities) - 944 in the same period. "The Counted" tracks 27% of all individuals killed by police in 2015 as having "mental health" issues, or 270 people. The Washington Post currently reports 235 individuals with "signs of mental illness" shot by police. To put these numbers in context, according to 2014 figures from the National Institute on Mental Health, the best available estimate of the number of adults with any diagnosable mental disorder during that year was nearly 1 in 5 Americans, roughly 19% totaling an estimated 43 million people. These facts reflect a tragic reality, yet UPS understands

see [Community on page 24](#)



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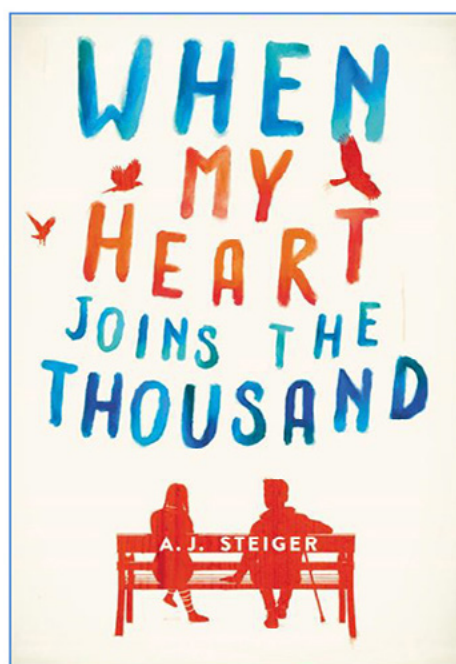
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# AUTISM SPECTRUM NEWS DESK

## Preparing the Field of Disabilities Services for Managed Care

*Managed Care Community of Practice Offering Training and Technical Assistance to Providers of Services to People with Intellectual and Developmental Disabilities in NY State*

By The New York Alliance for Inclusion & Innovation

August 27th, 2018, marked the first day in a series of webinar trainings designed to help providers of services to people with disabilities prepare for and transition to Managed Care.

New York completed its first significant step in the transition with regional implementation of Care Coordination Organizations (CCOs) throughout the state. The Managed Care Community of Practice, a project of the NY Alliance for Inclusion and Innovation, will aid further in the transition by offering training, technical assistance and resources to all providers of services to people with I/DD. This will include:

- Understanding the principles and concepts commonly associated with managed care (e.g. managing risk, utilization management, prior authorization)



**Ann Hardiman**

- Guiding providers through the operational changes necessary to function and thrive in managed care (e.g. information



**Michael Seereiter**

- technology and billing system requirements, grievance procedures, interface with other service providers)

- Factors to consider when contracting with managed care organizations
- Demonstrating impact and value in preparation for value-based payments

Funds in the 2018-19 State Budget enable the New York Alliance for Inclusion & Innovation to launch this technical assistance project. Trainings and learning opportunities are free of charge and start today with introductory webinar on the Introduction to Managed Care Community of Practice in I/DD. Other such webinars include Managed Care Basics; and Talking to Not-for-Profit Board of Directors about CCOs and Managed Care.

“Building on the model and expertise gained in bringing technical assistance to providers in the behavioral health sector, we are pleased to bring this same type of resource to providers in the I/DD sector” said Ann Hardiman, President & CEO of the New York Alliance for Inclusion

*see Managed Care on page 25*

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### Suicide Risk from page 1

group to see if a particular condition or treatment affects an outcome.) People with autism had a higher risk of suicide attempts and suicide than the comparison group, even when scientists factored in the presence of depression and attention deficit disorder, according to research presented at a 2018 international autism meeting.<sup>5</sup>

In fact, their close relatives – parents, siblings, and children – also had a higher risk of suicidal behavior. Having other psychiatric problems, in addition to family risk factors, “are important explanations to the increased risk of suicidal behaviour in ASD,” the Swedish scientists in concluded.<sup>5</sup>

Among people with autism, the risk was highest for those who did not have intellectual disability, especially women, in Sweden. Other studies have shown a higher risk for depression<sup>22,24,25</sup> and suicide<sup>13</sup> in that same subset of the autism community – people with at least average intelligence. Some researchers speculate that those with “high-functioning” autism may have a higher suicide risk because they have more psychiatric problems, or have a greater awareness of their differences and social isolation.<sup>12,13</sup>

It’s also possible that researchers simply know more about risk in people with milder forms of autism because they are studied more often and more thoroughly than people “severely affected by autism.”<sup>26</sup>

#### Is Autism Itself a Risk Factor?

Is having autism itself a risk factor for a suicide attempt? Yes, according to one study in Taiwan. Using medical insurance records, researchers compared two groups of teenagers and young adults, one with a medical diagnosis of autism and a similar, or control, group that did not have autism. (In the U.S. this age group has the highest rate of suicidal thoughts in the general population.<sup>27</sup>) Neither the 5,600 people with autism nor the 22,500 controls had a history of suicidal behavior when the study began. Researchers followed them for three to 10 years, and compared the number of reported suicide attempts when the study ended in 2011. Almost 4 percent of the ASD group had attempted suicide, compared to less than 1 percent of the control group.<sup>8</sup>

Not surprisingly, the teens and adults with autism also were more likely to have attention-deficit hyperactivity disorders, intellectual disability, anxiety disorders, depression and bipolar disorder than controls.<sup>8</sup>

Because certain psychiatric conditions



**Suzanne V. Rybczynski, MD**

may raise the risk of suicide, researchers took those differences into account when assessing the youth and adults. In their analysis, the researchers concluded, having autism itself is an “independent risk factor to attempted suicide regardless of the presence of psychiatric [conditions], including depression, bipolar disorder, and alcohol and substance use disorders.”<sup>8</sup> The Taiwanese researchers urged doctors to monitor “suicide-related symptoms,” as well as mental and behavioral disorders, in patients with autism.

#### What About Social Communication Problems?

Although the Taiwanese study found that having autism raised suicide risk, a British study said it did not. In fact, British researchers found that having certain characteristics common to autism, but not necessarily autism itself, increased a teenager’s risk. Those scientists followed more than 5,000 British youth from birth through age 16. By age 16, youth with poor social communication skills had a higher risk of suicidal thoughts, plans and behaviors than teenagers who did not have those deficits.<sup>9</sup>

Having a social communication problem is one of the two major symptoms of autism, but it does not mean someone has autism. The researchers found “no evidence” that having an autism diagnosis raised risk, but the number of youth with a medical or school diagnosis of ASD was low, making their analysis admittedly “imprecise.”<sup>9</sup> In

general, studies using many participants are more likely to detect differences between them than studies using just a few people with a certain trait, in this case, autism.

Perhaps not surprisingly, given what doctors know about depression, the study found a link between depression and suicidal behavior. Children with poor social communication skills were more likely to have symptoms of depression at age 12. That, in turn, raised their risk for suicidal behavior by age 16.<sup>9</sup>

#### Studying Those Receiving Psychiatric Care in Hospitals

In the United States, another group of researchers looked at a subset of the autism community that might be expected to be at greatest risk: youth with autism who have been admitted to a hospital for psychiatric care.<sup>23</sup>

Those researchers examined information supplied by parents of the 107 youth, who all could speak. The families reported that 22 percent, or about 1 in 5, of these youth had talked about death or suicide “often” or “very often” for several days at a time. Many of them also had a mood disorder or anxiety. All had been admitted to a psychiatric unit in a hospital that participates in the Autism Inpatient Collection (AIC) research project.

Of course, these results may be different in youth with autism who have not been admitted to a hospital for mental health reasons. For example, some studies of youth outside hospital settings showed lower rates of suicidal thoughts, according to the AIC researchers.<sup>28,29</sup> It’s also possible that some youth spoke frequently about death as part of an autism-related preoccupation, rather than a suicide wish, they acknowledged. Having an intense focus on a topic or object is a symptom of autism.<sup>30</sup>

#### Finding Those with Autism Who Need Help

Some of the same researchers are working on another study that could shed more light on suicide risk in autism – and could help doctors identify people who need mental health treatment.

In an interview, clinical psychologists Lisa M. Horowitz, PhD, MPH, and Audrey Thurm, PhD, of the National Institute of Mental Health, said they are planning to test a questionnaire to see if it would accurately assess suicide risk in autism.

The questionnaire, the Ask Suicide-Screening Questions, or ASQ, has been tested successfully for use with typically-developing

children and teenagers. Dr. Horowitz led the research team that, in 2012, determined that a four-question ASQ could identify the suicide risk in children who came to hospital emergency departments.<sup>31</sup> For example, youth are asked if they recently wished they were dead, felt they or their family would be better off if they were dead, or have been having thoughts about killing themselves. If patients answer “yes” to any of the first four questions, they then are asked if they are having thoughts of suicide “right now.” Youth who say “yes” to any of the questions require a brief suicide safety assessment.

“During that study,” Dr. Horowitz recalled, “I got a call from a psychologist in Toronto who wanted to know if we had included patients with autism spectrum disorder and intellectual disability in the study. I told her we had not. She reported her great need of a screening tool in these populations. We decided we needed another study to find out if the ASQ would work well in people with autism.”

Kennedy Krieger Institute, a hospital for children and young adults with developmental and nervous system disorders, conducted a preliminary study using the ASQ in 2017.<sup>32</sup> Nurses offered suicide screenings to patients ages 8 and older during appointments at outpatient clinics. (Parents could answer for the child or could refuse screening). If the screening showed a risk, then a doctor or nurse practitioner performed a more detailed assessment or consulted a psychologist or social worker.

Almost 14 percent of the patients from the autism clinic screened positive, compared to about 5 percent of the patients in clinics for youth with other medical conditions. “I was surprised how much higher the rate was for the autism clinic compared to the developmental pediatrics clinic and the neurology clinic,” said one of the researchers, Dr. Suzanne V. Rybczynski, the Institute’s medical staff services director and medical director of the Pediatric Rehabilitation Unit.

Dr. Rybczynski said some parents expressed concern that asking about suicide would cause their child to contemplate it. However, she said, “The research says that is not the case. Just talking about it doesn’t mean you’re planting ideas of suicide in their head.”

#### What Should You Do If Someone Talks About Suicide?

Dr. Horowitz urged parents to take note

*see Suicide Risk on page 22*

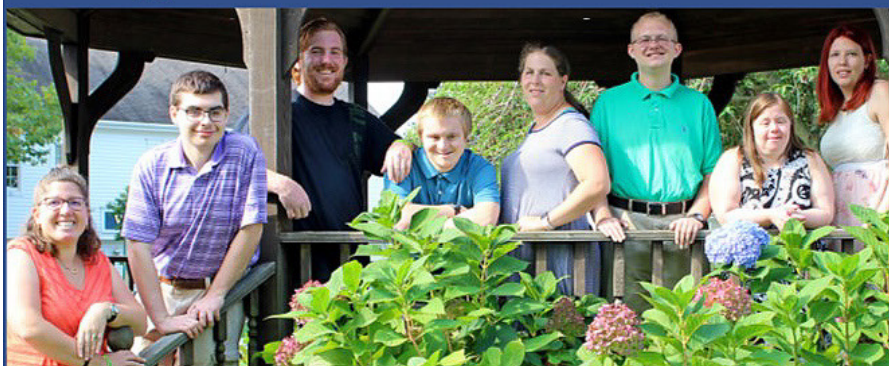


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# AUTISM SPECTRUM NEWS DESK

## New Biomarker Panel Could Accelerate Autism Diagnoses

*About 17 percent of kids with autism identified with metabolic blood test*

By UC Davis Health

Investigators at the UC Davis MIND Institute and [NeuroPointDX](#), a division of [Stemina Biomarker Discovery](#), have identified a group of blood metabolites that could help detect some children with autism spectrum disorder (ASD). Part of the Children’s Autism Metabolome Project (CAMP), the largest metabolomic ASD study ever attempted, these findings are a key step toward developing an ASD biomarker test. The research was published September 6 in the journal *Biological Psychiatry*.

“With this panel of alterations in amino acid metabolism, we can detect about 17 percent of kids with ASD,” said David G. Amaral, founding director of research at the MIND Institute and senior author on the paper. “This is the first of hopefully many panels that will identify other subsets of kids with autism.”

No biomarker tests for ASD currently exist. Children are diagnosed based on



David G. Amaral

their altered behaviors, which may not become evident until children are 2-4 years

old. Families often must wait over a year or more for an appointment with a specialist, delaying diagnosis even further.

CAMP researchers believe the answer lies in the metabolome – the molecules that remain after larger molecules have been broken down (metabolized). Metabolomics has the advantage of monitoring both genetic and environmental contributions to the development of autism.

“By the time you’re getting to metabolomics, you’re looking at how the body is working, not just the genes it has,” said Amaral, a professor of Psychiatry and Behavioral Sciences.

The team hopes to use these and other CAMP findings to accelerate diagnosis and move kids into intensive behavioral therapy at an earlier age, which has proven quite effective. The multisite study has collected blood samples from 1,100 children – about two-thirds having been diagnosed with ASD – between 18 months and 4 years old. This is the first publication from the CAMP effort.

“One of the major goals of the MIND In-


stitute is the development of early biological markers for detecting the risk of autism spectrum disorder,” Amaral said. “It would have been difficult for the MIND Institute to carry out the CAMP study on its own.”


Amaral added that CAMP is an excellent example of an academic/corporate partnership that has the promise of benefitting the autism community.

“It is unlikely that a single marker will detect all autism,” he said. “This paper demonstrates that alterations in metabolic profiles can detect sizable subsets of individuals with autism. The hope is that we will be able to generate a panel of biomarkers that will detect a large proportion of people at risk. Moreover, this approach highlights metabolic pathways that may be targets of intervention.”

In their work the research team compared blood metabolites – specifically, amino acids – in 516 kids with ASD and 164 children showing typical development. They found that 17 percent of the ASD children

see *Biomarker on page 24*





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### Bullying from page 1

can help keep kids safe.

#### Federal Civil Rights Laws and Youth with Disabilities

When bullying is directed at a child because of his or her established disability and it creates a hostile environment at school, bullying behavior may cross the line and become “disability harassment.” Under Section 504 of the Rehabilitation Act of 1973 and Title II of the Americans with Disabilities Act of 1990, the school must address the harassment. Read more about [federal civil rights laws](#).

#### Bullying Prevention for Children with Special Health Care Needs

Having special health care needs due to neurological, developmental, physical, and mental health conditions can add to the challenges children and young people face as they learn to navigate social situations in school and in life. While bullying and cyberbullying is an unfortunate reality for many young people, children with special healthcare needs are at greater risk for being targeted by their peers.

One reason children and young adults with special health care needs might be at higher risk for bullying is lack of peer support. Having friends who are respected by peers can prevent and protect against bullying. **Ninety-five percent** of 6- to 21-year-old students with disabilities were served in public schools in 2013. However, children with special health care needs may have difficulty getting around the school, trouble communicating and navigating social interactions, or may show signs of vulnerability and emotional distress. These challenges can make them be perceived as different, and increase their risk of aggression from peers.

Young people with special needs may benefit from, both individualized and class-wide approaches to address the specific effects of their condition and prevent

them from becoming the target or perpetrator of bullying. Teachers, school staff, and other students need to understand the specific impairments of a child’s health condition, so that they can develop strategies and supports to help them participate and succeed in class and with their peers.

#### Potential Perceived Differences

Children and youth with special needs are impacted by their conditions in a variety of ways. Every child is unique, and so are the ways that their health condition affects them. Some impairments, such as brain injuries or neurological conditions, can impact a child’s understanding of social interactions and they may not even know when they are being bullied. Here are a few ways that disabilities may affect children:

- Children and youth with [cerebral palsy](#), [spina bifida](#), or other neurological or physical conditions can struggle with physical coordination and speech.
- [Brain injuries](#) can impair speech, movement, comprehension, and cognitive abilities or any combination of these. A child or youth with a brain injury may have trouble with body movements, or speaking in a way that others can understand. It could take them longer to understand what is being said or to respond.
- Children and young people with [Autism Spectrum Disorder](#), [Attention Deficit Hyperactivity Disorder](#), and [Tourette’s Syndrome](#) may have difficulties with social interactions, sensitivities, impulsivity, and self-regulating their behavior or effectively communicating.
- A child or young person who experiences anxiety or depression or who has a [mental health condition](#) may be withdrawn, quiet, fearful, anxious, or vulnerable. They may exhibit intense social awkwardness or have difficulty speaking.
- Children who have [epilepsy](#) or [behav-](#)

[ioral disorders](#) may exhibit erratic or unusual behavior that makes them stand out among their peers.

#### Supporting Special Needs and Preventing Bullying at School

Strategies to address student’s special needs at school can also help to prevent bullying and have positive outcomes for all students, especially tactics that use a team approach, foster peer relationships, and help students develop empathy. Some strategies include:

- Engaging students in developing [high-interest activities](#) in which everyone has a role to play in designing, executing or participating in the activity.
- Providing general up-front information to peers about the kinds of support children with special needs require, and have adults facilitate peer support.
- Creating a buddy system for children with special needs.
- Involving students in adaptive strategies in the classroom so that they participate in assisting and understanding the needs of others.
- Conducting team-based learning activities and rotate student groupings.
- Implementing social-emotional learning activities.
- Rewarding positive, helpful, inclusive behavior.

#### Peer Support Makes a Difference

Here are a few examples of innovative strategies used by schools to promote peer-to-peer learning, foster relationships, and prevent bullying:

- One high school created a [weekly lunch program](#) where student’s with and with-

out special healthcare needs sat and ate lunch together. Several senior students led the group, and invited their friends to join. All kinds of students participated. The students got to know each other through question and answer periods and discussions over lunch. They discovered things they had in common and formed friendships. A group of them went to the prom together.

- Youth at one school held a [wheelchair soccer night](#). Students with special healthcare needs that used wheelchairs coached their peers in how to use and navigate the wheelchairs to play. The students helped another peer who used a wheelchair who was interested in photography by mounting a digital camera on her chair so she could be the game photographer.
- Another [school](#) created a club rule that required clubs to rotate leadership responsibilities in club meetings so that every member had a chance to run the group. This allowed students with special health care needs to take on leadership roles.

Peer support is an important protective factor against bullying. By working together, teachers, parents and students can develop peer education, team-building, and leadership activities that foster friendships, build empathy, and prevent bullying to make schools safer and inclusive for all students, including children with special healthcare needs.

#### Additional Resources

[Bullying and Children and Youth with Disabilities and Special Health Needs Tip Sheet - PDF](#)

[Keeping Students with Disabilities Safe from Bullying](#)

[Protecting Youth from Bullying: the Role of the Pediatrician](#)

### Dating from page 8

profile, which is often taken at face value, can be extremely challenging because of the subtleties and limited context. Despite having other online interactions, such as chat rooms or gaming sites, the stakes are higher for knowing if someone is who they say they are, in online dating. If individuals on the spectrum struggle to identify when something is amiss, they can be at increased risk of being deceived, “catfished,” or vulnerable to a scam. While some fake profiles are easy to detect, including those that are specifically asking for information, money, or sex, others are much more realistic in appearance and interaction and can lead to disappointment and further potential rejection.

Along with deciphering others’ profiles, individuals on the spectrum must write their own profile in order to have an online dating presence. Often, neurodiverse individuals tend to be honest and candid when asked to describe themselves (Baron-Cohen, 2007). While this is a positive quality in many regards, it can cause challenges when portraying oneself online. Individuals on the spectrum can struggle to understand the social context of how their

profile may be perceived by others and what they may be inadvertently disclosing about themselves. This may also be true for choosing images to use on dating profiles. It can be helpful to seek advice or review from peers or other supports in an individual’s life when they are creating a dating profile.

#### Support from Others

Roth and Gillis (2015) suggested that individuals on the spectrum would most benefit from further support on how to engage in online dating in safer, more successful ways. While this is often the goal of supportive therapists and family members, it does not always result in a positive outcome. Many well-meaning supports in an individual’s life may become overly involved in their online dating success, which can result in over-involvement in creating a profile, managing communicating over texts, or reminders of social conventions and rules throughout the process. While these can be helpful learning tools, especially for individuals who are new to online dating, it can also cause disparities between online communication and in-person meetings. These discrepancies

can then lead to rejection and further social isolation upon meeting someone for a date. Along with exacerbating in-person social challenges, many therapists are not always up-to-date with dating trends. This may lead therapists to offer advice or dating website suggestions that are not current, which can lead to further failures in dating. Working with a provider who is well-versed in dating and forming romantic relationships is essential.

#### Suggestions

Psychoeducation related to dating and intimacy is the biggest tool individuals on the autism spectrum can receive related to online dating. Understanding social conventions and progression related to dating can help individuals not only strengthen these skills but have a greater awareness when something is awry in their online communication. By better deciphering fake profiles or potential dangers, we begin to eliminate some of the most significant safety concerns. We also allow an individual to grow in their knowledge and ability to romantically connect with others in an authentic, successful way, which is the ultimate goal.

*For more information about Leslie A. Sickels, LCSW and the clinical services she provides visit [LeslieSickelsLCSW.com](#) or contact her directly at [LeslieSickelsLCSW@gmail.com](#).*

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### Wandering from page 12

said fear of their child eloping stopped them from attending or enjoying activities outside the home, increasing their social isolation; not surprisingly, 40 percent of these already exhausted parents said they lost sleep while worrying about a potential “escape” during the night.

So why do ASD children wander? While researchers still aren’t sure, parents ranked these as their child’s top five possible motivations:

1. He/she simply enjoys running and exploring (54 percent)
2. He/she is heading to a favorite place he enjoys such as a park (36 percent)
3. He/she is trying to escape an anxious situation like demands at school (33 percent)
4. He/she is pursuing a special topic of interest, i.e. when a child fascinated by trains heads for the train tracks (31 percent)
5. He/she is trying to escape uncomfortable sensory stimuli such as loud noise (27 percent)

#### Running to or Away from Something

Experts divide wandering into goal- and non-goal types. While the desire to find an alluring pond is goal-directed, running to escape a stressor is non-goal-related. “Our fight-or-flight kids will bolt” when anxious, says Lori McIlwain, chairwoman of the National Autism Association and a key player in the fight against wandering and elopement, adding that these are the children who get struck by vehicles. “We might see a snake and run away. Our kids may see something we wouldn’t be afraid of. But they are and the adrenaline misfires.” Still, the majority of parents surveyed reported that their child is playful or happy and focused while wandering; far fewer said their child is sad, anxious or “in a fog” when they take off.

Last week, autism advocates scored their first major victory in their campaign to better respond to wandering when the Centers for Disease Control’s safety subcommittee overseeing autism announced a new medical diagnostic code for wandering. This sub-classification, which will go into effect October 1, will allow clinicians to add a wandering code to an ASD diagnosis, akin to a diagnosis of autism with epilepsy. The code is not exclusive to autism; it covers other conditions where the child or adult wanders, including a range of cognitive disabilities.

#### Enabling Pediatricians to Help

“We really went for a medical code so pediatricians would be a central source of information” for parents of wanderers, McIlwain says, while creating a better understanding of the behavior as a medical

condition. Given that only 14 percent of study respondents said they got any guidance on the issue from their pediatrician or any other doctor, “the hope is the code will open the door for awareness, education, understanding, training and critical dialogue between doctors and caregivers.” McIlwain says the American Academy of Pediatrics is preparing a fact sheet on wandering so that physicians have ample information about the code and resources to share with parents.

“The best overall strategy,” McIlwain adds, “is a multi-tiered approach, which includes educating the child about safety and dangers using whatever means of communication works, including **social stories**, language and/or visual prompts. It’s also important that caregivers—and schools—work to understand what is causing, or contributing to, the wandering or bolting behaviors so that any triggers may be addressed or eliminated.”

#### Training for Police Officers

Alison Singer, president of the **Autism Science Foundation**, one of the advocacy groups behind the IAN survey, says advocates hope the code will also allow for more funding for research and proper training for police officers, firefighters and other first responders. These rescuers need to better understand those on the autism spectrum, including their behaviors. Otherwise, Singer says, they may not know how to locate a nonverbal or unresponsive wanderer. There’s also the danger that they might feel menaced if, for instance, an impulsive teen tries to reach for a shiny object like a badge or gun or a wanderer “invades their space,” as many on the spectrum often do; if that were to happen, the responder might mistakenly think the wanderer is high on drugs.

Advocates also hope the code can be used to establish that preventative measures such as tracking devices, locks, and door and window alarms are a medical necessity covered by insurance. Wandering has already led some parents to fit their children with tracking devices, which are registered with local law enforcement officials. However, unless they’re waterproof, they often fail to save lives.

This is what happened to 10-year-old Kristina Vlassenko, whose body was discovered in a water-filled hole at a construction site in Colorado. Her Care Trak tracking system, a watch-sized device, does not emit signals under water. By the time she was found, it was too late.

#### Concerns over Medicalizing Wandering

However, the code has not received universal support from the autism community. Adults with autism have voiced strong concerns that by categorizing wandering as a medical condition rather than a behavioral one, parents, schools and others will no longer ask why a person might be wandering. In his video “Autism and Wandering: An Im-

portant Message,” Landon Bryce, who runs the site **thAutcast**, asks, “If you couldn’t talk, and the only way you could communicate that something was bad was to move away from it, how would you feel about people making a law that should be ignored?”

He notes that a child might bolt because of sensory discomfort—perhaps a teacher’s perfume is making him sick, so he flees the classroom—or, in the worst-case scenario, abuse in the home. In the first example, a child might be placed in a more restrictive school setting, thus impeding his educational opportunities; in the second, it could result in him being returned to an unsafe environment. After the code was approved, Bryce wondered how long it would take before other advocates start “calling for insurance companies to pay for parents to get their kids implanted with microchips, like pets?”

But McIlwain says the code is aimed at protecting, not harming, children with the highest risk of wandering-related injury or death.

#### An Attraction to Water

Given the high number of wandering-related drownings, some in the community have come to speculate as to why those on the spectrum are drawn to water; one theory is that it has an alluring, calming effect due to the repetitive pattern of reflections, or the way it puts even pressure on the body, which sensory-seeking children may enjoy. However, Singer says there’s no data from the wandering survey to support those theories: “We just don’t know why.”

McIlwain says the wandering code could have helped in myriad ways had it been in effect when her son, Connor, had his most dangerous wandering incident. The boy, now 11, began wandering at school when he was 3. But at 7, he was able to leave the playground of his suburban Raleigh, N.C., school, despite McIlwain’s notes alerting the staff to “not let him out of your sight.” Motivated by his fascination with exit signs, the boy, who has autism, took off through the woods and was headed for the highway when a Good Samaritan picked him up and started driving him around, hoping to find his school.

When staff at the first school the man stopped at didn’t recognize Connor, they called the police. The officers took over the search without knowing who the boy was. (While Connor is verbal, McIlwain explains, his language was much more limited at the time. He was unresponsive to his rescuer’s questions, though “he did convey to the police that he was going on an adventure to find his favorite exit sign.”)

#### An Appropriate Response Plan

Meanwhile, no one at Connor’s school had called his mother — or the police. “He could have been struck by a car, raped, abducted,” McIlwain says. When the police saw people at Connor’s school searching for him, they realized he belonged there.

Only then did someone at the school notify her. The advocate notes that had the school had a proper emergency response plan — or if Connor had been wearing an ID — the situation could have been resolved quickly. Instead, “he was still in the cop car when they called me,” she says.

“I got him out of that school as fast as I could,” McIlwain says. She then enlisted a lawyer to help add a 1:1 aide to his Individualized Education Plan (IEP) to escort him during transitions, such as when he leaves the classroom to go to a therapy. With the added support, Connor is able to attend a school for typically developing children. McIlwain feels the code will help keep the aide should her son continue to need one, so in October she’ll have his pediatrician provide an updated letter noting the diagnosis for the school and his IEP.

While some adults with autism worry that a medical code could be used to justify the restraint or seclusion of a student, or place him in a more restrictive school environment, McIlwain says her experience with Connor demonstrates how the exact opposite could result. If more parents can use the code to get their wandering child the supports he or she needs, the child could enter a less, not more, restrictive setting.

#### Relieving Stress on Parents

Along with reducing wandering incidents and deaths, the code is aimed at relieving the incredible stress the behavior places on caregivers. Wandering children “are impulsive,” McIlwain adds, so their parents are “constantly in prevention mode for fleeing, bolting, unpredictability, biting. We need support. Instead, we get constant scrutiny and judgment from other parents. But these are the same folks who would say ‘Why weren’t you more protective?’ if something were to happen.”

At a time when parents who “hover” are often chastised, “the pressure from other parents and family members who say we’re too overprotective and overbearing may make parents think they’re doing something wrong,” she adds. “They may adjust their parenting to meet others’ expectations. It’s the wrong way to go. Parents need to stand their ground and focus on the child, not on how other people think they should be parenting.”

“Other parents don’t know our reality,” she adds, “and they never will.”

*For more information on waterproof tracking devices, ways to secure the home, and others measures to guard against wandering, see the **Autism Wandering Awareness Alerts Response and Education (AWAARE) Collaboration** site.*

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### Dangers from page 11

related to subjects in school, they can often be persuaded to do class assignments for others (as happened to me years ago as a student) or even assist in cheating on examinations; this can result in academic code violations and have damaging consequences to the autistic, for whom success in an area of interest often provides the greatest hope of a positive future outcome. With older adults, a similar situation exists when an employed individual enlists an unemployed autistic to do work for which the non-autistic gets paid.

#### The Internet and Illegal Activity

A new class of dangers for autistics in the modern age is found on the internet. Many of the same predators who have long victimized autistics can now be found on social media and other online venues. These dangers have long been publicized for various non-autistic populations (the lonely, the isolated, the elderly, etc.), and are similar in both the inducements (friendship, acceptance, romance, etc.) and hazards (e.g., taking financial advantage) as more traditional scams, but once again autistics are especially susceptible to such predations. The element of electronic communication, as opposed to direct personal interaction, further complicates matters because it

creates additional layers that can be used to conceal the deceptions.

Internet websites that involve illegal activities can be especially dangerous, because they are often monitored by law enforcement agencies which have capabilities to determine the locations of users that are accessing them. Of particular concern are sites that contain child pornography, information about weapons and explosives, or other materials that are illegal to possess or even look at. Unfortunately, a significant number of autistics have been known to browse such websites, sometimes quite extensively, purely out of their intense curiosity. They have no malicious intent whatsoever, but nevertheless attract the attention of officials who are monitoring the sites. In more than a few instances, this has led to the arrest of such autistics, who then faced severe legal repercussions. Autistics need to be made aware of this danger, taught to recognize and avoid any sites that might present hazards for them, and impressed upon them the capability of law enforcement to locate their computers (using internet addresses), track them down, arrest them, and confiscate the computers for evidence. These issues can easily be explained to the many autistics that are knowledgeable about computer technology; they perhaps can in turn be enlisted to help explain them to other autistics who are less so inclined.

### Bullying

Another very common danger faced by autistics of all ages is the problem of bullying (physical, verbal, etc.), be it in schools (at all levels), workplaces, or local communities. For those on the autism spectrum, bullying needs to be seen as nothing less than the victimization by one person with greater influence or power of another who is unable even to understand what is happening, let alone why it is being done. Also, autistics in any and all circumstances need to be provided with someone to whom they can report bullying, and who can help them address it in a manner that does not lead to further repercussions; this can range from practical advice about how to deal with such a situation to proactively taking whatever action is needed to stop the bullying. The fact that autistics are far more susceptible to bullying than most of the typical population also needs to be more widely recognized.

### Alcohol

Finally, many hazards that are faced by anyone in our society can affect autistics in a different and possibly unique manner. An example of this is the decision whether or not to consume alcohol and the understanding of its potential dangers, most of which are the same for autistics as they are for anybody. Because drinking is a part of so

many social activities, however, it is very easy for an autistic person with deficient social skills to get the impression that alcohol can benefit them in such situations, especially when they see others having successful interactions in these settings (I actually believed this at one time in my youth). What is in fact happening is that the alcohol reduces their social anxieties (this well-known effect of alcohol is actually regarded by some to be a legitimate use), but in no way enhances their social abilities. While this may seem like a minor technical point to most neurotypicals, it is of far greater importance to autistics who, whatever choices they might make, need to understand that alcohol functions as a drug that reduces inhibitions and is not “liquid social skills.”

### Conclusion

There are numerous other dangers and hazards which mainly affect autistics; I have only addressed a few that I could think of and that space permits me to discuss. These need to be identified, perhaps using the life experiences and stories of adult autistics as a guide, which can in turn be used to inform those who live and work with autistics so that they can be vigilant about them and serve as cautionary tales for autistics themselves.

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### Suicide Risk from page 18

if a child mentions suicide. “We need to take all talk of suicide seriously, and pay attention to it,” she said. “While suicide is a very rare event, if a child is talking about thoughts of suicide or wanting to kill themselves, it’s important to say to him, ‘You mentioned that you were thinking you wanted to die, or kill yourself. I’m glad you are telling me - I take this very seriously. My first priority is keeping you safe, and I want to be able to help you.’”

“Do not leave him alone, and if you’re concerned about his safety, take him to a hospital emergency room,” she advised. People also can contact suicide prevention help lines that are open 24 hours a day, seven days a week, she said. (See the [Additional Resources](#) section for numbers to call or text, or to start an online chat.)

Families are not the only ones being urged to pay close attention to depression and suicidal thoughts in people with autism. Health care providers should be “vigilant for suicidal behavior” in their patients with autism, according one research article.<sup>5</sup>

Physicians can be proactive with these patients, said Paul H. Lipkin, a pediatrician specializing in neurodevelopmental disabilities. “They should consider screening for suicide in order to identify problems early, and initiate mental health treatments before problems escalate,” said Dr. Lipkin, who directs the Interactive Autism Network and has been involved in suicide research.

Certainly, social and communication problems can make it harder for those on the spectrum to request help, or to have their difficulties noticed by others. “It is incredibly heartbreaking to think that individuals with autism feel trapped by social communication impairments and are unable to reach out for help, and do not have the same social support structure as those without autism,” said Dr. Halladay,

chief science officer of the Autism Science Foundation.

#### The Road Ahead in Autism Research

Autism researchers Darren Hedley and Mirko Uljarevic, who reviewed 13 studies on the topic, concluded that more research is needed into what causes the higher risk.<sup>12</sup> They also called for more study into the role of ASD severity – and IQ – in suicide risk, to confirm whether people with “high-functioning autism” have a higher risk than those with other forms of autism. Future studies also could sort out conflicting reports about whether suicide risks differ between males and females on the spectrum. And they concluded that more research is needed into what supports or help would reduce suicide risk for people with autism.<sup>12</sup>

“We must figure out what scientists can do to better help those in crisis,” agreed Dr. Halladay, “because we can’t assume that the strategies for helping those considering suicide are the same for everyone [with autism].”

#### Additional Resources

See the following resources for 24/7 help:

- The U.S.-based [National Suicide Prevention Lifeline](#) provides 24/7, free and confidential support for people in distress. Call 1-800-273-8255 or visit their website for a chat feature. The lifeline also has prevention and crisis resources, and information for professionals.
- Text TALK to 741741 in the U.S., to be connected by text message to a crisis counselor at the [Crisis Text Line](#).
- The [Canadian Association for Suicide Prevention](#) has a help line.

- The [International Association for Suicide Prevention](#) publishes information about crisis centers on every continent. (Click on the links under the heading “Categories,” under the map).
- [Be the One to Save a Life](#) has resources to help people in crisis, and people concerned about them.
- U.S. Centers for Disease Control and Prevention’s (CDC) online resources on [suicide prevention](#).
- Suicide prevention information from the U.S. [National Institute of Mental Health](#)
- [Download](#) the CDC’s report, “Preventing Suicide: A Technical Package of Policy, Programs, and Practices.”
- Download a [poster by Interactive Autism Network](#) researchers on “Suicidal Ideation and Behaviors in Children, Youth, and Young Adults with ASD.”
- Read Interactive Autism Network articles on “[Diagnosing Depression in Autism](#)” or finding a mental health provider experienced with ASD, “[Help Wanted: Mental Health Provider, Autism Experience Preferred](#).”
- World Health Organization’s [Preventing Suicide: A Community Engagement Toolkit](#)

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The complete list of references can be found at <https://iancommunity.org/aic/link-between-autism-and-suicide-risk>.

**Real Estate from page 4**

their careers or pursue a plethora of hobbies and interests to a focus on vital medical and/or mobility issues. A mature market affords a broader mix with healthy competition, rewarding those committed to the creation of more viable options.

**Proposed Study to Define the Marketplace**

As part of developing and enabling a marketplace to mature, we need to start speaking the same language. In many cases, we do not even have the words or definitions in various sectors to empower consumers to communicate what they want and need.

Led by First Place AZ and AHN, and together with leaders from across the country, we are advancing—and actively seeking support for—a sister study to *Opening Doors* offering a market analysis that includes universal nomenclature to describe the various housing models and long-term support service options available to potential developers and neurodiverse populations. The report will also include research on the assessment/evaluation processes for individuals with autism or other IDD, including the alignment of support needs and interests in preparation for transitioning to their homes.

Empowered with this information, we are also prepared to offer strategies for cultivating neighborhood collaborations and integrated communities, along with a “Supportive Housing Development Toolkit” compiling promising and best-practice models of various housing developments.

Ultimately, this overview and analysis will present the universal language offering a clear description of housing and support models despite variations among state government authorities, residents and families benefiting from improved and easier transition and long-term assimilation plans, as well as scarce funding saved from poor planning or misplacements. Most importantly, it will offer suggestions for creating accepting community cultures to enhance the lives of residents, resulting in opportunities for higher employment rates, increased support system, and reduced medical or other provider expenses.

We will be introducing our first think tank advancing this important body of work at the First Place Global Leadership Institute fall symposium this October, 2018, in Phoenix: <https://firstplacesymposiumfall2018.splashthat.com/>

Working together, we can build, grow and align communities to serve the vast and diverse needs of people with autism and other neuro-diversities by building a marketplace that is not only recognized and rewarded through market principles but documented through outcomes. By developing new tools tracking quality of life and other factors, we can collectively determine whether emerging models are effecting the desired change and, if not, offer recommendations for how to achieve the desired change.

Without supportive housing options, local communities will disregard and miss out on the important talents and contributions of their neurodiverse citizens. We can create models for shared alliances and leveraged resources that encourage more public and private home and community options serving vulnerable adults and reduce overburdened government budgets.

Now is the time for exploration, explanation, engagement and expansion of supportive housing development across North America. A new generation of dynamic housing models is only possible by collectively tapping private, government, non-profit and charitable interests—and that includes us all.

Graduating to the couch should not be the only option for young adults with developmental disabilities. We are already seeing them successfully navigate college, find their niche in the workforce, give back through volunteering, and be included in neurotypical social circles in the community. We are raising the bar on expectations, new realities—and dreams.

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**Exhibit A First Place Design Goals & Features**

Nov-15				
	Icon	Design Goal	Description	First Place Features
1		<b>Ensure Safety &amp; Security</b>	Ensuring a safe living environment is the top priority. Issues range from providing appropriate security systems to selecting nontoxic products and materials.	Single point of entry with 24-hour concierge (reference from private market sector used throughout); electronic keycard system for strategic door-lock access and monitoring; nontoxic, low-VOC materials used throughout.
2		<b>Maximize Familiarity, Stability &amp; Clarity</b>	Changes and transitions can be problematic for adults with ASDs, so creating continuity and connection with the past is important. Design strategies include logical, spatial layout and use of familiar materials.	Expressed thresholds and transition spaces at unit entries and community spaces; materials strategically repeated throughout to increase familiarity.
3		<b>Minimize Sensory Overload</b>	Simplify the sensory environment by designing spaces to be quiet, visually calm and well-ventilated with appropriate lighting.	Refined material palette and subtle wayfinding colors provide clear understanding of spaces. Acoustic baffles, diffuse LED lighting and ample natural lighting provide even, comfortable illumination. Operable windows with window limiters provide safe, controlled access to fresh air and ventilation.
4		<b>Allow Opportunities for Controlling Social Interaction &amp; Privacy</b>	To accommodate personal preferences, the design of any home should provide residents with a variety of social opportunities, including within a singular space.	Community spaces designed to support groups of all sizes—from a small gathering of two in a breakout space to a large party in the community room. All designed with flexibility and opportunities for chance interactions.
5		<b>Provide Choice &amp; Independence</b>	The physical environment should be designed so that options are available—but few and flexible so that it can be adapted to change based on residents' needs over time.	Units and community spaces are designed with flexibility in mind, allowing for multiple furniture arrangements and various-sized gatherings. Special features include an electronic game room, LEGO lounge, fitness and zen rooms, culinary teaching kitchen, sports pool and more.
	Icon	Design Goal	Description	First Place Features
6		<b>Foster Health &amp; Wellness</b>	To address any ongoing health vulnerabilities, the physical design should promote healthy living through the use of nontoxic materials, the availability of natural light and good ventilation, and the incorporation of universal design strategies.	Nontoxic and low-VOC materials used throughout. Secure, operable windows provided in each unit for ventilation. Large windows provide natural light. Amenities include a fitness room, swimming pool, health and wellness center and culinary teaching kitchen promoting healthy cooking tips.
7		<b>Enhance One's Dignity</b>	Everything from selecting a neighborhood that accepts diversity and supports its residents to designing a home that allows residents to personalize their spaces and define their living arrangements serves to enhance one's dignity.	First Place—Phoenix location selected for its supportive, surrounding community and resident opportunities community connection. Design makes architectural statement, adding to community beauty and character. Flexible unit plans allow for a variety of furnishings for residents to define their personal space.
8		<b>Ensure Durability</b>	Investing in high-quality materials, fixtures and appliances at the outset will result in lower maintenance/ replacement costs and will optimize resident safety.	Durable materials such as quartz countertops, fiberglass doors and recessed light fixtures provide functionality and longevity. Floor drains and extra waterproofing installed in each unit bathroom.
9		<b>Achieve Affordability</b>	Designing for longevity and incorporating green building practices can lower costs over the lifetime of the home.	Durable fixtures, finishes and systems maximize longevity while minimizing operation costs over time. The First Place Global Leadership Institute also opens doors to other residential options through training/education of support service providers and works with affordable housing developers.
10		<b>Ensure Accessibility to &amp; Support of the Surrounding Neighborhood</b>	Site selection is critical to the overall success of any residential development. Access to transportation, community services, entertainment and shopping—coupled with a supportive neighborhood community—will create optimum results for residents.	Urban site provides access to many community amenities, including public transportation, lifelong education, health, employment and recreational opportunities.

### Safety from page 6

(social cognition); and summaries to capture main ideas.

BE SAFE can be used for individuals with autism, other disabilities, or no disability at all. The Movie has captions to ensure that Deaf individuals have access to key concepts and vocabulary. Captions can also help learners with ASD process information more effectively. The Movie has Spanish subtitles and the curriculum is available in Spanish to reach doubly at-risk populations.

BE SAFE Teaching Edition offers a differentiated Companion Curriculum with lessons matched to each episode of the Movie. Parents, educators and interventionists can select activities and materials to reach learners with diverse verbal and cognitive abilities. Students can use the curriculum scripts to practice and roleplay scenes from the movie.

BE SAFE the Movie and Companion Curriculum can also be used to help learners expand on concepts beyond the film, including preparing them for an evacuation or an active shooter situation. It can be streamed into classrooms or clinics in ABA format, via subscription from TeachTown. Students can go at their own pace, with progress tracked electronically. Teachers have access to curriculum materials to build key safety skills for everyone.

In addition to anecdotal success stories

and feedback from teachers and students, BE SAFE is currently being studied for effectiveness as part of a National Institutes of Health study (Ravindran & McCleery, 2017). It will compare the effectiveness of BE SAFE to teach skills for interacting with the police (the control condition) to a different technology platform.

#### Bridging the Gap Between Police and the Autism Community

While training both officers and individuals with disabilities is essential, another key element is necessary to promote safety: **relationships**. Sometimes encounters go wrong because officers and community members are unfamiliar strangers. A BE SAFE Interactive Movie Screening (IMS) brings officers and individuals with ASD together to learn with *and* from one another.

At an IMS officers are paired with individuals on the spectrum. They watch scenes from BE SAFE together. Then the police practice specific skills with participants, such as asking for help, following instructions, and keeping hands to themselves. The event promotes mutual understanding, comfort, and trust. In addition to having fun and building safety skills, many participants report decreased fear and anxiety around interacting with police.

The police benefit from an IMS in multiple ways. It supports community policing, giving officers the opportunity to know

and interact with diverse individuals in the community they serve. Second, the police consider it “eyes-on” training, witnessing how diverse people on the spectrum act, react and interact. Officers hear the range of communication styles. They can relate on a personal level and practice accommodating these differences.

Safety can't be left to chance. Experience Autism® and BE SAFE are useful tools for addressing this critical need for individuals with ASD (and maybe even saving a life). After first participating in Experience Autism® and then being paired with an individual on the spectrum at an Interactive Movie Screening, one officer commented, “This is a game-changer.”

*Emily Iland, MA, ET, is an award-winning author, advocate and researcher, and an adjunct professor in the department of special education at California State University, Northridge. She is the mother of a son on the autism spectrum, which inspired her to personally train thousands of peace officers about ASD. Emily worked with Joey Travolta and young adults with disabilities to create BE SAFE The Movie. She travels across the country to bring the disability community and local police together to learn from one another at BE SAFE Interactive Movie Screenings. For more information, visit [www.BeSafeTheMovie.com](http://www.BeSafeTheMovie.com) and [www.ExperienceAutism.com](http://www.ExperienceAutism.com) or contact Emily Iland, [emily@BeSafeTheMovie.com](mailto:emily@BeSafeTheMovie.com)*

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### Community from page 16

that interactions with law enforcement can be and must be done better.

UPS makes it a priority to work with community stakeholders to strengthen and build communities of support. “At UPS, we have a proactive approach that aids in the prevention of such irreversible tragedies,” said Yvette B. Andre. “Unique People Services believes that inclusion and understanding are vital to a flourishing community,” she further stated. Their approach helps them to include individuals in the mainstream of society. They provide guidance and resources to community residents, build relationships with local law enforcement and consistently engage public officials; a simple approach that works. They realize that relationships are key.

At their most recent open house, the police community relations officer attended, and she brought along some community summer youth to introduce them to the residents. In a conversation with the officer, she stated, “Law enforcement is there

for the protection of all and participating in these types of events are important.” When asked why she felt it was important to bring youth from the community, she replied, “Once you know someone and build a relationship with that person, it changes your perspective. That is how we all stay safe.”

Evidence supports that people with autism and disabilities face severe marginalization, victimization, and crime.

**Autism Now reports** that “Although more research is needed, studies consistently show people with intellectual and developmental disabilities are more likely to experience violence than people without disabilities.” In the **latest data released** by the U.S. Department of Justice’s Bureau of Justice Statistics, “persons age 12 or older who had disabilities experienced 1.3 million nonfatal violent crimes and for each racial group measured, persons with disabilities had higher age-adjusted violent victimization rates than persons without disabilities.”

“We are founded on the principle that everyone deserves the right to be understood

and accepted. We know that something as simple as an open house or community introductions create a safe environment for our individuals and their neighbors. These types of actions work to benefit all involved. Individuals have the right to inclusive living situations in their communities. The only way for that to occur is to create opportunities for a collective community experience,” stated Yvette Andre.

UPS has learned that by promoting integrating experiences between its residents and the overall community; it generates a positive ripple effect in the neighborhoods they serve, which continues to strengthen overtime. Working with community residents and law enforcement, acceptance occurs, friendships build, and the support circle widens.

Being a part of a community and feeling included and safe is extremely important to those individuals with intellectual disabilities and on the autism spectrum. While community integration takes time and effort, with a sound approach, a knock on the door by a magnificent individual with special

needs, the results are truly gratifying, life changing and empowering for all involved.

*Donna Davis is President & CEO, The DG Group. To learn more about Unique People Services visit their website at [www.uniquepeopleservices.org](http://www.uniquepeopleservices.org).*

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David M. Perry, PhD, Lawrence Carter-Long, *The Ruderman White Paper in Media Coverage of Law Enforcement Use of Force and Disability: a Media Study (2013-2015) and Overview March 2016* [http://rudermanfoundation.org/wp-content/uploads/2017/08/MediaStudy-Police-Disability\\_final-final.pdf](http://rudermanfoundation.org/wp-content/uploads/2017/08/MediaStudy-Police-Disability_final-final.pdf)

### Biomarker from page 19

had unique concentrations of specific amino acids (metabotypes) in their blood. Though a 17 percent subgroup may seem small, it is actually quite significant. ASD encompasses a complex array of symptoms, and no one expected to find a single group of markers that would diagnose all subsets. Rather, the researchers hope to create a number of metabolomic assays that cover all variations.

“The long-term vision is, once we’ve been able to analyze all the data from CAMP, we would have a series of panels,” said Amaral. “Each of these would be able to detect a subset of kids with autism. Ulti-

mately, metabolomics may be able to identify most children with autism.”

In addition to enabling earlier diagnosis, this work also could help generate targeted interventions for specific ASD groups. Amaral points to phenylketonuria (PKU) as a possible template. PKU is a rare disease in which the amino acid phenylalanine builds up, causing brain damage. However, relatively small dietary adjustments can make a big difference.

“With just a simple dietary modification, a child can move from being profoundly disabled to one who lives a reasonably normal life,” said Amaral. “That’s the hope with autism as well.”

The CAMP researchers will continue to

validate these results while simultaneously investigating other metabotypes.

“I’m optimistic this is not a one-off,” said Amaral. “There are going to be other panels that can detect other groups of kids with ASD.”

Other researchers included Alan M. Smith, Joseph J. King, Paul R. West, Michael A. Ludwig, Elizabeth L. R. Donley and Robert E. Burrier at Stemina.

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David G. Amaral receives research funding from Stemina and is on the Scientific

Advisory Boards of Stemina Biomarker Discovery, Inc. and Axial Therapeutics.

At the UC Davis MIND Institute, world-renowned scientists engage in collaborative, interdisciplinary research to find the causes of and develop treatments and cures for autism, attention-deficit/hyperactivity disorder (ADHD), fragile X syndrome, 22q11.2 deletion syndrome, Down syndrome and other neurodevelopmental disorders. For more information, visit [mindinstitute.ucdavis.edu](http://mindinstitute.ucdavis.edu)  
*This article is reprinted with permission from the UC Davis Health. You may view the original article, published on September 6, 2018, at <http://www.ucdmc.ucdavis.edu/publish/news/mindinstitute/13135>.*



**Literacy from page 10**

to the story “Brown Bear, Brown Bear, What Do You See?” By Bill Martin Jr. To answer questions, the reader would have to know the meaning of the word “see,” “Who did the blue horse see?”

- Difficulty with interpersonal knowledge (Brown et al., 2012)

Example: Understanding that David, the character in “No, David!” by David Shannon, is offending various people in his day to day life due to his disruptive behaviors.

- Difficulty with gathering information to make inferences (Turner et al., 2017)

Example: Identifying conversation bubbles and facial expressions to determine how the pigeon is feeling in the book “Don’t Let the Pigeon Drive the Bus” by Mo Willems.

- Difficulty understanding someone else’s or a character’s perspective (Turner et al., 2017)

Example: How did the three bears feel when Goldie Locks went into their house? Or Why were the three bears upset at Goldie Locks?

- Difficulty with the social and pragmatic aspects of language, specifically with structuring a narrative to retell a story (Turner et al., 2017)

Example: In the Three Little Pigs, the wolf blew down the straw house first, the stick house second, and attempted to blow down the brick house last.

#### Strategies an Assistive Technology for Supporting Learners with Autism

When considering the following, it is important to note the definition of assistive technology, as stated in the Individuals with Disabilities Education Act 2004 (IDEA) as being “any item, piece of equipment, or product system, whether acquired commercially off the shelf, modified, or customized, that is used to increase, maintain, or improve the functions of a child with a disability.” The continuum is composed of low technology, mid technology,

and high technology options (Dell, Newton, & Petroff, 2017).

*Visuals for Communication* - Devine (2016) explains that visuals are a part of everyone’s communication system and are essential for individuals with autism. She further discussed that pictures allow the opportunity to make requests, communicate feelings, and make comments.

The following are some examples of assistive technologies that can be used to teach learners with autism how to communicate:

- Picture Exchange Communication System (PECS)

Low technology option that teaches individuals how to exchange a picture for a request (Devine, 2016). For more information on PECS, you may visit <https://pecsusa.com/pecs/>

- Gestures

Using gestures as communicative forms provide vocabulary and comprehension development. Gestures can be implemented through different versions of sign language and a program called Makaton (Devine, 2016 & Walker, 1987)

- Big Macks and Switches

Mid technology tool that can have symbols associated with a pre-recorded message and offer learners the opportunity to make choices and communicate simple phrases (Devine, 2016). For more information on Big Macks and Switches, please visit <https://www.ablenetinc.com/technology/switches>

- iPad Application: Proloquo2go

High technology option that provides a dynamic display for communication (Devine, 2016). For more information on Proloquo2go please visit <http://www.assistiveware.com/product/proloquo2go>

*Gaining Attention* - Devine discusses the importance of making books and reading appear interesting and fun in order to gain the reader’s attention. The following are strategies recommended by Devine:

- Sensory stories are a low technology option that may be used to assist children in

experiencing a story through their senses (Devine, 2016). For more information on sensory stories, please visit <http://sensorystories.com/>

- Using displays is another low technology way to enhance comprehension by making a book interactive. When creative with a story display, the reader will be able to answer questions, sequence, and build vocabulary (Devine, 2016)

#### Conclusion

Visual supports help to gain attention, reduce anxiety, provide a focus on communicative messages, and make abstract concepts more concrete for all learners, particularly those with autism (Rao et al., 2006). Therefore, incorporating them into the everyday classroom touches upon the implementation of a Universal Design for Learning. As a practitioner, incorporating the use of interactive read-alouds not only engages my learners, but provides them with opportunities to express their understanding of a story by matching pictures to story concepts.

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**Managed Care from page 17**

and Innovation. “Partnering with experts like NYU’s McSilver Institute, which has headed up the Managed Care Technical Assistance Center (MCTAC) for behavioral health providers for the past several years, we can avoid reinventing the wheel and expedite bringing these resources to

the field.”

“We are so pleased to have partners in this project with such a deep understanding of managed care and what it takes to operate in the managed care environment,” said Michael Seereiter, Executive Vice President and COO. “They include Manatt Health, Negri Management Resources NYU’s McSilver Institute on Poverty Pol-

icy and Research and VORYS Healthcare Advisors.”

To learn more about the technical assistance available, experts involved, and how to access available resources, visit <http://files.constantcontact.com/5b48ae9f601/f722ef6d-92af-4b2f-aec3-3370ce40b955.pdf>.

About the NY Alliance

for Inclusion and Innovation

The NY Alliance for Inclusion and Innovation (New York Alliance), is one of the state’s largest associations of non-profit providers advancing the interest of provider organizations and people with Intellectual and Developmental Disabilities (I/DD). For more information, visit <http://nyalliance.org/about.php>.

### Free Support Group for Families of Adults with Asperger’s Syndrome and High Functioning Autism

The focus of the support group is to assist families in understanding the complex issues related to their adult child impaired with Asperger’s Syndrome or High Functioning Autism. At many of our meetings, we have speakers address various topics of importance related to these syndromes.

Website: [www.FAAHFA.com](http://www.FAAHFA.com)

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

Meeting Dates 2018: 11/18, 12/16 2019: 1/27, 2/24, 3/24, 4/28, 5/19, 6/9 Location: Westchester Arc - The Gleeson-Israel Gateway Center 265 Saw Mill River Road (Route 9A), Hawthorne, NY 10532

### Socialization and Life Skills Group for Adults with Asperger’s Syndrome and High Functioning Autism

This group is focused on Employment and Vocational Issues, College Coaching and Supports, Socialization, Self-Advocacy, Dating, and Relationships

Website: [www.ASDGroupsWestchester.com](http://www.ASDGroupsWestchester.com)

Facilitators: Robin Kaufman, PhD, and Lauren Greiner, PhD  
[ASDGroupsWestchester@gmail.com](mailto:ASDGroupsWestchester@gmail.com) (914) 497-1590

### Analyzing Health from page 13

ever, may discover a very specific area that should be addressed first, as it causes the most injury despite accounting for only a small percentage of the overall behaviors. This type of insight can then inform a more focused, personalized treatment protocol targeted towards the largest decrease in behaviors that causes injuries.

**Incident Tracking** - Comprehensive incident tracking, often referred to as “unusual incidents,” provides your organization with an abundance of useful, actionable information to improve the well-being of individuals and inform organization-wide systemic improvements that benefit all your individuals. In this way, incident tracking can be so much more than meeting regulatory or internal reporting requirements; it can be the foundation to a better program.

Incident tracking databases tend to have many dozens of measures, so it is important to take the time to ensure you have identified the right measurements to record. After accounting for any measures (“fields”) required by regulatory authorities, you want to add your own fields that speak to kind of reporting you want to get from the dataset. For example, by regulation you may be required to record the general location of the incident, like “residence,” for a fall that happened in the residence. But for the purposes of organizational improvement, you

may want to have a second, more specific field, like “lower-level bathroom” because that will give you enough information to investigate if the environment played a role in the incident. If so, that environment could be modified to make it safer for walking, or new policies, like not leaving a floor wet, could be implemented.

#### Spreadsheets and Databases

**Spreadsheets** - The first step to improved health informatics data collection is choosing the data collection platform. Spreadsheets and databases are the two main technologies used for the recording of data, but they are not interchangeable. Spreadsheets are essentially tables in which data can be entered directly, manipulated by formulas, graphed and analyzed. Almost all organizations work with spreadsheets, like Microsoft Excel and Google Sheets, on a daily basis. Spreadsheets are useful for smaller, simpler datasets that have single tables, and are often the first choice for small organizations to get started organizing their health data in a format which can produce immediately useful graphs and charts for analysis.

**Databases** - Databases, like SQL, are quite different. A database is collection of data that is organized, usually into multiple tables of data with defined relationships between the data from table-to-table and

across the database. Databases are structured to match the real-world situation for which they are collecting data; they are not merely large spreadsheets. Using the previous examples, the sleep, weight, well-body, and incident databases can be brought together in way which maintain relationships between the data across all the tables within all the databases. This consolidation of data results in far more robust reporting and analysis capabilities on the individual and organizational level. Consolidation of data allows you to quickly analyze the individual’s sleep quality versus weight, and likelihood of involvement in an incident the following day, for example. As long as there are common threads, like individual name, location, even specific interventions, those relationships can be used to connect and analyze data in bigger ways. At the organizational level, you can connect the dots between specific locations, or staff, or intervention types in your organization and analyze the interplay among them, discovering connections that inform program-wide improvements.

**Workflow and Automation** - Procedural, reporting, and alerting workflow can be custom programmed into both spreadsheets and databases. Often, rule-based, repetitive procedures like emailing a form to a supervisor upon submission or emailing nursing upon a well-body check report or weight issue are programmed to occur

automatically. Beyond reducing work for staff, this type of workflow can give an organization the peace of mind that important alerts and processes that require action are not being missed. This workflow can mean the difference between treating proactively, like modifying the diet of an individual who is starting to gain weight at an unhealthy rate, versus reactively, like acting only when staff has already visually noticed unusual weight gain. Automating workflow can also help ensure your organization meets regulatory requirements in much the same way.

#### The Final Analysis – Benefits to Individuals, Staff and Organizations

Health informatics data empowers your organization to improve the health, safety and wellness of individuals, clients and staff, while informing decisions that can improve the organization as a whole. Connecting the dots between individuals’ health measures, outcomes, and organizational measures can unearth invaluable insights that become the foundation of continuous improvement. Adding automated intelligence like workflow, regulatory requirements, emailing, and alerting to your database applications brings further efficiency and peace of mind to your individual and your organization.

For more information, please visit [www.melmark.org](http://www.melmark.org), or [www.melmarkne.org](http://www.melmarkne.org).

### Santabarbara from page 14

plan to give all New Yorkers with disabilities a stronger voice.

#### Autism Spectrum Disorder Advisory Board

With Autism Action NY, thousands of families have seen some big wins and important steps taken towards addressing the challenges we all face together. In 2016, the critical piece of my Autism Action Plan was signed into law (Chap. 469 of 2016). The measure created New York State’s first Autism Spectrum Disorder Advisory Board to develop, implement and update a statewide Autism Action Plan, incorporate new information as it becomes available, and established a central location for available services. New York is now one of the only states to have a statewide Board like this.

#### Statewide First Responder Training Program

Since then, the plan has grown with new

ills, new funding and new legislation signed into law that is making a difference for thousands of families. This year a number of key bills were passed in both houses and are now signed into law. Among them was an autism training program for first responders. This is the first-of-its-kind statewide program that ensures police and first responders are properly trained to recognize the signs of autism and how to respond (Ch. 57 of 2018).

With 1 in 59 children now born with autism each year in the United States it is essential that our first responders have the proper training. Individuals with autism like my son Michael often struggle with communicating, making eye contact, and responding to simple questions, even if it’s asking for their name. Across the country we have seen how routine encounters with law enforcement can escalate simply because they are misunderstood. The program was designed to help bring attention to areas that need specialized training so that officers are better prepared when responding to those with autism spectrum

and related disorders.

Whether it’s helping a family find a missing child or responding to an adult with autism whose behavior may be misunderstood, recognizing the signs of autism and knowing how to react is important. This training is a valuable resource to those serving in law enforcement and after years of working on this initiative, I’m so very pleased to finally see it become a reality here in New York.

#### Standardized Autism ID Card

Also the first of its kind, a companion bill was passed to make New York’s first standardized Autism ID card available to families and individuals, replacing locally issued cards and homemade notes. Offered as a communication tool, it can help describe some of the challenges a person with autism may face and can also provide important information during an emergency. First responders will be trained to recognize the card through the new Autism

Training Program for First Responders program (Ch. 209 of 2018).

Michael is 16 now. He’s my inspiration and he’s my angel. He doesn’t talk much, but he teaches me new things every day. As a father, it’s hard to watch him struggle with words and I know it’s hard for him to make friends, but he’s my best friend and whatever we do, we’ll do it together. It’s from challenges in our life that we gain perspective, compassion and wisdom. Over the years, despite the many challenges Michael and I have faced, we continue on our journey together and we continue to overcome. We are showing that disability does not define you and we hope the rest of the world will follow.

To contact New York State Assemblyman Santabarbara, call (518) 382-2941, email [santabarbaraA@nyassembly.gov](mailto:santabarbaraA@nyassembly.gov), or visit <https://assembly.state.ny.us/mem/Angello-Santabarbara>. Correspondence may be sent to: 433 State Street, Center City, Schenectady, NY 12305.

### Identification from page 15

the child and family (see for example [www.pcpcc.org](http://www.pcpcc.org)). This approach benefits all and may be especially ideal for traditionally underserved populations.

In summary, approaches to improve access and reduce disparities to care for young children with ASD must include attention to improving applicability and format of screening tools, location of where and how screening is provided, communication between providers and families, and methods to promote linkage to services once children have been diagnosed. All of these areas are needed to help ensure that all children with ASD meet their potential.

For more information, email [jharris@childrens-specialized.org](mailto:jharris@childrens-specialized.org), call 908-301-

2525, and visit [www.childrens-specialized.org](http://www.childrens-specialized.org).

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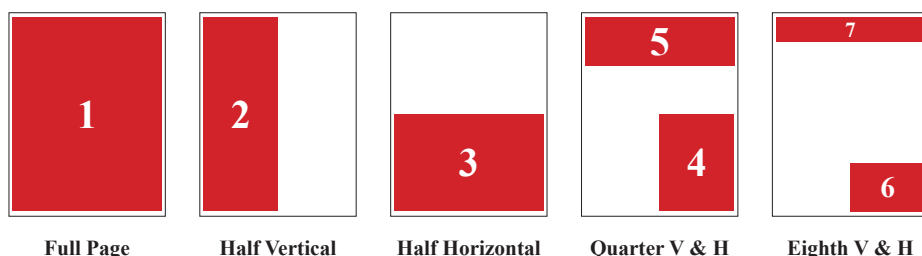
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