# Autism Spectrum News

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WINTER 2020 INFORMATION, ADVOCACY, AND COMMUNITY RESOURCES

VOL. 12 NO. 3

# **Autism and Neurodiversity**

# **Neurodiversity: The New Normal**

By Mandy H. Breslow, LCSW, MS Ed Founder and President Indie Living, Inc.

ver the years, many terms have been used to describe the various neurological conditions that result in developmental, cognitive and behavioral disorders. In the early days of diagnosis and treatment, diagnosis' ranged from relatively neutral terms like Hyperkinetic Impulse Disorder, (Kimberly Holland and Valencia Higuera, 2017) to overtly offensive terms such as moron, idiot and imbecile (Wikipedia, 2019). With improved research and understanding, disorders such as ADHD, Autism, Intellectual Disabilities, etc. are now often described using the term "Neurodiverse," meaning "that neurological differences like autism and ADHD are the result of normal, natural variation in the human genome" (John Elder Robison, 2013).

So, what does this mean practically and how does it affect the way we view and



treat Neurodiverse individuals? For one thing, it views individuals from a strength's perspective; that is, highlighting what they are good at, rather than their deficits. In his book, Neurodiversity in the Classroom, Thomas Armstrong likens neurodiversity to cultural diversity and biodiversity. He

uses the example of the variations in skin color as an example, stating that we don't refer to light-skinned people as having a "pigmentation dysfunction." We just use different descriptors to identify the variations (Armstrong, T., 2019). Neurodiversity allows individuals to celebrate their

uniqueness in the way they relate, communicate and process the world around them. Instead of asking the square peg to fit into the round hole of "normalcy," we add square holes to the neurological spectrum. By doing this, we acknowledge that no two people, whether they are considered to be "typical" or "disordered" by common standards, are alike. This is generally referred to as a wellness model: that shifting focus from a disease state to a health state. The push for a wellness model can be seen in other fields as well. Mental health is now the more common term than mental illness. The term "mental health" has become so ubiquitous that we don't even think twice about using it. Though the term was first used in the early 1900's, it didn't truly make its way into the mainstream until the last couple of decades. Mental health was not just the absence of a clinically diagnosed psychiatric disorder, it was a description of the person's whole emotional state of being (Mental Health and Illness, 2019).

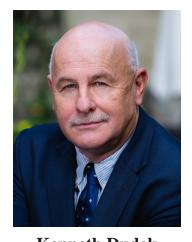
see New Normal on page 22

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Deadline: March 5, 2020

Summer 2020 Issue "Siblings and Autism" Deadline: June 4, 2020

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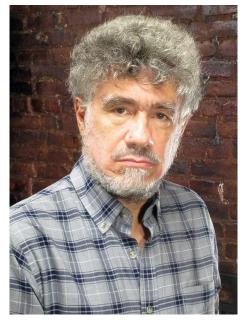
Mindy Appel, LCSW, ACSW, LMFT Young Child NYC Expo and Conference Chapel Haven

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# Neurodiversity: An Idea Whose Time Has Come and A Call for Unity

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

When I hear the word "neurodiversity," I immediately become concerned that it will be dismissed as simply another form of "political correctness," and not seen as encompassing a wide variety of serious issues that affect virtually everyone in the Asperger Syndrome / autism spectrum community. As such, I fear that the very idea will not be taken as seriously as it should be. I am especially worried by the proliferating idea that autism is merely an excuse to justify and allow inappropriate behavior in public. Even with the improved public awareness of the broader autism spectrum that has come about in recent years, there are many issues of acceptance and inclusion that still need to be addressed. Much as society has made significant progress concerning racial, ethnic, religious, gender, sexual orientation, and other identities, I find it telling that people I have known who are both on the autism spectrum and in these categories (including myself – I am Hispanic even though you would never know this from my name!) feel that they have been marginalized, excluded, and generally suffered more for their autism (directly or indirectly) than for the other category; this to me indicates how much further society still has to go in this regard. Neurodiversity issues



Karl Wittig, P.E.

are present in the school, workplace, community, and just about any social group including the family.

#### Hidden Curricula

One of the greatest obstacles to acceptance and inclusion of autistics in our society is the dramatic explosion of "hidden curricula" that has occurred over recent times – by this I refer to the collection of

social and societal "rules" that everyone is expected to follow but are not explicitly taught or even stated. Autistics, who have difficulty with things that are not articulated in a literal manner, are at a great disadvantage here. This is not to say that autistics should always be excused from adherence to all such rules (although many are completely arbitrary and even pointless), simply that their inability to "pick them up" as easily as the typical population does needs to be recognized within their communities and by society as a whole, and allowances must be made for such.

Hidden curricula need to be explained to nearly everyone on the autism spectrum in as literal, explicit, and unambiguous a manner as possible. This, in fact, may not be as easy as it might seem. Even those autistics who are "rule followers" can easily misinterpret the real meanings of such rules, especially when they take them too literally. Others who might understand the rules may still not fully appreciate the effects of not following them on others, given the theory-of-mind deficits so common in autistics, and thus not take them as seriously as they should. Consequently, not only do hidden curricula need to be articulated, but their underlying reasons need to be expounded upon until they are fully understood; in particular, the consequences of not following them need to be made very clear. All of this can go a long way towards the goal of promoting the acceptance and inclusion of autistics by society. At least, though, this is one instance where autistics can be directly helped to improve their situation; in many others, they will need to depend upon greater tolerance on the part of society.

#### Personal Differences

Many of the social difficulties encountered by autistics involve their inability to communicate effectively, fixation on specialized and unusual interests, obliviousness to things that are readily perceived by most people, and sensory sensitivity issues, among other things. Once again, society needs to be made aware of these challenges so that they can be accommodated wherever possible, and allowances made for such when necessary. This must be done in schools, workplaces, communities, and throughout society.

The easiest of these to deal with is probably the intense special interests. Although an autistic person with such interests may seem "odd," their focus on and ability in their unusual area is also a positive trait that, under the right circumstances, can be of (perhaps great) value to others, to their community, and possibly even to society. Rather than marginalize such individuals simply because their interests do not conform to more conventional ones such as

see Unity on page 34

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# The Journey to Self-Determination

By Pilar Page Program Director College Internship Program, Berkeley

he journey to adulthood can be daunting and overwhelming for anyone, especially for young adults with autism spectrum disorders (ASD). As parents, friends, professionals, and members of the community, we play a vital role in empowering our young adults to start their journey to becoming self-determined adults. Young adults who are self-determined are more likely to succeed as adults and transition to living happy, independent and productive lives. This journey starts with equipping our young adults with the knowledge, skills, and attitude they will need to navigate their own journey to independence.

Self-determination refers to the idea that individuals can control their own destiny. Field, Martin, Miller, Ward, and Wehmeyer (1998) describes self-determination as possessing "a combination of skills, knowledge, and beliefs that enable a person to engage in goal-directed, self-regulated, autonomous behavior..." Examples of self-determination include identifying and developing long-term and short-term goals, whether educational, vocational or living skills. A self-determined young adult must foster key essential skills to successfully navigate resources, support



Figure 1.1 Continuum of Growth

Reference: Autism and Learning Differences Toolkit

and their community to achieve their goals. For self-determination to become a reality, supporters must be committed to "letting go" and instead empower their young adults to make decisions for themselves.

Supporters of young adults with ASD often seek external support to assist with the letting go process. Transition programs

such as the College Internship Program (CIP), assist young adults to strive towards self-determination by empowering them to set goals, make choices and practice self-advocacy skills. CIP utilizes a person-centered planning (PCP) approach to assist young adults to develop meaningful life goals that highlight their dreams, strengths, talents, and capabilities. Identifying goals provides a path for young adults to track their progress and make adjustments as needed. Self-determination becomes a reality when young adults identify a goal and begin their progression through the "continuum of growth." For this tool to be effective, a young adult must have the desire and motivation to work towards independence.

Young adults with ASD will eventually grow up to become adults with ASD. This is why the journey to self-determination must start with self. Implementing the "Continuum of Growth" (Figure 1.1) model guides young adults to take the necessary steps to attain self-determination. Young adults will begin to gain confidence through self-awareness, self-understanding, and self-acceptance as they work towards achieving their identified goals. The journey starts with self-awareness. McManmon (2016) states that "young people need to be reminded that they are separate individuals with unique personalities." Young adults must be aware of their own unique strengths, limitations, talents,

and gifts, in order to fully understand how their diagnosis may affect their journey to accomplish their future goals.

The construct of self-awareness serves as the foundational step to understanding one's own attitude, abilities, and limitations, all of which are essential in decision making and problem-solving. Self-awareness starts with young adults identifying their own character, feelings, motives, and desires ultimately achieving self-acceptance. According to McManmon (2016), young adults can achieve self-understanding through self-acceptance by, "using what they are learning or have learned, instead of comparing themselves with others or trying to be people they are not." Self-understanding focuses on young adults knowing themselves as individuals, including their actions and reactions. This includes making and learning from their decisions. Self-understanding also includes understanding one's needs and differences and accepting those differences. This understanding and acceptance allows one to develop their own strategies to problem solve and make decisions. Young adults must embrace and accept their own unique gifts, talents, and limitations to be able to successfully navigate their future

The journey to self-determination includes empowering young adults to develop

see Self-Determination on page 34





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# The Superpowers of Neurodiverse Couples

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

hile many articles focus on the challenges associated with being in a neurodiverse partnership, there are countless strengths that are unique to relationships in which one or both partners are on the autism spectrum. When partners search online forums, read books, or even access clinical services, the difficulties associated with having neurodevelopmental differences are often highlighted. While neurodiverse couples do face challenges because of areas of dissimilarity, these differences can also make their relationships rich and rewarding. This article proposes a paradigm shift in the literature to focus on the strengths and benefits of being in a neurodiverse relationship. Since the strengths of each partnership vary, a review of three common "superpowers" of neurodiverse couples will emphasize how differences can begin to be viewed as relationship assets.

#### **Expanded Perspectives**

Everyone has slightly different world views, which includes beliefs, thoughts, and opinions. For neurodiverse couples, perspectives of situations may be more



Leslie A. Sickels, LCSW

dichotomous due to differences in brain wiring. While this could lead to conflict and misunderstandings, it can also help each partner expand their overall perspective and experience of a situation, much more than would be possible viewing the scenario independently. When couples collectively use these different lenses, they can create more comprehensive and effective plans and approaches. For example, if a husband on the spectrum has an idea about the most logical, quickest way

to complete a task, and their neurotypical spouse offers a perspective of how this may impact them or the feelings and experiences of others, they can incorporate both logical and emotional approaches to develop a better plan than either would have devised autonomously. Couples therapy should focus on where each partner is coming from, and how to ground in context and communication. By deepening trust and improving communication, each partner can more effectively express their ideas so they can be incorporated in an overall plan. Receptiveness to other opinions and paradigms is crucial for successful integration of this strength. Inflexibility can be a core feature of Autism Spectrum Disorder for some individuals and may make integration of other perceptions more difficult (American Psychiatric Association, 2013). Thus, working to paradigm shift, or actively understand, consider, and incorporate each other's thoughts and perspectives, can lead to enhanced ideas about the world and approaches in a variety of situations, from marriage to other areas of life.

#### Passions/Interests

Individuals on the spectrum may sometimes exhibit highly restricted interests (American Psychiatric Association, 2013). An individual with autism may spend significant amounts of time pas-

sionately reading, watching, or studying this interest, which can be about any topic. At the onset of neurodiverse relationships, some neurotypical partners describe themselves as their partner's special interest. This level of devotion and focus on a person can support couples in connecting to build rich, fulfilling relationships. While the intensity of this interest may wane over the course of a relationship and cause a shift in focus to a different interest, which can evoke challenges, having more specialized interests can still be a major strength in a relationship. These interests can lead to shared activities or encourage the neurotypical partner to more deeply explore their own passions. When each partner has their own interests and hobbies outside of the relationship, it can increase their individual support systems, connections to others, and overall joy in life. This can take pressure off of the relationship to be the sole sense of fulfillment in a person's life and allows each partner to independently explore interests and passions that are most enjoyable to them.

#### Commitment and Acceptance

At the onset of couples therapy, intentions and goals for the therapeutic work are set. These can range from couples wanting

see Couples on page 16



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# How Mobile Technology Groups Benefit People with Intellectual and Developmental Disabilities

By Charles Umaña AHRC New York City

s time progresses, so does technology. Whether it's opening a door or setting an alarm as a reminder, technology has become more available and accessible, especially to individuals with intellectual and other developmental disabilities (I/DD). Technological advances have created an opportunity to increase a person's independence and enable him or her to accomplish their goals on their own.

A 2013 study proved that, with iPod use and instructions, adults with moderate intellectual disabilities could use an ATM with 100% accuracy, compared to 25% accuracy prior to the introduction of the iPod.1 Using self-modeling videos created with the iPad, adolescents with autism and intellectual disabilities were able to improve their problem solving skills.2 However, these findings show that access to technology does not always ensure an increase in task completion or independence. Having resources available, such as prompts, guides or modeling examples on how to use technology is just as important as having the tech itself. With proper planning, use in technology can aid with increased independence among people with I/DDs.3



Charles Umaña

To aid with efficient use of technology, AHRC New York City's Day Habilitation without Walls in Staten Island started a technology group. The bi-weekly meeting is designed for individuals seeking guidance in the use of mobile technology, including tablets, smartphones and laptops. While the tech used is primarily based on devices provided by families, AHRC NYC has provided technology to those within the group to ensure maximum access to devices. The devices were purchased through

a New York State Balanced Incentive Program grant awarded to AHRC NYC.

"Access to mobile technology is one challenge for people with I/DD, but the bigger issues are the lack of adequate support and training," said Marco Damiani, CEO of AHRC NYC. "Just like anyone else, they want to connect with friends on Facebook and other social media. They enjoy the sense of community."

Group members suggest topics, which are based on their goals, inspirations, and desires. As the group's instructor, I research their suggestions to find appropriate software/hardware that would be most beneficial. Recommendations are based on a combination of experiences of people in other programs, and their support staff. Applications are also found by the Individualized Technology Strategies Department, whose focus is bringing efficient use of technology to the people AHRC NYC supports.

Lesson plans for the group are based on the information obtained and covered in future gatherings, held at a community library. Started in 2015, the group's topics have included employment, art, health and wellness, traveling, budgeting, stress relief and recreation.

The members of the group have changed over time, as some members move on to employment. The current group consists of a mix of old and new members.

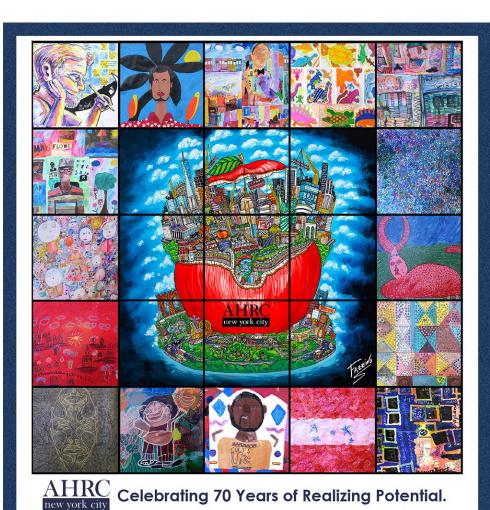
"I like learning about apps like Google Maps and budgeting, and Fudget," said Andrew Neuschaefer, a group member since 2016. "(The group) has helped me to learn about which apps to download." Andrew uses his iPhone in the group. He keeps track of buses and trains on his phone while commuting in the community during program hours.

Jaclyn Tirone joined the group in 2018. "I like it. It's fun listening and talking about apps," Jaclyn said. She primarily uses her iPhone, but also has an iPad at home. Jaclyn enjoys using photograph apps such as Prisma, and she's improving her reading with applications like Newsela. "Newsela helps me look at news."

Mobile tech devices have allowed for greater access to the world and the opportunity to become more independent. These devices have become the "Swiss army knife" of technology, with applications and software being readily available for matters of any kind. With proper guidance and support, like groups mentioned above, people of all abilities would have the potential to reduce their hurdles and challenges. Having access is important, but having groups for growth is the next step for bridging gaps to independence.

Charles Umaña is a Technology Deployment

see Technology on page 29



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# The First Step in Bullying Prevention Is Normalizing Our Differences

Dave Thompson Director of Workforce Development Nicholas Center at Spectrum Designs Foundation

through each day wasn't just hard, it was painful to my soul. In school I was cast aside, manipulated and laughed at. Friendships were made solely based on the bond my classmates would form over their common interest in teasing me. My teachers didn't understand me, and in hindsight, they didn't even support me, because they didn't know how.

There was one instance I never will forget: Once, a classmate walked in front of me and said 'Josh, one day I'll be a movie star and you will be a homeless guy living in a box.' I have yet to see her TED Talk or any of her films, but I hope for her sake that she's watching mine. At 13 years old, after tons of meetings and doctors' appointments, I got diagnosed with Autism.

There was a time when I thought that girl from class years ago was excluding me out of pure selfishness. I realize now that what she did wasn't truly selfish, and what would have been truly in her own self-interest would have been to include me. Little did she know how much I had to offer. Over the years I've realized I see the world differently from others—but



**Dave Thompson** 

that doesn't mean I'm less capable or less deserving than anyone else. I hope if you all take away one thing, it's that different perspectives are valuable, and that we have more power to change the world *together*."

- Josh Mirsky, from his TEDx Talk "Be Selfish: Embrace Neurodiversity"

According to a 2012 survey of 1,200 parents who had a child with Autism, 63% of them were known to have been bullied, a number three times higher than that of their siblings who didn't have Autism (Anderson, 2012). As someone who had a dif-

ficult time with my peers in school and has been working with the ASD population for a long time, I'm not okay with that. Now I'm on a mission to fix it.

My first gig as a young idealist was at a New York City group home, working with teens caught up in the foster care system. Typically developing teens lived alongside those with both mental health issues and developmental differences, in a co-ed nine bed facility. Helping with homework after school, one of the residents became frustrated with his work. I leaned in and said, "I know this stuff can be frustrating, man. The truth is I have ADHD too—and dyslexia. All you can do is take your time and figure out what works for you."

"Don't ever say that on the job again. Whatever you say in this house is gonna be used against you by somebody. Your weaknesses are the first thing they'll go to when things get rough. They'll tear you apart," my supervisor explained privately. I was scared and eager to comply with the intimidating woman, in her 70's, who had been working in the field since decades before I was born. So I listened—never speaking of my own challenges in a professional setting again until now.

I spent the next three years learning just what she meant. The group home was a hostile environment. The individuals tended to prey on each other's challenges and differences, and those with Autism were most certainly preyed on the most. Not just

at the residence, but at school, on home visits, and on the basketball court. I participated in a workplace culture that promoted the idea that your personal struggles should stay private—as a professional, as an educator, and even as a parent.

The truth is that I was part of the problem—and it wasn't until many years later, when I became close with a young, passionate dude named Josh Mirsky that I truly came to understand that. Josh has Autism and was tormented as kid. We have that in common, but where we differ is that the way Josh overcame his difficult time, which trickled into his work experiences in adulthood, was by owning it. Josh and I had an incredible synergy and agreed on most things. We began speaking publicly together, writing, and even doing our own podcast, Sounds Like Autism, where we celebrate people's differences. But I still ask myself: how much more of an impact could I have made had I self-disclosed to my coworkers, and more importantly, to those I support from the beginning?

"When you disclose – no one can make fun of you. You have nothing to hold against me. When you take that power away, the negative thing that someone holds against you, you turn it into a positive. It puts the power into you. When people do that, they're actually empowering themselves.... The system gains so much knowledge

see Bullying on page 14



# Navigating Neurodiverse Relationships: Disclosure and Self-Advocacy

By Katherine Cody, PsyD Licensed Clinical Psychologist **Spectrum Services** 

f you are an adult who has had a longstanding diagnosis of ASD or a newly diagnosed individual, then you probably grapple with these ongoing decisions:

- If and when to disclose your diagnosis
- The pros versus the cons of disclosure
- How to go about sharing this information with others
- What do you do after disclosing your diagnosis to others?

The reality is that diagnosis disclosure is a component of navigating neurodiverse relationships across domains of life: with family, friends, romantic partnerships, coworkers, supervisors, etc. Engaging in diagnostic disclosure is a step toward effective self-advocacy and increasing a shared understanding of your needs and unique ways of processing the world around you; however, it can also be intimidating and connected with emotions which means that being prepared with a framework of approach is useful.



Katherine Cody, PsyD

WHY and WHEN to Disclose

WHY: Research indicates that first impressions of adults with ASD improve when diagnostic disclosure occurs (Sasson & Morrison, 2019). This finding suggests that neurodiverse relationships improve with provision of disclosure, and the potential to forge new relationships increases when disclosure happens. Disclosure

provides opportunity for others to develop an increased understanding of strengths, challenges, needs, and processing differences. When disclosing, it is imperative to be very clear about the purpose of the disclosure - DEFINE A GOAL. Ask yourself what you are hoping to get out of disclosure. Is it to obtain understanding or support? Link what you disclose with this defined goal.

WHEN: There is no clear "right" time to disclose diagnosis. The tricky part about this is that there is no clear rule for which circumstance indicates which kind of disclosure, and self-awareness is needed to guide the disclosure process.

- Up Front Timing: Many adults with ASD feel that they do not want to be in relationships or work environments that do not openly support their ASD, so using this up-front approach is right for them. Examples include before meeting someone for an interview or a first date; however, this approach is only useful for people who embrace an approach of putting all the information out there from the beginning and with awareness of the "why."
- Wait Until Someone Knows You Better: There are other times when it is appropriate for disclosure to occur as someone is getting to know you or after getting hired and during onboarding of a job

with a human resources department and requesting specific accommodations.

Partial Disclosure: Disclose a need (Ex: "I am a better employee when tasks are assigned to me in writing versus only aloud.") without disclosing the diagnosis itself. Use this for specific situations and circumstances in which advocating for a need is present.

PROS & CONS of Disclosure

- Even if the other party does not have prior knowledge and understanding of ASD, disclosing diagnosis is an opportunity to increase this awareness of
- Diagnostic disclosure is an opportunity to communicate with others to form a shared understanding of your unique needs, differences, challenges and strengths.
- If you do not share what your needs are and why, then people do not realize that there are needs to be fulfilled; therefore, sharing your needs is a means of self-advocacy that initiates the opportunity for your needs to be met.

Presented by

see Disclosure on page 32

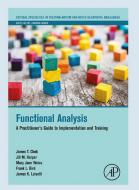


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# A Personalized Approach: Three Portraits of Incorporating Neurodiversity in Life Skills Programming for Autism

By Becky Lipnick, Organizational Communications Coordinator Vista Life Innovations

woman sits at a table with a thick sheet of paper and a photograph of a landscape, drawing the scene in confident, hard strokes. A man measures out his ingredients, careful to get the exact measurement. A woman steps forward on stage, dancing with the music and singing out to the audience. Each of these individuals has autism, yet they are clearly a talented and diverse group. This should not be surprising when remembering neurodiversity. Neurodiversity accounts for the differences in each person's brain, a concept which has gained popularity in the autism community (Baron-Cohen, 2019). In addition to creating an inclusive point of view, this idea is valuable for developing independence for those with disabilities. Vista Life Innovations, a nonprofit organization devoted to assisting adults with disabilities achieve personal success, takes neurodiversity into account with functional skills support. During Vista's programming, students and members work to develop necessary skills for independent living while discovering their passions. The philosophy of Vista is simple: Everyone has a unique mind with



Daniel and Emily Wing, Vista Program Instructor, assisting with Thanksgiving preparations

neurological differences; therefore, students will learn best with individualized programming.

Sometimes, a neurological trait can be both beneficial and a source of challenges. One Vista member, Cara, has a strong sensitivity to sensory information. Walking into a room with faint background music can be an overwhelming experience. To combat this obstacle, Cara has developed specific coping strategies for dealing with unpleasant noises like humming to drown

out the sound. Often, mentally preparing herself and choosing to engage can be enough to help Cara overcome her sensitivity. For instance, Cara elects to plug her ears and turn on the garbage disposal at her house when it needs to be run, even though the sound bothers her. Being highly aware of sensory information can be difficult, but it supports Cara to do what she loves most: art. Samantha Listori, Vista's resident artist, has worked with Cara for five years. She explains, "Cara's very good with color. She sees colors in a photo that other people wouldn't notice and creates optical mixing by separating every tone.' Ironically, the same awareness of sensory details that challenge Cara auditorily is what helps her to have a strong artistic perspective. Her small drawings are bold, richly saturated and show a clear eye for proportion. Currently, Cara is working with Listori to apply her drawing skills in the realm of large oil paintings. She is even collaborating with a prominent New York City gallery owner to further her work. As a quiet individual, she enjoys time by herself, art provides Cara with a world of her own to explore and share with others.

"Did you see how flexible I was just now?" Daniel asked, before giving his Program Counselor Ashley DiGuilio a huge

see Life Skills on page 29

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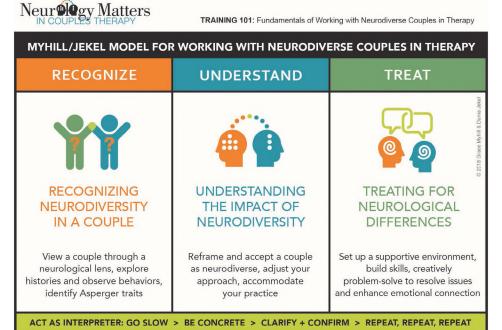
# **AANE's Online Training for Therapists Gives Hope to Neurodiverse Couples**

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

n 2018, AANE launched our NEU-ROLOGY MATTERS IN COUPLES THERAPY online training. Since then, 27 therapists have completed both TRAINING 101: Fundamentals of Working with Neurodiverse Couples in Therapy, and CERTIFICATION 201: Case Presentations and Advanced Topics in Neurodiverse Couples Therapy. In this article, we share how one couple's relationship turned around once their AANE-trained therapist started seeing and treating them through the lens of neurodiversity.

Prior to taking the AANE training, Nicole did not know that her clients Richard and Tina were a neurodiverse couple--and neither did they.

Nicole: "Richard, a retired electrical engineer, and Tina, a retired second grade teacher, presented with typical couples issues. They felt so unable to understand each other that it was as if they spoke two different languages. They had no emotional or physical intimacy. Trying to navigate the demands of daily life together led to conflict and resentment. None of the therapists they saw previously helped them resolve their issues.



Before getting the AANE training, I worked with Tina and Richard for six months, without seeing the progress I expected. They left our sessions hopeful, but came back the next week without having done the homework or experienced any progress. We all felt frustrated."

Once Nicole was trained, she started to apply the principles of AANE's Myhill/ Jekel Model to her work with Richard and Tina.

Recognize Neurodiversity in a Couple

Nicole recognized traits of Asperger's in Richard's career history:

- Loyalty: Richard had worked for his entire career as an electrical engineer at the same company.
- Superior intelligence, visual thinking: Richard had a gift for solving technical

problems. "It was as if I just saw the solution in my head."

• Executive function and communication challenges: Early on, he was promoted to a management position, but was unable to keep track of many different tasks at once or communicate with the people he was supposed to supervise.

As Nicole further explored Richard's life history, she recognized more Asperger traits:

- Superior memory helped Richard excel in grade school, high school, and college.
- Weak social skills: When he was young, Richard was shy and didn't relate to his peers. he spent his free time alone at home with his baseball cards.
- Limited and delayed romantic experience: In college, he spent most of his free time in the library, which is where he met Tina. She eventually asked him out. They dated through college, and married right after graduation.

Nicole also observed Asperger traits in therapy sessions:

see Training on page 30

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is the most valuable I have gotten from a training course. I learned a tremendous amount, and it has already influenced my own clinical work. Training 101 is an amazing advancement in the field of neurodiverse couples therapy!"

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- Peggy Kriss, PhD, clinical psychologist



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#### Bullying from page 11

when people talk about their truths. The system becomes stronger and smarter because the individuals themselves are disclosing. So, the individual gains power and the system gains knowledge also."

-Josh Mirsky

The last straw for me came in October 2019, when I got the opportunity to attend the Autism at Work summit in Jupiter, Florida. The three-day event was an intimate gathering of employees with Autism, academics and government officials, as well as representatives from huge companies, like DELL and JP Morgan Chase, with the purpose of discussing best practices for hiring, training, supporting and retaining em-

ployees with Autism. On the first day of the conference, someone from the U.S. Federal Department of Labor got on stage and began presenting. About a minute into his talk, he said "Oh, wait. I introduced myself and I told you about my job, but I didn't tell you about me. I don't have Autism, but I do have social anxiety and ADHD." He went on to give one of the most energetic and impassioned talks of the conference. Over and over, other attendees self-disclosed what made them different throughout the conference. A recovering alcoholic, a woman with a prosthetic leg, dyslexia, depression, eating disorders, OCD, and of course, Autism Spectrum Disorder. It made for one of the most mission-reinforcing and overall unifying atmospheres of which I've ever been a part – and I'm a punk rocker from New York City.

So, join me. Start in safe spaces and work your way out to the big ones. Tell the students in your class about your cousin with Autism. Tell your kids it's okay to talk about their asthma in school. Tell your coworkers that you're proud to think differently, and you feel that it's important, not just for yourself, but for the betterment of man, to stand tall and voice your truth. Because the truth for all of us, as people, is that we're different – and the sooner we can be honest with each other about our own differences, the sooner we will all be more kind, understanding, empathetic and compassionate to each other.

Dave Thompson is an educator, innovator and advocate in the Autism field for over 10 years. As Director of Workforce Development for Nicholas Center

at Spectrum Designs Foundation, Dave has unique insight into just how valuable yet undervalued, deserving and yet under served the neurodiverse community is. He has an insatiable desire to see the world around him continue to evolve through employment opportunities, access to services, assistive technologies, and a more inclusive collective attitude toward people labeled "different."

For more from Dave Thompson and Josh Mirsky, visit www.soundslikeautism.com.

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# Stuck Between Two Worlds: Having a Brain that is ½ Autistic and ½ Neurotypical

By Michael Gilberg Attorney-at-Law

e often talk of Neurodiversity in terms of a binary between Autistic and Neurotypical when in reality it is much more complicated. We all know Autism exists on a spectrum but commonly assume if someone is on the spectrum, they are one side of a binary line, regardless of where they fall on the spectrum while if someone is neurotypical they are on the other side of the binary line. We assume autistic people's brains work one way regardless of where we lie on the spectrum and neurotypical brains work in a different format, similar to the difference between a PC and a Mac. People often say being Autistic is like "Having a Mac brain in a PC world." However, I believe from my own life experience that this is not true, that you can actually have a brain that is both. This is like having a brain that is sometimes a Mac and sometimes a PC in a PC world. While this ability sounds like a good idea in theory, in practical effect it creates other challenges.

I was not diagnosed with Asperger's Syndrome until I was 18 years old, and even then I resisted the label for a number of years, feeling like most children that



Michael Gilberg, Esq

age; I didn't want to be disabled, I just wanted to be "normal." The truth is as we all know there is no such thing as normal, especially when it comes to the areas of Human Behavior. As time went by, I grew to accept my diagnosis and understand it better. As I have written before, I had a challenging childhood and never felt like I quite belonged and growing up was always a bit of an outcast. That however is a story for another article on another day.

Like most people on the Autism Spectrum I have often felt isolated and out of place in many social situations. I have experienced the loneliness and isolation that many people with Autism experience. Many of us on the Autism Spectrum do find that sense of community with others on the Autism Spectrum as well as neurotypical friends who are accepting and understanding, and of course I have had this as well. However, I noticed something else interesting going on in my own life.

When I have taken Autism inventories or rating scales I routinely score just over the "autistic" line as autistic but barely so, while many others I know will score as "more" autistic for lack of a better term. There are many traits common in Autism I have routinely found I do not have such as sensory issues, I do not stim or engage in repetitive behaviors, and I do not have the common autistic special interests (trains, sci-fi, weather) or any really special interest that would be considered an autistic interest or outside the mainstream or one with the trademark level of intensity. I also have never had communication deficits and have had people comment on the fact that, for someone on the Autism Spectrum, I am amazingly self-aware and perceptive of what others think about me. I do not have any problem understanding facial expression or most non-verbal communication and I do generally have empathy for others. However, I have struggled with social relationships, emotional regulation, and can be sometimes inflexible in my thinking though I do not have the rigidity or need for sameness traditional in Autism.

This has led to me often feeling as isolated in the autistic world as the neurotypical world. As I have stated like many on the autism spectrum I often have been in social situations where I feel out of place or have had difficulties because of social skills issues with neurotypicals. However, in many situations with other groups of Autistics I have also felt out of place especially when I have found them acting "strange" to me viewing them in a neurotypical context. I was taught years ago by a cousin who is also autistic that I had what she termed "Aspie superiority," where I acted superior to some other autistics I felt were more challenged then me and have had to learn to not behave this way and be more understanding. I had come to realize I was acting in a way that many neurotypicals do towards autistics. What I realized was I felt too "normal" in much autistic company and too "autistic" in neurotypical company. I felt I was trapped between two worlds and could only describe it as having a brain that was half autistic and half neurotypical.

see Two Worlds on page 25



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# Telehealth Program for People with I/DD Launches in New York

By YAI - Seeing Beyond Disability

new way of delivering health-care to people with intellectual and developmental disabilities (I/DD) has come to New York. Launched in September, Premier HealthCare's Telehealth Services enables patients with autism and other types of I/DD to access mental and physical health services without a trip to a doctor's office or a break in their daily routines — both of which can be disruptive and unnerving for people with I/DD.

Piloted in six residences, Premier's Telehealth program is the first service of its kind for people with I/DD in New York State.

"For the people we support, this is a game changer," said George Contos, CEO of YAI, a network of I/DD agencies which includes Premier. "By removing obstacles that often hinder people with I/DD from accessing medical and mental health services, we can meaningfully improve outcomes for one of the most underserved segments of our population."

Using the Telehealth Services portal on a computer and assisted by specially trained staff, patients attend virtual appointments with mental health, primary care, and neurological specialists. Medical specialists use video chat to speak with patients while a nurse or other accredited staff member



Elizabeth Ducat, a Psychiatric Nurse Practitioner at Premier's Manhattan clinic, conducts a session with a patient living at a YAI residence in the Bronx

stands by to check the patient's vitals and report symptoms. After the appointment, the doctor or specialist uploads patient plans, diagnoses, and notes to a secure portal that can be accessed by the patient's direct support staff within 24 hours.

In a 2018 survey conducted by Medpod, a telehealth company that creates portals like those used by Premier, 93 percent of direct support staff reported reduced anxiety in patients with I/DD who switched from in-person to virtual doctor's visits.

According to Hope Levy, Premier HealthCare's Executive Director, enabling patients with I/DD to access medical care from the comfort of home has a profound effect on their quality of life.

"For people with I/DD - especially those with behavioral challenges - having to travel an hour to and from a clinic can cause a lot of stress," Levy said. "Not only does this harm their overall wellbeing, but it can exacerbate a lot of adverse behaviors that staff must contend with, too. Telehealth dramatically decreases these challenges, allowing for more consistent care."

YAI is joined in this innovation by Quality Services for the Autism Community (QSAC), which operates three of the participating residences in the Bronx and Queens. Though it's only been a month since Premier's Telehealth Services were rolled out to YAI and QSAC residences, Cory Polshansky, President and COO of QSAC, said the benefits are already apparent.

"We've seen a significant positive impact on the people we serve," he said. "They no longer have to leave their day program or job early or miss out on recreational activities due to health-related appointments. Moreover, the anxiety surrounding getting to and from clinics and sitting in waiting rooms has been eliminated."

Yvonne Patrick, YAI's Bronx Regional Director, agreed.

"When we began using the telehealth portal at three of our residences in the Bronx, the differences were striking," she said. "Residents who previously had a lot of fear around going to appointments told me that completing their doctor's visit at home made them feel much more relaxed."

Premier HealthCare's Telehealth Services portal is available to all Premier patients, regardless of whether they live in the community or in a residence. Telehealth Services are covered by Medicaid, Medicaid Managed Care, Partners Health Plan, and most major private insurers.

If you or someone you know would like to learn more about Premier HealthCare's Telehealth Services, please contact Premier HealthCare at 212.273.6272.

About YAI – Seeing Beyond Disability

YAI is a nonprofit organization that delivers more than 300 programs and services that create opportunities for people with intellectual and developmental disabilities (I/DD) to live, love, work, and learn in their communities.

For more information, visit www.yai. org/premier.

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#### Couples from page 8

to work to maintain their relationship, separate/divorce, or there can be uncertainty about the next steps. Regardless of the goals of neurodiverse couples therapy, couples set intentions to work collaboratively in the service of their relationship. While partners may report feeling as though they are "speaking different languages" or that their styles are incompatible, their intentions are important because it speaks to the larger goals of the relationship (Myhill & Jekel, 2015). This allows neurodiverse couples to begin looking at differences as either something they can accept or actively work to change. When couples accept differences, they can shift from perceiving them as flaws or annoyances, to seeing them as qualities that makes their partner unique or even endearing. When this shift occurs, both partners can be more tolerant of differences and ground in the good intentions they have for their relationship. For areas of the relationship that require change, it allows neurodiverse partners to commit to addressing these topics in couples therapy. Commitment and acceptance lends to increased dedication and positive feelings towards one another, which can make neurodiverse couples happier and more satisfied in their relationship.

#### Conclusion

While not all areas of strength apply to

each neurodiverse relationship, there are ways for every partner to shift their perspectives to see the differences in their relationship as positive benefits. This requires couples to acknowledge and understand how neurodiversity is impacting their relationship (Myhill & Jekel, 2015). Once they have an understanding of why differences are present, perspective-shifting to the strengths of neurodiversity can be a focus of the relationship and clinical work. By focusing on the positive attributes of neurodiversity, partners can deepen their connection and feel more fulfilled in their relationship because of their neurological differences, not in spite of them.

For more information about Leslie Sickels, LCSW and neurodiverse couples ther-

# Looking for Renter(s)/Housemates

My name is Jed Williams and I am on the spectrum and currently looking for one or two fellow aspies to rent out a large one-bedroom apartment in Bella Vista, PA

It is a three-story building. The 3rd floor rents for \$1,400/month and I live on the 2d floor with a business on the first floor.

I am looking for some more support for my autism/issues as well, so it would be good if any new possible tenants were friendly and tolerant of others on the spectrum, etc. The building is managed by Slatehouse Properties.

If you are interested, please contact Jed Williams at jedwilliams@gmail.com so we can set up a meeting and then I will give you the number for the person at Slatehouse Group who manages the building.

#### apy visit LeslieSickelsLCSW.com.

If you are a therapist and want to learn more about supporting neurodiverse couples, Neurology Matters offers a training and certification program available at: aane.thinkific.com.

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# Leaders to Be Honored at Our June 30th Reception in New York City



Marco Damiani
Chief Executive Officer
AHRC New York City
Excellence in Autism Award

By Staff Writer Autism Spectrum News

ental Health News Education, Inc. (MHNE), the nonprofit organization that publishes *Autism Spectrum News* and *Behavioral Health News*, will be honoring four outstanding champions of the autism and behavioral health communities at its annual Leadership Awards Reception on June 30, 2020, at the NYU Kimmel Center in NYC from 5:00 pm to 8:00 pm. See pages 18 and 19 for full registration information.

Debbie Pantin, MSW, MSHCM, President and CEO of Outreach, and MHNE Board Chair, made the announcement stating, "MHNE has selected four prominent leaders from well-known New York organizations who represent some of the very best in the fields of autism and behavioral health. We are honored to pay tribute to them in recognition of their many years of dedicated service to the autism and behavioral health communities"

Ira Minot, Founder and Executive Director of MHNE stated, "We are so pleased to have this opportunity to recognize these champions of the communities MHNE serves. I am also pleased to announce that Anita Appel, LCSW, Senior Health Care Consultant, at Sachs Policy Group, and Matt Loper, CEO, of Wellth, who are both MHNE Board Members, will serve as Event Co-Chairs for our 2020 Leadership Awards Reception."

David Minot, Associate Director of MHNE stated, "Our 2020 Leadership Awards Reception is attended by over 200 recognized leaders from the autism and behavioral health communities who gather to share comradery and network with each other before the summer. This year's event will be an evening to remember, as we pay tribute to our distinguished honorees, their friends, family and colleagues.

Proceeds from this event will go towards expanding and developing the nonprofit educational mission of *Autism Spectrum News* and *Behavioral Health News*.

Marco Damiani CEO AHRC New York City

Marco joined AHRC New York City with a varied and progressive career in the field of intellectual and developmental dis-



Kenneth Dudek
Senior Advisor
Fountain House
Lifetime Achievement Award

abilities (I/DD), behavioral health and general healthcare as a clinician, consultant and agency executive. Founded in 1949, AHRC NYC is one of the largest organizations in the nation supporting 20,000 people with I/DD and their families. AHRC NYC has over 5.500 dedicated staff, an annual budget well over \$300 million and provides a broad range of programs, services and supports across the lifecycle. Marco's career began at FEGS as a direct support professional and clinician, shortly after the implementation of the landmark Willowbrook Consent Decree and progressed through the years with positions in New York State government to Executive Vice-President at YAI Network where he led a broad and expansive portfolio of health and behavioral healthcare, research/program evaluation and a large community-based support, information and referral program, to Executive Vice President at Cerebral Palsy Associations of NYS, to his most previous position as CEO of Metro Community Health Centers, a network of 5 Federally-Qualified Health Centers in NYC devoted to supporting patients of all abilities.

In addition to his executive leadership positions, Marco was previously Chair of the Manhattan Developmental Disabilities Council and Chairman of the Alliance for Integrated Care of New York, the first Medicare Accountable Care Organization in the nation focused on individuals with I/DD. Marco is a Mayoral Appointee of the NYC Community Services Board I/ DD subcommittee, a Board member of the Inter-Agency Council of I/DD Agencies, New York Disability Advocates and Care Design NY, an I/DD Health Home, and is also an Appointee to the New York University College of Dentistry Dean's Strategic Advisory Council. In recognition of Marco's contribution to the work of its school and to the field of oral health, and for his leadership and advocacy in promoting healthcare innovation models for people with disabilities, the NYU College of Dentistry awarded Marco with the College's highest honor, the Kriser Medal.

Marco earned a BS in Psychology from Manhattan College, a Master's Degree in Developmental Psychology from Columbia University and pursued doctoral studies in Educational Psychology at New York University. He attributes his success to the extraordinary collective work and shared vision of his many colleagues over the years, their enduring commitment to



Allison Sesso

Executive Director
RIP Medical Debt

Behavioral Health Advocacy Award

promoting social justice for people with disabilities and his never-ending quest to being more than just a so-so guitar player.

> Kenneth Dudek Senior Advisor Fountain House

A recognized leader in the mental health field, Kenneth J. Dudek has directed Fountain House and the development of clubhouses since 1992. He has pioneered programs that address the housing, employment, educational, and health needs of people living with the most serious forms of mental illness. Kenn retired as President of Fountain House in September 2019 but continues as a Senior Advisor.

During his 27 years of service, Kenn created and implemented a strategic vision that positioned Fountain House as a leader in the global search for cost-effective, humane and successful solutions to the ongoing humanitarian crisis of serious mental illness. Through public-private partnerships, Kenn developed cutting-edge programs that respond to the evolving needs of people with serious mental illness and to changing social trends.

During Kenn's presidency, Fountain House became the first mental health organization to receive the largest and most prestigious recognition of humanitarian efforts, the Hilton Humanitarian Prize. The organization is lauded by academics, researchers, practitioners, psychiatrists, government officials, and others in the mental health field in the US and internationally.

Kenn has never lost touch with his roots as a social worker and established relationships, comradery, and trust with Fountain House members – people living with serious mental illness. Kenn is modest and unassuming but full of passion for the underserved and marginalized. His confidence in the capacity of members has empowered many individuals with serious mental illness to represent the organization and advocate for issues impacting their lives in the broader community.

Kenn's work deserves special recognition because it focuses on the most seriously mentally ill. This differentiates what he does from the majority of mental health programs. Kenn focuses on those who need help the most. Many have no family, no friends, no social network, no housing, and no treatment until they join Fountain House.

Kenn is highly regarded as a dedicated, tireless, leader by the Fountain House



Ian Shaffer, MD, MMM, CPE
VP and Executive Medical Director
Healthfirst - Behavioral Health
Corporate Leadership Award

Board, staff and members, and within the larger sphere of programs based on the Fountain House model locally here in New York, and globally.

Prior to joining Fountain House, Kenn was Director of Community Support at the Massachusetts Department of Mental Health where he created 25 model clubhouses and many other community-based mental health programs.

Allison Sesso Executive Director RIP Medical Debt

Allison Sesso has served as the Executive Director of the Human Services Council of New York (HSC) since March 2014 and previously served for many years as the Deputy Executive Director. HSC is an association of 170 nonprofits delivering 90% of human services in New York City.

Under her leadership HSC has pioneered the development of nationally recognized tools designed to illuminate risks associated with government contracts, including an RFP rater and government agency grading system known as GovGrader.

During her tenure at HSC she has led negotiations with government on behalf of the sector and partnered on the development of policy and procedural changes aimed at streamlining the relationship between nonprofits and government. In 2017, Allison led the Citywide "Sustain our Sanctuary Campaign," which successfully pushed for investments in human services contracts totaling over \$300 million to address the nonprofit fiscal crisis.

When the largest human services non-profit in NYC abruptly filed for bankruptcy, she turned tragedy into opportunity by organizing a coalition of experts to evaluate the systemic operational challenges facing human services nonprofits; resulting in a nationally recognized report, New York Nonprofits in the Aftermath of FEGS: A Call to Action, with nine recommendations viewed widely as a roadmap to long-term sustainability of human services nonprofits.

Allison also organized and led a commission of experts focused on social determinants of health and value-based-payment structures that recently completed a highly anticipated report, Integrating Health and Human Services: A Blueprint for Partnership and Action, examining the



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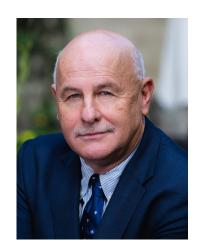
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Proceeds from this event will go towards expanding and developing the nonprofit educational mission of *Autism Spectrum News* and *Behavioral Health News*. With these publications, Mental Health News Education, Inc. aims to reduce stigma, promote awareness and disseminate evidence-based information that serves to improve the lives of individuals with mental illness, substance use disorders and autism spectrum disorders, their families, and the provider community that serves them.

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# First Responders Promote Awareness and Training Through the Autism Patch Challenge

By Christopher T. Greco Detective and PBA President New Rochelle Police Department

simple idea to bring autism awareness to the New Rochelle Police Department and the City of New Rochelle, NY, has since spread to over 350 first responder agencies around the United States, and continues to grow with each passing month.

On February 7, 2017, I made an appointment to meet with New Rochelle Police Commissioner Patrick J. Carroll (Retired) to discuss a community outreach project for autistic children in New Rochelle. With proto-type in hand, I remember vividly walking into his office to request permission to place a custom designed New Rochelle Police Autism Awareness Patch (magnet) on our patrol cars. The Commissioner loved the idea and granted permission to place the autism magnets on our emergency vehicles, along with patches of the same design on our uniforms during Autism Awareness Month. Once approved I challenged three near-by police agencies to do the same. Each agency accepted the challenge and then challenged three other agencies to follow along. As a result, the New Rochelle Police Autism Patch Challenge (or #AutismPatchChallenge) was



Detective Terrance Fudge (left), Detective Christopher Greco (middle) Detective Frank Provenzale (right)

born. The challenge has three simple goals:

- Create an agency autism awareness patch (to display on vehicles and/or uniforms)
- 2. Review, improve or implement new autism training protocols
- 3. Fundraise and donate the proceeds to

<u>local programs</u> benefiting autistic people

I started the challenge primarily to honor my non-verbal autistic son Christopher and to demonstrate to our community and to surrounding communities that first responders were aware of the concerns expressed by parents and other caregivers - that first responders lack the training to detect autistic behavior and lack the nec-

essary skills to respond to calls for service involving autistic children. What started as a simple gesture to honor my son quickly turned into a nationwide campaign.

Agencies from all of the country are now actively involved in autism awareness campaigns, training and fundraising. A small selection of participating agencies include the NYPD Counter Terrorism Unit, the Port Authority of New York and New Jersey Police Department, the Boston Housing Police Department, the Dallas Police Department, San Leandro Police Department (CA), Lea County Sheriff's Department (NM), Cook County Sheriff's Department (IL), Metropolitan Police (DC), FBI Philadelphia, West Liberty (IA), Pulaski County Sheriff's Department (MO), Mountain Brook Police Department (AL) and the Jupiter Police Department (FL).

Every participating agency that creates an autism patch continues to spread autism awareness and training throughout their communities and throughout the country. Today, many agencies may not even realize where this endeavor started or why, but what is clear is that since 2017, over 350 agencies have been identified as creating their own autism awareness patch and that each participating agency has had a direct and positive impact within their own communities.

see Autism Patch on page 28

# Authentic Strength-Based Practice: Can Neurotypical Professionals Make a Paradigm Shift?

Kristie Patten Koenig, PhD, OT/L, FAOTA Associate Professor and Chair New York University Steinhardt

hen I talk about my work, it is not about understanding autism from a neurodiverse perspective. That is not for me to do. I am not autistic. I have learned immensely from my partnerships and interactions with autistic individuals. Autistic self-advocates should be leading the way, compensated as experts in educating the professional community about neurodiversity, autism and what interventions are most helpful and what research is needed. Instead, I would like to focus on how professionals can shift to a strengthbased practice, embrace neurodiversity and recognize how a neurotypical bias may impact our ability to engage in authentic strength-based practices.

Professionals are able to identify deficits and maladaptive functioning, that is what we are trained to do in fields such as special education, occupational therapy, and speech and language therapy for example. We do identify strengths in our assessments and observations, often by default, but need to emphasize weaknesses in order to provide services. This emphasis has narrowed the scope of both practice and research to the deficiencies demonstrat-



**Dr. Patten Koenig** 

ed by autistic individuals, and goals and treatment programs that then are centered around remediating areas of weakness. No one, however builds their lives on remediated weaknesses. We build our lives on things we do well, and our interests. Saleeby (2001), an early proponent of using strength-based models in the field of social work, identified that a problem orientation begins to look like an exercise to meet the needs of the professionals rather than those they serve. The chosen focus of intervention, whether it is through a strength-based lens or a deficit focus will be critical for long-term outcomes including quality of

life, well-being and the ability to live a self-determined life. By holding a longer view of success and outcomes, a shift away from a primary focus on deficiencies is in order (Patten Koenig & Shore, 2018). Can professionals replace a deficit lens, with one in which challenges, especially those caused by the environment and social attitudes are addressed, but competence becomes the bias?

It is a radically different practice perspective from the problem-focused approach and there are neurotypical biases that make it difficult for professionals to make this shift. A strength-based practice has its roots in self-determination theory, including a) autonomy, being able to freely choose things in your life and not being controlled, b) competence, doing things you initiate and that make you stretch, and c) relatedness, choosing your relationships with others (Ryan & Deci, 2000). Practice begins to look different if these core psychological needs are held as primary. This can be illustrated by using restricted or focused interests as an example.

Professionals often discourage the use of interests in the classroom or during therapy, or hold them out as rewards. Controlling use of rewards is in direct opposition to the development of autonomy (Ryan & Deci, 2000). Patten Koenig & Williams (2017) surveyed 80 autistic adults as to how they characterized and utilized interests both as

children and now as adults, and while 87% of the participants wished that teachers and professionals would have used their interests in the classroom, only 12% reported that their teachers actually did use their interests as strengths to support learning. These adults overwhelmingly reported that their interests were positive, helped calm them and mitigate stress, were not interfering or anxiety producing and should be utilized for learning and mastery, development and autonomy (Patten Koenig & Hough Williams, 2017), two core skills of self-determination. The neurotypical professional bias often sees these interests as part of the problem, versus a solution.

There is a neurotypical bias as to how professionals should address social skills. Approaches to social interventions for autism are framed by neurotypical definitions of being social. Heasman and Gillespie (2018) investigated how autistic individuals build social understanding and found that in a high-interest activity, there is a generous assumption of common ground, which can lead to rapid rapport. Instead of a social skills group to increase competence in discrete social skills, a strength-based practice could have the therapist utilize inclusive interest-based groups that students are autonomously motivated to participate in, have a competent knowledge base in

### If My Son Could Speak

By Robert Naseef, PhD Psychologist Alternative Choices

y son, Tariq, is turning 40 this November. He is autistic, as well as nonspeaking, and he has a severe intellectual disability. Like many other parents of nonspeaking autistic children, I have had imaginary conversations with him many times over the years, and I wonder what he would tell me if he could speak.

If Tariq could speak, here is what I think he would tell me:

First - It's Not About You, It's About Me

No one died, so please don't mourn for me. You didn't get to play baseball with me, or build model airplanes, or do science experiments. We don't have philosophical conversations, but we do have a relationship. Working through your grief about the loss of the relationship you expected was necessary for you to get on with your life. That's about you, but it has *nothing* to do with me. It's about your dreams and expectations that through no fault of either of us, were unmet.

Autism is not a thing I have, but it is my way of being. It colors every perception, thought, emotion, and experience. I wouldn't be the same person without it.



Tariq giving his dad, Dr. Robert Naseef, a high five

You talk about dreaming new dreams, so focus on that and on the relationship we do have. None of us are happy all of the time, but I am happy most of the time. Please remember that I love you, and I like spending time with you and don't want you to be sad.

Second - Be Patient

I understand why you tried so hard to change me, and I'm glad you stopped!

Even now when you are impatient with how I naturally act, that feels bad to me. When I hear or sense your disappointment in me, I feel the negativity. Even though I cannot speak in words, I can see, and hear, and feel. I can tell what's going on with you, and every day I know who is kind and who is mean to me. When people are kind and patient, we get along so much better, and I can do more.

I've seen you experience a rocky stress-

filled road of getting services and learning how to make a difference in dealing with my autism as an evolving condition. To get the services that I needed, you needed to convince people about how severe my challenges are which was hard for you to highlight. You would get angry and worried and lose sleep over it. The result was more grief and negative thinking. Once again that affected me, but was all about you, not me. Thanks for advocating for my needs though. Fortunately, those days are over. I am safe.

Third - Be Positive

Just like neurotypical children, I need positive energetic parents who enjoy life, celebrate my accomplishments, and accept me as I am. When I don't understand what you are expecting, I get confused and frustrated. Positive reactions to what I can do feel good. You often measure my accomplishments in inchstones instead of milestones. That's an improvement, Dad. but must you still measure them at all? I'm proud of whatever I'm able to accomplish even when to others it can seem very small. Recently, for example, I started helping my staff in the kitchen. I like stirring whatever's in the pot, and I now put my dishes in the sink. I also make sure everyone is wearing their seatbelt when we go out, and

see Son on page 33





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# Corporate Neurodiversity Hiring Programs: Scratching the Surface?

By Marcia Scheiner President Integrate Autism Employment Advisors

n 2010, Integrate Autism Employment Advisors ("Integrate", originally known as The Asperger Syndrome Training & Employment Partnership) was started to engage Fortune 1000 companies in hiring autistic college graduates. In March 2013, SAP announced that it hoped to have 1 percent of its workforce be comprised of autistic employees by 2020. This was an incredible commitment, at that time, for a Fortune 500 company. With SAP's announcement, hopes were high that doors would begin opening at large employers interested in including autistic jobseekers in their ranks throughout the world.

Six and a half years later, where do we stand with employment for autistic adults in the corporate world? To fully answer this question, it is necessary to look at the data, as well as the supports in place to help employers achieve their goals. Let's start with the data. The table below shows the most recent results of the four largest U.S. autism hiring programs:

#### **SAP**

- Started 2013
- 160+ employees in full and part-time roles, internships, contractors, vocational training



**Marcia Scheiner** 

- 28 roles including HR, operations, consulting, data science, software engineering
- 13 countries
- 92% retention rate

#### JPMorgan Chase

- Started 2015
- 155+ employees
- 40+ roles, primarily in technology/engineering/quality assurance
- 8 countries
- 95% retention rate

#### **Microsoft**

- Started 2015
- 100+ employees
- Technology roles such as software engineer, service engineer, build engineer, lab engineer, data analyst or data scientist
- 5 US locations, with international expansion planned
- 92% retention rate

#### ΕY

- Started in 2016
- 80+ employees
- Roles in artificial intelligence, cybersecurity, data analytics, emerging technologies
- 5 locations in the US, 3 more opening
- 90%+ retention rate

These four employers are very open about their efforts to date and provide this data publicly. They share information, via a roundtable, with other employers seeking to create similar autism hiring programs. They have also published a playbook that details how to launch an autism hiring initiative - https://disabilityin.org/what-we-do/committees/autism-at-work-roundtable/. Integrate estimates approximately fifty large U.S. corporate employers have launched autism specific hiring initiatives in the past two to four years, though none have yet to achieve hiring numbers as large as SAP, JP-Morgan Chase, Microsoft and EY.

When looking at the success of these four programs, however, are there factors affecting their ability to see continued growth? The largest employer of autistic individuals, SAP, with over 160 autistic employees hired, is still far from their original goal of just under 700 autistic employees by 2020. SAP's global workforce is the smallest of the four listed, with 96,498 employees worldwide. EY has the largest global workforce with 270,000 employees, followed by JPMorgan Chase at 254,983 and Microsoft at 144,106. While all these companies employ a significant number of people, many of their jobs require higher educational levels and very specific skill sets. The nature of their hiring needs limits their candidate pool, regardless of whether a candidate has a disability or not.

When SAP announced their goal to have 1% of their workforce be comprised of autistic employees in 2013, the incidence rate of autism, as published by the CDC, was 1 in 88. Today it is 1 in 59. A study completed by Paul Shattuck of Drexel University in June 2012 showed that 35% of youth with an autism spectrum diagnosis (ASD) attend college (https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3362908/). For employers like SAP, and others who have followed in their footsteps, even though the incidence rate for autism continues to rise, the autistic candidate pool for the jobs they

see Hiring on page 28

#### New Normal from page 1

Utilizing a wellness perspective when working with individuals with developmental disabilities allows us to not only de-stigmatize the perceived deficits, it removes the concept that these differences are deficits. Changing the concept of what is considered a deficit is a significant paradigm shift. What if there is no "normal?" What if "normal" is actually a spectrum of different skills and personality traits? Then everyone fits into society. No peg has to try to squeeze into an ill-fitting hole.

We would be remiss if we didn't recognize that some neurodiverse individuals struggle socially and emotionally. The world can be a chaotic, confusing and overwhelming place in general. Those who can function, process and react easily are at a significant advantage to others who struggle in this area. This challenge is what typically differentiates "typical" individuals from "atypical" ones. But struggling in one or more areas of functioning can often times be remedied with appropriate, benign accommodations. There are stepstools for people with short stature, left-handed desks for the minority of people who are not right-handed, and pencil grips for individuals with weak finger strength, hearing and visual aids for many. These accommodations are commonplace and level the playing field. These are prime examples of how neurodiverse individuals can utilize various accommodations so that their other skills and strengths are not overshadowed by their challenges. Under the "disease" paradigm, the unique talents such as rational thinking (even in emotionally charged situations), eidetic memory, strong analyt-



Mandy H. Breslow, LCSW, MS Ed

ical ability, strict adherence to rules and order, etc. are seen as deficits and weaknesses that need to be corrected in order for the individual to fit into and function in society. The concept of neurodiversity views these traits as strengths rather than barriers. If social, occupational and educational opportunities that embrace differences without asking the neurodiverse individual to conform to existing systems, we would likely see increased participation, employment and overall quality of life. Perhaps social isolation, lack of employment, and solitary activities are a by-product of the exclusionary world we've created rather than symptoms of a disorder (Robertson, S., 2010). Looking at this from the reverse perspective, if we asked a Broadway actress to take a job as a computer programmer, she would likely feel overwhelmed, awkward and out-of-place. Chances are, she would not be successful in the job and would either quit or be fired. Now imagine that this same actress only had access to recreation activities involving computers and programming. Would she be motivated to engage in these activities, or would she withdraw and be regarded as socially isolative? She would be the square peg trying to fit into the round hole. We're actually setting her up to fail, thus reinforcing the disease paradigm.

The key factor in promoting the acceptance of neurodiversity is education and advocacy. Rather than focusing on causation and cures, neurodiversity focuses on integration and understanding. Unfortunately, the majority of research is targeted towards "fixing" and preventing issues such as Autism. Little research has been done on integration and regarding Autism as a variation of the normal human brain. When using the neurodiversity paradigm, we remove the question of why and instead ask how. How do we make the world a more comfortable and inclusive environment for everyone? One way is to tailor different situations to meet the needs of neurodiverse individual with supports and accommodations that allow them to more fully participate in everyday societal activities. We celebrate diversity in every other aspect of life, why not celebrate it in the human brain?

Neurodiversity is not just a politically correct term, nor is it just semantics. It's the understanding, acceptance and embracement of the human condition. It is the new normal.

Mandy H. Breslow, LCSW, MS Ed., is Founder and President of Indie Living, Inc. She is also an Independent Special Education Consultant and Counselor.

Mandy H. Breslow, LCSW, MS Ed., is a social worker in practice for 22 years. She earned her Master's in Social Work in 1997 from Adelphi University and her Master's in Early Childhood Education in 2008 from Touro College. Her work has focused on improving the lives of children and families dealing with Autism. Mandy's professional career includes direct service to clients both in mental health facilities and in their homes; community education and advocacy and teaching original curricula to psychiatry residents. She has a private practice in Long Island, NY and is the founder of a developing housing initiative called Indie Living. Mandy lives on Long Island with her husband and has two teenage sons with Autism.

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### Autism, Neurodiversity and Employment: Working Together for Positive Futures

By Barb Cook, M.Aut. Researcher, University of Wollongong Australia

utistic people are confronted with an array of barriers in many situations throughout their life. These situations centralise around what general society expects of all people, a one size fits all model, without the distinct consideration of disability, difference and inclusion. With the added individual challenges of effective communication skills, lack of self-advocacy and self-determination skills, and the overall impact of anxiety, feeling inadequate and little self-confidence, autistic people are desperate for their voices to be heard (Paradiz, Kelso, Nelson & Earl, 2018). These voices must therefore be acknowledged, respected and acted upon in educational and employment settings, as these aspects of life heavily decide the outcome of the future for the autistic person. If these individuals are not set up for success, given the tools and strategies that they can implement to support and advocate for themselves, then we, as a society are failing at providing pathways to include and value them.

Research reports that autistic people have the lowest employment rates and more specifically, the lowest rate of employment amidst all disability groups



Barb Cook, M.Aut.

(Roux et al., 2013). In my home country, the Australia Bureau of Statistics (2014) states a low employment participation of 42% by autistic people, highlighting the glaring concerns as to why these individuals are failing to gain employment. Again, the United States documents only 58% are in paid employment with Canada's extraordinarily low participation rate at 21.5% (Roux, Rast, Rava, Anderson & Shattuck, 2015; Zwicker, Zaresani & Emery, 2017). In 2016, the United Kingdom's National Autistic Society's *Too Much Information* 

campaign exposed that only 16% of autistic people are in full time work, and overall only 32% are in some kind of paid employment. Despite their ambition to work and, more so, their capacity to work affirms the necessity in identifying barriers and critical strategies on how to effectively support autistic people in gaining and maintaining meaningful and fulfilling employment.

To truly understand the needs and supports of autistic people is to listen. Society as a whole must support the autistic person in finding their voice, and facilitate them in conveying what their goals, vision and dreams are for the future. To attain these visions, suitable, quality and satisfying employment is the key in attaining these life goals. However, the autistic community has clearly identified its barriers and are demanding change in focus of all stakeholders that propose to support these people.

Important changes occur when stake-holders have a goal and feel connected to having a purpose in making change (Senge & Kleiner, 1999). These changes need to start with educators listening to the parents and the autistic child's needs and supports, work with them collaboratively and inclusive of both their concerns, and jointly work together in finding solutions that provide the best possible future. Young autistic adults need to be heard and supported in finding their voice so they can advocate for themselves, setting them up for adulthood and a future that they can independently

decide for themselves. Employers need to work with autistic people in creating working environments that support them, consider their sensory needs and value their unique way of viewing the world, and facilitate them in expressing new ideas and concepts that can effectively benefit all in the workplace.

Employers can step up and embrace the challenge of change through re-evaluating the way their business approaches and identifies potential employees. The antiquated recruitment model segregates and excludes diversity in thought and expression. Competent communication skills, and, more specifically, that of verbal language skills, is still currently viewed as an essential skill in expressing one's personal talents and worth to a potential employer, particularly in the interview process and in the workplace. Effective communication often poses as a significant barrier for autistic people (Hendricks, 2010), experiencing great difficulty in conveying not iust their needs and concerns, but also their worth and value. Changing the interview process to reduce the focus on communication savviness is a critical start. Placing emphasis on identifying the value in "outside of the box" thinking, ascertaining the importance an employee who is dedicated, honest, reliable and trustworthy, makes good business sense.

see Positive on page 24

# How To Navigate The Topic Of Driving with ASD

By Andrew Arboe Event Facilitator Planning Across The Spectrum

ow you ever thought of your loved one with an autism spectrum disorder (ASD) having the ability to drive? Are you worried about how one can drive, despite being on the autism spectrum? I am writing as someone with ASD who has had their license for over a year, and I want to light a path for parents and individuals to consider. My state (CT) has typically avoided addressing the ASD-related driving inhibitions, despite various workshops and presentations I seen over the last five years addressing those with special needs. I do not blame them; Autism is complex. While there may not be many resources or places to turn to for these needs in your area, the span and outreach of knowledge is growing. At Planning Across The Spectrum, learning to drive has become an integral part in our coaching the transition process. The following topics include what I believe to be among the most important things for parents and individuals to consider when tackling the topic of driving.

#### Motivation

The first aspect to consider is the motivation of the individual who wants



**Andrew Arboe** 

to drive. We all have a reason to drive. Some of these include employment, college, socialization, or just enjoyment. All of these revolve around the freedom to do something so important for ourselves and our own care. My personal motivation was a combination of employment, socialization, and just self-improvement. I wanted to stay in my work field, which is the autism community. Most jobs in the autism field require the need to travel a certain number of miles to do the job. During the time period I was working towards my driver's license, I was also

working towards my Associate Degree as a Disability Specialist. As I started closing in on the end of my college degree, I realized that I needed the driver's license to keep improving myself as a person and navigate the professional world. It was that motivation and determination that helped set up the path to getting my license. I believe once an individual's motivation is established, it can light up some possible paths to take to take up driving. There is no time frame on this; I got my license when I at 25 years old. If you want to do it, finding your motivation is key.

#### A Support Team

The second aspect I find important is to know your support team and make sure they are 100% on board. I speak at organizations in my state and constantly note recurring themes of power struggles between teens/young adults and their parents. There are so many cases where the parents support (or even force the issue) their teen/young adult or the individual interested in driving, but also struggle with the idea of giving and trusting their loved one with the responsibility.

In my case, my father was nervous about me driving because of my autism. He was worried that I would lose focus on the road and in traffic. The beginning was difficult because of that dynamic, and I learned to hate the words "pay at-

tention" because of my mind associating it with the autism. My dad had a "just do it" attitude while I just needed more time to get used to it and more opportunities to learn, which is not something I was receiving. My saving grace was being hired for a position in the ASD community that was 45 minutes away from home once a week. My father would let me drive there and home and it was the perfect opportunity to build my skills. As the weeks went on, my dad became more comfortable about me driving and let me practice more and more.

My advice to the parents of those in a similar situation as mine is to follow the pace of the person who is learning. If you are their teacher, allow them to practice. Be patient. Allow them to make mistakes. Listen to what they are telling you and asking of you. Start slow and build up as skills improve. If you are the learner, ask for what you need. It will get better. You will get better. When my father finally commended me for how much I had improved, it was exactly what I needed to hear and really helped my motivation. All parties need to understand that anxiety is going to play a major role in this, and it is going to take time. There is no magic time frame to learn here, no magic age. I was 25, my co-worker was 40. Take it slow. Listen to each other. Let it happen as everyone is ready.

see Driving on page 30

# AUTISM SPECTRUM

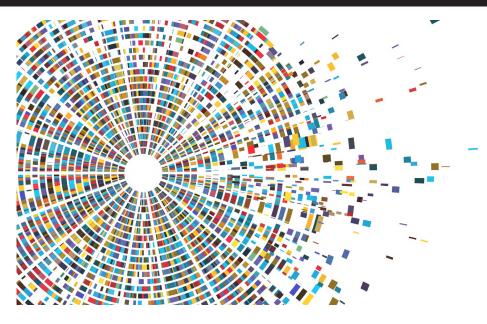


# Genome Testing for Siblings of Individuals May Aid in a Diagnosis Before Symptoms Appear

#### By The Autism Science Foundation

ne of the key priorities of interventions for autism spectrum disorder (ASD) is starting early, with some evidence showing infants as young as seven months old could benefit. Yet, most children in North America aren't diagnosed with ASD until they're over four years of age. New research led by The Hospital for Sick Children (SickKids) and the University of Alberta published on December 5, 2019 in *Nature Communications* has found testing the DNA of siblings of individuals with ASD may be predictive of a future diagnosis even if symptoms aren't yet apparent.

ASD refers to a group of neurodevelopmental conditions resulting in challenges related to communication, social understanding and behaviour. Studies show families who have a child with ASD have a 6.9 to 19.5 per cent chance of another child having ASD and a 30 to 40 per cent chance of another child having atypical development.



Genomic Factors Linked to ASD-Related Traits

According to Dr. Stephen Scherer, Senior Scientist and Director of the Centre

for Applied Genomics (TCAG) at Sick-Kids, Director of the McLaughlin Centre at the University of Toronto and principal investigator of the study: "Genetic factors are the most likely reason we see a clustering of ASD related traits in families. We wanted to investigate the possible benefits of genetic testing for infants whose older sibling had already been diagnosed with ASD. If we can identify those children early, we may be able to enroll them earlier in therapies."

The researchers looked for the presence of genetic alterations that have been linked to ASD called copy number variations (CNVs) in over 288 infant siblings from 253 families. By age 3, 157 siblings were either diagnosed with ASD or developing atypically. DNA testing revealed CNVs in genes relevant to ASD in 11 (7 per cent) of the 157 siblings who were eventually diagnosed.

The study found that the presence of an ASD-relevant CNV in a sibling had a high likelihood of predicting a future diagnosis of ASD or atypical development. This marks the first time that scientists have been able to quantify the predictive value of CNVs in determining these diagnoses.

see Testing on page 32

#### Positive from page 23

Employers that expand on the inclusion initiative by supporting and growing their potential and current autistic and neurodivergent employees will reap the benefits in a multitude of ways and become the leaders in change and true inclusion. The key to change is responsible communication. Communication must focus on listening and implementing supports and strategies that assist the autistic or neurodivergent person. Every opportunity should be presented through application and interview processes that assists them in conveying their worth, value and potential. When employed, feedback and communication is essential in growing together with the employee. Through my experience when working with a breakdown in the workplace, the key element to this breakdown is the disintegration in communication. Either or both sides feel unheard, misunderstood or unsupported. An employer that takes the initiative and time to step back, understand and identify how they can support their employee will reap the benefits ten-fold. An employee that feels valued and supported will often do their utmost in return. And this applies for all employees; listen, communicate, act and support.

As understanding grows around neurodiversity within the workplace, employers embracing differences and supporting autistic and neurodivergent people to grow into their potential - these genuinely inclusive practices strengthen and ignite positive growth within business. Autistic and neurodivergent people bring a unique strength, dedication and high work ethic to the workplace that must be embraced, with an environment provided for them to grow. These people, when supported and given every opportunity to flourish, become the role models of a dedicated and loyal employee. They are the potential compassionate and moralistic leaders of our future and can be pioneers of a new way of thinking and evolving together that benefits not just autistic people, but every person within the workplace, creating a truly inclusive work culture.

Barb Cook, M.Aut., is a Developmental Educator (DE) and Autism and Neurodiversity Employment Consultant. Barb has a Master of Autism (Education) with focus on employment from the University of Wollongong, Australia, where she is also a tutor in this program and a research assistant in the area of self-determination and self-advocacy for adults on the autism spectrum.

In 2009, Barb was formally diagnosed on the autism spectrum along with ADHD and phonological dyslexia at age 40. She is editor and co-author of the internationally acclaimed book Spectrum Women: Walking to the Beat of Autism, and founder of Spectrum Women Magazine. Barb is an internationally recognised speaker and writer and was keynote and a panel participant for a special event "A Woman's Voice: Understanding Autistic Needs" for the National Institute of Mental Health (NIHM) in Washington DC, USA.

As a Developmental Educator, Barb fo-

cuses on developing individualised learning strategies, tools and supports with positive outcomes for individuals across the lifespan. Barb embraces a collaborative approach by working with health and educational professionals, support staff, employers, employees, families and caregivers to develop their skills, knowledge and understanding of a person-centred approach in fostering positive support and enhancement of life outcomes. Barb has extensive experience in working with people on the autism spectrum, ADHD and dyslexia, especially with adults in creating pathways in attaining life goals in the areas of education, employment, health and interpersonal relationships.

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# AUTISM SPECTRUM



# NIH Awards \$4 Million in Funding for Early Autism Screening

Funded projects will help develop and validate screening tools used to detect autism in the first year of life

By The National Institutes of Health (NIH)

ovember 6, 2019 - The National Institutes of Health (NIH) has awarded more than four million dollars in FY 2019 to support seven research projects aimed at developing and validating screening tools to detect signs of autism spectrum disorder in the first year of life. Approximately 19 million dollars is projected to be awarded to these projects by NIH over the duration of the funded projects.

"Early detection and treatment of children with autism spectrum disorder are two of the most important factors for optimizing children's outcomes," said Dr. Joshua Gordon, director of the National Institute of Mental Health (NIMH). "It is critical that we develop screening tools that can pick up on early emerging signs of autism risk so that doctors can be vigilant in tracking children's development and ensure they get intervention services as early as possible."



It is estimated that autism spectrum disorder (ASD)—a developmental disorder that affects social communication and behavior—affects 1 in 59 children in the United States. Reliably detecting autism in

young children is difficult, and the average age of diagnosis for ASD hovers around four years of age. Delays in diagnosis can have profound and long-lasting effects on children, since early intervention has been demonstrated to improve cognitive and behavioral outcomes for young children with ASD.

Because early treatment is so critical for children with ASD, efforts have been made to try to reduce the age of diagnosis by universally screening all children for signs of autism. Children who are found to be at high risk for developing autism can then be connected with intervention services as soon as possible. Although well-validated instruments exist to screen toddlers for ASD between 18 and 24 months of age, there is evidence that many infants at risk for ASD show differences in the way social attention and early forms of communication develop over the first year of life.

The seven projects—supported jointly by the NIH's NIMH, the Eunice Kennedy Shriver National Institute of Child Health and Human Development, the National Institute of Neurological Disorders and Stroke, and the National Institute on

see Screening on page 29

# Becca Lory Hector Joins Autism Spectrum News Editorial Board

By Staff Writer Autism Spectrum News

ental Health News Education, Inc., publisher of *Autism Spectrum News*, is proud to announce that Becca Lory Hector, CAS, BCCS, Autism, Neurodiversity, & Inclusion Consultant/Speaker/Author/Advocate, has become the newest member of the ASN Editorial Board.

Becca Lory Hector was diagnosed on the autism spectrum as an adult and has since become a dynamic autism advocate, consultant, speaker, and author. With a focus on living an active, positive life, her work includes autism/neurodiversity/inclusion consulting; public speaking engagements; a monthly blog, "Live Positively Autistic"; a weekly YouTube news show, "Neurodiversity Newsstand,"; and being an Assis-

tant Editor/Feature Writer for Spectrum Women Magazine.

Becca has published multiple articles about life on the autism spectrum with the goal of spreading acceptance, building understanding, and encouraging self-advocacy. She spent four years supporting the autism community in the non-profit sector in her work for grass-roots organizations that provide resources and services directly to individuals on the autism spectrum. Becca left non-profit to pursue dual certifications as a Certified Autism Specialist (CAS) and Cognitive Specialist (BCCS), and to open her autism consulting business.

An animal lover with a special affinity for cats, Becca spends most of her free time with her many animals, her husband Antonio Hector, and their Emotional Support Animal (ESA), Sir Walter Underfoot. Sir Walter Underfoot travels, does woofing engagements, and has his very own Insta-

gram to help share with the world his life as an ESA to an autistic adult.

Pat Schissel, LMSW, ASN Editorial Board Member and New York Director of AANE, remarked, "Becca is perfect for the Editorial Board and I'm proud to serve with her! She has solid instincts and an excellent feel of timely and valuable information."

David Minot, Associate Director of MHNE and Publisher of *Autism Spectrum News* stated, "Becca has been instrumental in developing this issue on Neurodiversity and has been an unofficial advisor for many issues in the past. I look forward to working with Becca in her new role as we continue on our mission of providing a trusted source of science-based information, education, and advocacy for the autism community."

To see the full listing of the Autism Spectrum News Editorial Board, please visit www.autismspectrumnews.org/about/.



**Becca Lory Hector, CAS, BCCS** 

#### Two Worlds from page 15

As time has gone by, I have learned to both be more accepting of others and help others be more accepting of me. I have made friends who are both Autistic and Neurotypical and learned to sometimes use the challenge of being stuck between the two worlds as a strength not a weak-

ness. I have found that while being half and half as I stated creates a number of challenges it also creates opportunities for me to be a bridge between the two worlds. It gives me the ability to understand how neurotypicals think and use that to teach them to be more understanding of autistics and likewise to teach autistics how to behave in a way that will allow them to get

by in a neurotypical world.

What my own life and experiences have taught me is that we need to stop thinking of Autism vs. Neurotypical as two different ways of thinking but rather as part of a larger continuum. Instead of viewing neurology as a continuum of Autism vs. neurotypicality in a binary, we need to view it all as part of a larg-

er continuum since so many of us have a mixture of autistic and neurotypical traits and ways of thinking.

Michael Gilberg is a Special Education Attorney representing families and Self-Advocates and can be reached at michaelgilbergesq@gmail.com or http://www.michaelgilbergesq.com.

# **Local Nonprofit Dog Treat Company Expands Their Mission of Employment for the Disabled Community**

By Good Reasons®

ood Reasons® Dog Treats, a non-profit dog treat company that provides employment for people with autism and other developmental disabilities is growing its mission.

Since launching in 2014 Good Reasons has shown significant growth, now offering 6 delicious flavors of their all natural, human grade, locally baked and packed dog treats. They are now selling nationwide via their website in addition to several Whole Foods, Hannaford's, Tops, and DeCicco's supermarket locations. Last year Good Reasons was also featured on QVC and ABC World News, and have received generous donations from Thomas Agnes Carvel Foundation, Sterling Bank, Workforce Development Institute, and won a generous grant from Impact 100 Westchester.

All these factors have enabled Good Reasons to grow their mission even further, introducing GR Pack, a fulfillment and packaging division. GR Pack provides a needed service in the community by being a fulfillment partner for companies seeking assistance with assembly and packaging of various products. GR Pack strives to offer integrated and meaningful employment for people of all abilities.

"Opening our new Westchester space as given us the opportunity to create more jobs. We all desire a purpose in life, and a job where you can make friends, and money is a way to achieve that." – Dr. Vicki Sylvester, CEO.

The continued development of this local social enterprise also means more commu-



The Good Reasons Team hard a work for local company Brewster Plastics

nity involvement and partnerships. Good Reasons donates treats on a regular basis to local shelters, and SPCA's and often runs promotions that raise money and awareness for other great causes. Most recently, during October Good Reasons donated \$1 from every pink Bella P.B bag sold to Miles of Hope Breast Cancer Foundation. In November, many bags of Tucker's Turkey flavor were donated to NY and CT shelters, the Patterson Rotary and local food pantries. During the month of Dec many not for profits will receive donations of the red Gracie's bag, ensuring lots of furry friends are spoiled during the holiday season too.

Recently a vendor and featured panelist at the YAI Hudson Valley Autism Conference, the Good reasons team is always looking to spread awareness of their mission, and that of likeminded companies. Welcoming many visitors to the new space and always seeking ways to improve the lives of people with disabilities. Hosting Brewster Chamber's networking breakfast and marketing seminar is one way Good Reasons attracts new eyes to what they are doing. "We want other local businesses to see with their own eyes the impact having a job can have on someone's life. Hopefully by seeing our mission in action other employees will be more motivated to embracing the many benefits of an integrated work team." – Kelly Apfel, Communications and Development Manager.

Excited for the launch of their new website in the early New Year, Good Reasons will be regularly highlighting the importance of what they are doing within the community. Additionally, several new human consumable products will soon be

available for sale, all delicious recipes created by their very own Chef and culinary graduate, Allan Katz.

The the search for more packaging jobs continues, and Good Reasons role as a business leader within the community is something the entire team is passionate about.

Good Reasons' parent company, Community Based Services (CBS) has been providing residential and community support programs since 1981. With 10 residential homes providing 24/7 care for people with disabilities, a growing day hab without walls program, respite, supported and pathways to employment, the agency leads the charge for self-advocacy and community inclusion for all people. Most recently, CBS opened up a new farm in Hopewell Junction, NY. This Dutchess location will be home to the Cultivating Dreams program and will offer overnight respite capabilities.

#### About Good Reasons®

Good Reasons® is a dog treat company on a mission. Located in Westchester, NY they create healthy and delicious dog treats while providing opportunity and employment for people of all abilities. Founder, Vicki Sylvester, Ph.D., merged her professional experience as an advocate for the disabled community with her love of animals to create a company that supports an integrated workforce. Unleashing love and potential in every bite!

For more information, contact Kelly Apfel, Communications & Development Manager at 914-236-1129 and info@goodreasons.com or visit www.goodreasons.com.

#### Leaders from page 17

challenges of operationalizing relationships between health and human services providers and offering seven recommendations. She also served on the New York State Department of Health's Social Determinants (SDH) and Community Based Organizations (CBO) Subcommittee helping to formulate recommendations around the integration of CBOs into Medicaid managed care.

Allison has overseen disaster recovery and preparedness efforts on behalf of the nonprofit sector, including coordination with government and was tapped by the Mayor to serve on the Hurricane Sandy Charitable Organizations and Houses of Worship Recovery Task Force and served as its chair. She was also appointed to the OneNYC Commission; responsible for developing a comprehensive plan for a sustainable and resilient city that addresses the profound social, economic, and environmental challenges ahead.

Sesso's past professional experiences include working at a prominent investment bank, at the New York Public Interest Research Group, and as the coordinator of a program for victims of domestic

violence and sexual abuse. She holds a Master of Public Administration degree from Baruch/CUNY's School of Public Affairs.

Allison is the Board Chair of the non-profit Hollaback!, a global movement to end harassment powered by a network of grassroots activists. Additionally, Allison serves on Fund the People's Advisory Council, a national group that aims to encourage investments in the nonprofit workforce as the best way to increase performance and impact across the social sector

Allison's work on behalf of the human services sector has led City & State to recognize her as number 8 on the Nonprofit Power 50 in 2018, and as one of the 25 most influential leaders in Manhattan in 2017 and New York City's 100 "Most Responsible" in 2016.

Ian Shaffer, MD, MMM, CPE VP and Executive Medical Director Healthfirst - Behavioral Health

Ian Shaffer, MD, MMM, CPE, is Vice President and Executive Medical Director, Behavioral Health for Healthfirst responsible for behavioral health program management. Prior to this he was Vice President Behavioral Health Program Design and Research for Health Net Federal Services responsible for behavioral health program design and research with a specific focus on the military and veteran populations and their families. Previously at Health Net, Inc., Shaffer was MHN's Chief Medical Officer, responsible for setting the company's clinical policies and guidelines and ensuring clinical excellence. Dr. Shaffer oversaw MHN's quality improvement and disease management units and was accountable for the coordination and quality assurance of clinical care.

In addition, Dr. Shaffer has overseen quality and outcomes monitoring for the Military & Family Life Consultant Program services and collaborated with his Health Net Federal Services colleagues to ensure optimal care and service delivery for TRICARE beneficiaries.

Prior to joining MHN in 2003, Dr. Shaffer served as executive vice president and chief medical officer of a national managed behavioral health organization, working closely with several Fortune 100 companies. He three times served as chairman of the Association for

Behavioral Health and Wellness (ABHW) (formerly the American Managed Behavioral Healthcare Association - AMBHA), and he has also served on several federal government committees, including a three-year term on the National Advisory Committee for the Center for Mental Health Services arm of SAMHSA. He remains involved in national behavioral health policy issues, including parity and autism.

As the President of Behavioral Health Management Solutions, LLC Dr. Shaffer has provided consultation to a variety of startup and ongoing behavioral health programs that have been redesigning to meet the changing needs of health care delivery and reimbursement.

Dr. Shaffer, a Life Fellow of the American Psychiatric Association, is board-certified in psychiatry and addiction medicine, and has received fellowship training in child psychiatry. He received his medical degree from the University of Manitoba and psychiatry and child psychiatry training at the University of Southern California. Dr. Shaffer, a Certified Physician Executive also holds a Master's degree in Medical Management from Tulane University.

# Learning Neurodiversity in a College Program for Middle / High School Students with ASD

By Elizabeth Byington, James Lawler, and Brittany Schneider Pace University

ollege students without disabilities are not cognizant enough of the different needs of neurodiverse students. The commonality concept of neurodiversity, of students with Autism Spectrum Disorder (ASD) being deserving of equal opportunity (Silberman, 2015), is not evident frequently with students without disabilities. College students without disabilities can be advocates however for neurodiversity in empowering students with disabilities in an engaging neurodiversity program.

#### Introduction

Pace University in New York City is engaging in an Area of Knowledge (AOK) community computer information systems (CIS) outreach program with the AHRC New York City Middle / High School (M/HS) in Brooklyn, New York, where Pace students are mentoring M/HS students with ASD.

The focus of the program is to involve the M/HS students with the undergraduate students on mostly personalized projects



**Elizabeth Byington** 

of virtual reality (Furler, 2018) sites on the Web, proposed by the M/HS special education teachers.

The foundation for the program comes "from person-centered planning principles (Holburn, Gordon, & Vietze, 2007) on other projects initiated since 2009 with the M/HS," comments Professor James Lawler, coordinator of the program at the university.



**James Lawler** 

The goals of the program are to involve freshman to senior undergraduate students in learning about the humanity (Prizant, 2015) interests of the M/HS students, and to involve the M/HS students in learning about the humanity interests of mostly peer undergraduate students, one-on-one on the premises of a major metropolitan university, so that the undergraduate students are learning about neurodiversity (Baron-Cohen, 2019)



**Brittany Schneider** 

in outreaching to the M/HS students.

For the undergraduate students, they are learning neurodiversity in practicing recognition and respect (Baron-Cohen, 2019) of not only M/HS students with ASD, but also other undergraduate students with ASD, most of whom they do not meet often in the university.

see College on page 31



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#### Shift from page 20

order to make connections, and socially participate in a more meaningful, self-determined way. Teachers could incorporate strengths and interests into subject matter, routines and social relationships by simply respecting the inherent value they have for the individual versus pathologizing these interests. This builds relationships in a way that is meaningful to the student. The framing matters. If I view interests as positive and an avenue for learning and goal attainment, I must find a way to incorporate them into all aspects of professional practice. If I frame these interests as interfering, then I must eliminate them.

Autistic individuals are expressing anger and frustration at therapeutic interventions that diminish interests (Bagatell, 2010) and advocacy groups are making a distinction from interventions that provide supports and services to help individuals achieve personally valued goals versus "normalization" of their behavior (Parsloe, 2015). If practitioners can adopt

a strength-based practice, their thinking will shift away from any intervention that attempts to "normalize," unless it is personally valued (Patten Koenig, 2019). These shifts in thinking will require the professional to question him or herself regularly and ask questions such as: Am I focusing on weaknesses in the absence of strengths? Am I offering activities and choices that are related to interests? Am I viewing autistic interests as strengths versus motivators or worse yet suppressing them as maladaptive behaviors? Am I combining a strengths perspective with the challenges that are being addressed? The first place to find the answers to those questions is to examine our evaluations, goals, individual educational plans and interventions. If the answer is a one-line response for "strengths," it is time to see the biased perspective and make the shift to an authentic strength-based practice.

Kristie Patten Koenig, PhD, OT/L, FAO-TA, is Associate Professor and Chair at the New York University Steinhardt School of Culture, Education and Human Development Department of Occupational Therapy. If you would like to contact Dr. Patten Koenig, she can be reached via email at kpk3@nyu.edu.

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#### Autism Patch from page 20

On April 18, 2019, 125 first responders from over 35 surrounding agencies in Westchester County (NY) received free training on autism detection and response (paid for by Christopher's Voice). On November 13, 2019, 60 first responders from 20 different agencies throughout the Milwaukee Wisconsin area received similar training from Blue Line Spectrum LLC. In NJ, thanks to P.O.A.C. Autism Services over 65,000 first responders have been trained by Gary Weitzen since 1999.

In addition to training, local autism programs have benefited significantly and will likely continue to benefit in the months and years to come. A small sample of fundraisers from around the United States include the following – In Massachusetts, the Randolph Police Department recently raised \$3,000 by selling autism patches and donated their proceeds to the May Institute for Autism. In Kent, NY, their police department raised \$1,000 for the Anderson Center for Autism. In Mobile Alabama, their police officers sold patches and donated \$1,235 to Woody's Song School for autistic children. In Lea County New Mexico, their Deputy Sheriffs raised \$4,500 and donated their proceeds to the Light it up Blue Foundation for Autism. In North Smithfield (RI), their officers raised money for The Autism Project; In Wilmington Delaware, their officers raised money for the Doug Flutie Jr. Foundation. In Seal Beach (CA), officers raised funds for their Special Education PTA and in NY/NJ; the Port Authority Police Department raised \$5,600 and donated their proceeds to two local autism charities - Christopher's Voice and P.O.A.C. Autism Services (Full



**Sample of Autism Patches** 

disclosure - I am the co-founder of Christopher's Voice).

These are just a few examples of what is happening in police departments, fire departments and EMS agencies from around the country. As I continue to network with officers from different states, I continue to recognize a common trend between the officers that take the lead within their agency. Most officers have a child with autism and each officer wants to honor their child in their community, just as I did.

The inspiration for the Autism Patch Challenge was my son Christopher. Christopher, who was diagnosed with autism at 11 months, has had a very challenging life - one that has been overwhelmed with medical issues. Since April 2018, Christopher has been hospitalized at Blythedale Children's Hospital in Westchester County with epilepsy and dystonia. Losing his ability to walk, Christopher is now confined to a wheelchair or hospital bed. Prior to being hospitalized Christopher led

a limited but happy life. He spent most of his days running joyfully around the house, swinging on his swing, jumping on the trampoline and eating to his heart's content. Being non-verbal and possessing almost no life skills, Christopher relied on my wife (Tracy), his teachers, therapists and aids for almost everything - except making a mess. Prior to being hospitalized Christopher attended William Ward Elementary School in New Rochelle, where he received constant love, support and friendship. It was there, in April of 2017 (and each year since) that over 75 first responders from over 35 different agencies converged onto the school campus for the first ever multi-agency first responder autism awareness day in New Rochelle. Each responding agency came with their Autism Patch affixed to their emergency vehicles. Responding officers spent quality time with special education students and "regular" students. They distributed autism patches to all the children and completed demonstrations for them. It was a great opportunity for hundreds of children to "meet and greet" with local heroes.

Many of you may be wondering why I wrote this article and the answer is simple - I want the challenge to continue and I want you to encourage your local police and fire agencies to participate. The cost for them to participate is nominal and the return on investment is priceless. Your communities will be thankful, your first responders will be more aware and better trained and just maybe you might have one of these special moments - the ultimate story that demonstrates the success and impact of the New Rochelle Police Autism Patch Challenge.

This story hails from Berlin, Massachusetts. On April 2, 2019 Michael Gomez, a

13-year-old autistic teenager was on his bus going to school when the bus driver began experiencing chest pains and was no longer able to drive or call for help. Michael jumped into action and ran from the bus into his school. Michael pleaded for help and an ambulance responded. The driver was transported to a local hospital where he remained for several more days. Why is the story so special? Because on this day, April 2, 2019 it was World Autism Day and affixed to Michael's shirt was the Berlin Police Department's Autism Awareness Patch. "I felt like a first responder" Michael told reporters (during his press conference) and it was the autism patch that gave him "the courage to act." Priceless!

To this day I remain grateful to the New Rochelle Police Department that continues to allow me to honor my son Christopher and children like him everywhere.

To learn more about the challenge and to read more great stories from around the country visit our Facebook page @ New Rochelle Police Autism Patch Challenge.

Christopher Greco is a Detective with the New Rochelle Police Department since 1996. He currently serves in the General Investigations Unit. Detective Greco is also the PBA President. In 2016 Detective Greco raised \$15,000 and implemented the New Rochelle Police Project Lifesaver Program. Detective Greco is married to Tracy Camillone Greco and together they have two children, Christopher and Gabriella. Detective Greco and his wife Tracy are the founders of Christopher's Voice – a charitable organization for autistic children.

For more information, you can email Detective Greco at Cgreco@newrochelleny.com.

#### Hiring from page 22

need to fill is a fraction of the entire population of those with autism.

Additionally, almost all the 495+ roles filled at these four employers since 2013 have been in technology. But not all those 35% of individuals with an ASD diagnosis that attend college have the skill sets to fill technology roles. Integrate has had 213 autistic young adults who are in college or have graduated from college attend our Employer Connect job skills/networking program. The majors/career interests of those autistic young adult participants break down as follows:

- STEM: 33%
- Humanities: 23%
- Communications/Media: 18%
- Business/Finance/Economics: 10%
- Social Sciences: 8%
- Arts/Design/Music: 8%

As can be seen from these numbers, once the educational and skill set requirements are applied to the overall autistic population, the pool of available candidates to fill these employers' hiring needs shrinks even further.

The second limiting factor for large scale autism hiring programs is the challenge with sourcing candidates or outreach. Despite the data above, many individuals with the required skills for positions in organizations such as these are unemployed. So why have these organizations and others, some who have indicated they would have hired more autistic employees by now if

they could "find them," not done so? As the Autism @ Work playbook opening states, "Organizations interested in establishing Autism @ Work programs often don't know quite how or where to start." The playbook also states that employers need not only internal partners to champion and support the effort, but external partners in the community to help them "plan, launch and sustain their programs." The most critical factor to success, they state, is the ability to source talent.

Sourcing autistic talent can be a challenge. While U.S. citizens with a disability are entitled to vocational support services from the government, the U.S. vocational rehabilitation (VR) system is a state-based system, preventing national employers from accessing one central system to find and hire employees with any type of disability. Also, not everyone with autism, particularly college graduates, registers with their state VR agency. Employers' too report mixed experience with VR. In a 2018 study completed by the General Accounting Office, it was found that "(e) mployers in one of four discussion groups said that VR does not always provide enough qualified job candidates to meet their needs, and employers in another discussion group said that job candidates referred by VR are not always good matches for their hiring needs" (https://www.gao. gov/assets/700/694369.pdf).

The vocational support structure for autistic individuals within states is also extremely fractured. Just because an individual is registered with their state VR agency doesn't mean that agency will be

aware of and have access to the types of job opportunities that are appropriate for that individual. So, an employer looking for autistic job candidates needs to have an incredibly broad reach when seeking candidates. As an example, when Integrate conducts a search for an employer, our outreach for candidates may include anywhere from 50 to 100 colleges, universities, vocational organizations, autism organizations, private clinicians, support groups, therapeutic programs, Facebook groups, etc. where potential jobseekers may be seeking services or community. Few employers have the time and resources to conduct such an extensive outreach to hire individuals who will ultimately be a very small percentage of their entire employee base, which is why they need to rely on partner organizations. And those partner organizations can vary greatly in their reach and capabilities.

A more streamlined system for autistic jobseekers to make their availability for employment known to employers and for employers to make their hiring opportunities known to autistic candidates is needed. Attempts at creating an online marketplace for autistic jobseekers and employers, similar to Indeed or Monster, have been tried or are under development. These efforts can help. But they need to have safeguards to ensure autistic jobseekers do not fall prey to unscrupulous employers looking for a cheap source of labor or employers that have not invested in the training and infrastructure to provide autistic employees with the supportive environment necessary for their success.

A national VR system that is user friendly and allows candidates to register once and become known to agencies and employers throughout the country would also greatly improve the ability of candidates and employers to connect. Lastly, while it is important to have Fortune 500 companies publicly taking the lead in showing how hiring autistic workers is good for business, it is important to remember that almost 60% of U.S. workers are employed by companies with less than 1,000 employees (https://www.bls.gov/web/cewbd/ table\_f.txt). It is critical to engage this segment of the employer marketplace in efficient ways to include autistic workers in their ranks.

A handful of large corporate employers are leading the way in creating greater employment opportunities for neurodivergent individuals. These efforts are still in their nascent stage, however. Six years into these efforts, the unemployment rate for autistic individuals has not improved. Our system for connecting autistic jobseekers with employers needs to be re-imagined making it easier for them to connect, and for employers to understand the many roles neurodivergent employees can fill in their organizations.

Marcia Scheiner is the President and Founder of Integrate Autism Employment Advisors. Integrate works with employers to help them launch and scale neurodiversity hiring initiatives by providing assessment, training & education, recruiting and employment support services. For more information, visit www.integrateadvisors.org.

#### Life Skills from page 13

smile and a high five to celebrate. Daniel has a warm personality with a smile that beams through any picture. He is incredibly goal-oriented and one of his longterm goals is to be a "flexible thinker." For Daniel, being a flexible thinker means that he will work through unexpected changes. Many individuals with autism demonstrate rigidity or inflexibility toward unwelcome news, change, or abstract concepts, according to Kenworthy and Strang of the Organization for Autism Research (2017). To assist with this goal, DiGuilio breaks down unexpected changes into smaller parts so Daniel can process one component at a time. She can recall a few instances when Daniel had to wait for his spending money because of bank delays. While not the ideal situation, Daniel decided the best thing to do was wait patiently instead of becoming anxious after DiGuilio described that there was a "tech issue." To prevent feeling blindsided by upcoming changes, Daniel prefers to write down the expectation for the situation in clear steps. That way, he can process the information at his own pace or refer to his notes. Daniel may struggle with rigidity, but his inflexibility can be used to overcome itself. Kenworthy and Strang (2017) argue that inflexibility can be a strength, writing, "Inflexibility drives persistence and perseverance." Daniel's strong worth



Cara with completed drawing for "Artist of the Month" exhibition at JJ's A Gift Shop in Oracle, AZ

ethic and goal-oriented personality are likely linked to the inflexible nature he is working hard to combat. With his determination, DiGuilio and the Vista team are hopeful to see how he will continue to grow as a flexible thinker.

Christine is charismatic, highly organized, and often relied on by those around her. She has an exceptional memory, which serves her in multiple areas of her

life. Although she does not use a calendar or even store contact information in her cell phone, Christine precisely recalls names, dates, and phone numbers with ease. On top of managing her medication, finances, and work responsibilities, Christine is a regular actress and dancer for Vista's A Shared Stage Productions. Last year, Christine took on two roles in Sister Act involving dialogue, singing, choreography and multiple costume changes. Yet, she was often the one helping her fellow actors. Kitty Fitzpatrick, Vista's Director of Engage Services and an acting enthusiast, reminisces, "In Sister Act, we were backup dancers for Deloris. She picked up the dancing right away. I found myself leaning on her to remind me of the moves." Christine's strong memory and attention-to-detail could be linked with inflexibility, a trait she shares with Daniel. Inflexibility often means "being able to keenly focus on certain activities, topics, or routines...Think of the young person who fixates on a certain topic (like computer programming) and becomes a true "expert" (Kenworthy & Strang, 2017). Cara, Daniel, and Christine benefit highly from routine and can struggle when that routine changes. Unlike Daniel, who prefers to process these adjustments with written communication, Christine prefers verbally reviewing the change. Saying an unpleasant fact out loud helps her become okay with it. Likewise, talking to her fam-

ily over the phone is another way she sorts through her emotions.

Neurodiversity is one piece of a larger concept: everyone is different. At Vista, members work with staff to come up with goals and strategies that will work for them as they gain the skills needed for independence. While the path to independence can be difficult for those with autism, it is important to remember the talents, strengths and resolve that can come from having an atypical brain.

Becky Lipnick is the Organizational Communications Coordinator at Vista Life Innovations. For 30 years, Vista has supported individuals with disabilities achieve personal success. Learn more at www. VistaLifeInnovations.org or contact Becky at BLipnick@VistaLifeInnovations.org.

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#### Technology from page 10

Specialist/Trainer for AHRC New York City with over 10 years of experience working with technology in collaboration with peo-

 $ple\ with\ I/DD\ and\ their\ supporting\ staff.$ 

Footnotes

1. Scott R., Collins B., Knight V., & Kleinert,

H (n.d.). "Teaching Adults with Moderate Intellectual Disability ATM Use via the iPod"

2. Schaefer Whitby, P. J. (n.d.). "The Effects of Solve It! on the Mathematical

Word Problem Solving Ability of Adolescents With Autism Spectrum Disorders"

3. Hickson, L., & Khemka, I. (n.d.). "Independent Review of BIP Innovation Project Outcomes"

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#### Screening from page 25

Deafness and Other Communication Disorders—seek to translate findings related to early-emerging signs of autism into practical ASD screening tools that can be implemented in the general population and in community settings.

The grants awarded include:

Community-Viable Screening for AS in 9-month-old Infants Using Quantitative Eye-Tracking Assays of Social Visual Engagement Warren Jones, PhD, Emory University

In this study, researchers will measure the ability of an eye-tracking-based assessment of social visual engagement performed during children's 9-month wellchild visits to screen for ASD and other actionable developmental delays.

Validation of the Social Communication CheckUp and Autism Risk Indicator in the First Year of Life Amy Wetherby, PhD, Florida State University

The goal of this study is to validate the effectiveness of a new automated online screening tool—the Social Communication (SoCo) CheckUp—to screen for communication delay and autism at well-child visits at 9, 12, 15, 18, 21, and 24 months of age.

#### Novel Approaches to Infant Screening for ASD in Pediatric Primary Care Geraldine Dawson, PhD, Duke University

The overall goal of this project is to develop and validate a novel screening tool, called SenseToKnow, for use in a primary care setting. This tool identifies risk for ASD in infants based on patterns of attention, orienting, affect, vocalizations, and motor behavior.

Neonatal Cry Acoustics and Neurobehavioral Characteristics as Early Markers of Risk for Autism Spectrum Disorder Stephen Sheinkopf, PhD, Women and Infants Hospital—Rhode Island

This project seeks to identify children at risk for autism in infancy by developing and validating a novel tool/process that analyzes features of crying and neurobehavior that preliminary evidence has shown may be atypical in infants at risk for autism.

#### Novel Video-Based Approaches for Detection of Autism Risk in the First Year of life

Sally Ozonoff, PhD, University of California at Davis

In this study, the researchers aim to investigate and validate the Video-referenced Infant Rating System for Autism, a brief web-based instrument that utilizes video depictions rather than written descriptions of behavior to detect signs of ASD.

Novel Computer Vision-Based Assessment of Infant-Caregiver Synchrony as an Early Level II Screening Tool for Autism Robert Thomas Schultz, PhD, Children's Hospital of Philadelphia

This project tests a new method of screening for Autism Spectrum Disorders in infancy by detecting alterations in the dynamic social coordination between infants and caregivers during brief, playbased interactions.

#### Development of a Telehealth Screener and Assessment for Infants At-Risk for ASD in Diverse Communities

Meagan Ruth Talbott, PhD, University of California at Davis

The goal of this project is to develop a telehealth screener to assess infants' early ASD symptoms that will improve families' access to specialized screening and decrease the significant wait time for an expert evaluation.

This article has been reprinted from https://www.nimh.nih.gov/news/science-news/2019/nih-awards-funding-for-early-autism-screening.shtml

#### Training from page 14

- **Literal:** Richard is mostly quiet, only giving short, literal answers to direct questions.
- **Special interest:** He usually has a flat affect, but becomes animated when he talks about his passion, baseball.

In the AANE training, Nicole also learned about common characteristics of neurotypical spouses in neurodiverse relationships. While some people with Asperger's marry other people with Asperger's, many of them marry neurotypical partners in caregiving professions.

Nicole noticed neurotypical spouse traits in Tina:

- Very social helping professional: Tina enjoyed teaching children, maintained friendships with coworkers, and enjoys visiting her children and grandchildren.
- Able to express ideas and feelings fluently: In therapy, Tina talks more than Richard does. She not only answers questions I ask her, but tends to answer for Richard. Initially this seemed controlling, but with my shifted lens I realized she was helping Richard communicate. For example, I learned from Tina that when Richard was promoted to the management position at work, he slept poorly and dreaded going to the office. Even though it was difficult for Richard to address his unhappiness with his boss, she helped him ask for his technical position again.

Understand the Impact of Neurodiversity on the Couple

Nicole recognizes that the couple's relationship dynamic is typical for a neurodiverse couple, with Tina speaking "neurotypical talk" and Richard speaking "Asperger-ese."

- They do not share the responsibility of decision making. Richard avoids making decisions, even minor ones like where to have dinner, because he's afraid he'll make the wrong choice. Once Tina makes a decision, Richard gets extremely upset if anything changes, because people with Asperger's like to know what to expect.
- They do not have conversations. Richard likes to spend time alone relax-

ing and focusing on his special interests. He speaks only when Tina initiates a conversation, and even then may give one word answers or not respond at all. Tina says she feels like she is living with a ghost.

- They do not talk about their feelings. Richard can talk fluently about baseball statistics. When Tina tries to talk about feelings, however, Richard is silent or changes to the subject to something factual. He just doesn't seem to know how to talk about feelings.
- They can't seem to get things done around the house even now, when they have both retired and in theory should have plenty of time. Tina asks Richard to help with household chores, but he doesn't do them. He gets confused if asked to do more than one thing at a time, or gets anxious if Tina asks him to do something that would interrupt his usual routine.
- Conflict avoidance: Richard forgets to submit reimbursement paperwork to their insurance company. When Tina asks if he did it, Richard says he did--but later Tina finds out he missed the deadline. Many people with Asperger's fail to understand the future consequences of avoiding conflict in the moment.

Recognizing Tina and Richard as a neurodiverse couple, Nicole adjusted her therapeutic approach and her expectations. She knew progress would take time. She knew that, due to Richard's executive function and communication challenges, she needed to give him concise information and explicit directions. Nicole explained to Richard how his traits impacted Tina. She explained to Tina that Richard shuts down because he struggles to identify and verbalize his feelings; then, when Tina got upset, his anxiety soars and further impedes his ability to communicate. None of this dynamic is due to lack of caring about each other.

Nicole thoughtfully shared with the couple that they *are* neurodiverse, and that because of their neurological differences they really *do* speak two different languages! She started by discussing Richard's Asperger-based strengths with them: his prodigious memory for facts and figures, superior intelligence, and ability to solve technical problems--traits which led to success in his career and a high standard of living for the family. He also cares deeply about social justice and ethics, is faithful,

and wants to make Tina happy.

Next, Nicole pointed out Richard's challenges with social communication, anxiety, perspective taking, and executive functions.

Nicole asked whether Richard and Tina had ever heard the term Asperger's or Autism Spectrum Disorder (ASD) used to describe this perplexing combination of strengths and challenges. As one of their grandchildren was recently diagnosed with ASD, they already knew a little about it. Nicole encouraged them to read first-person stories by people on the spectrum and their family members on AANE's website (www.aane.org).

The idea that they are a neurodiverse couple brought Tina and Richard new understanding of their relationship dynamics, relief, and hope.

Treat for Neurological Differences

Nicole used the tools she learned in the basic course TRAINING 101, and applied them to Tina and Richard's issues, as she had learned to do in the advanced class CERTIFICATION 201. She taught them structured exercises, had them practice a lot during sessions, and gave a short, concrete homework assignments.

- She helped the partners see themselves as members of the same team, develop strategies to support each other, and share practical decisions and tasks so as to minimize conflict.
- She helped Richard understand the effect his behavior was having on Tina and vice versa.
- She taught them communication techniques she had learned in the training, so they could discuss logistics and plans, thoughts and feelings, hopes and dreams.
- She helped them develop a third language, a common language of connection, using numbered scales, code words and other tools, that both could understand.

As Tina and Richard came to understand and appreciate each other more, they experienced moments of real connection. They felt new hope and satisfaction in their relationship, and their level of intimacy increased.

Now More Help is Available for Neurodiverse Couples

Thirty-five therapists have completed

TRAINING 101: Fundamentals of Working with Neurodvierse Couples in Therapy. Therapists who have also completed CERTIFICATION 201: Case Presentations and Advanced Topics in Neurodiverse Couples Therapy have practices in Australia, the UK, Mexico, and many regions of the U.S.A. Neurodiverse couples can search for a therapist on the AANE website: https://www.aane.org/neurodiverse-couples-institute/. Some therapists are able to work with couples remotely.

Neurotypical partners, partners on the spectrum, and neurodiverse couples can also find support through AANE's online groups. See <a href="http://www.aane.org/resources/adults/support-social-groups-couples-partners/">http://www.aane.org/resources/adults/support-social-groups-couples-partners/</a>.

Training in working with neurodiverse couples is available to therapists everywhere. For more information about AANE's NEUROLOGY MATTERS IN COUPLES THERAPY online training see https://aane.thinkific.com/.

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

For more information on Grace Myhill, see https://www.gracemyhill.com/.

A special acknowledgement to Stephanie Loo, M.Ed. AANE Senior Family Support Specialist, for editing.

Grace Myhill is a pioneer and leader in the field of neurodiverse couples therapy. Currently, Grace serves as Director of the Peter M. Friedman Neurodiverse Couples Institute and Director of Couples and Partner's Services at AANE. Since 2004, she has worked with hundreds of neurodiverse partners together or separately in her private practice and through the AANE neurodiverse couples coaching program. Grace offers a variety of groups, in-person and by video conference, for the many facets of this unique population: for neurodiverse couples together, for partners with an Asperger's profile, for neurotypical partners who are currently in a neurodiverse relationship, and for neurotypical partners who are co-parenting with an ex-partner with an Asperger's profile. Grace moderates online discussion forums for the neurotypical partners in a neurodiverse couple and for neurodiverse couples therapists who have taken TRAINING 101. She diagnoses adults with Asperger's/Autism Spectrum Disorder and offers professional consultations for clinicians about understanding and treating neurodiverse couples.

#### Driving from page 23

#### Use Your Community

The third thing to focus on is to use your community. Look into driving schools or find friends in the community that can help. Don't be afraid to ask for help. My father was my primary teacher, but I had friends and other individuals that helped throughout the process. Some helped with improving my parking skills, some helped take me out on the highway, some were

better at explaining the laws, etc. Together using their individual strengths, I became a well-rounded driver. I find that it is a good idea to have different people helping the individual because it allows the opportunity of the individual to have different accounts on their progress. For driving schools, look at the reputation of local areas and ask if they ever had any experiencing teaching people with ASD how to drive. This doesn't mean you have to disclose anything or even give your name—just ask questions. The driving school I

attended was very supportive, and using them gave me access to tools I wouldn't have at home (such as a vehicle that the teacher can also control if something goes wrong, helping alleviate my anxiety). As I discovered, there are many resources that are out there, but hidden away and one must find them. Do your research and ask questions.

#### Summary

Driving is a scary topic in the ASD

world. I do have to say that choosing not to drive at all is a valid choice and there are always different transportation options. Choosing to drive or not will not determine your success or value. It is one of many options, and one that I believe can be attainable with the right tools, team, and community.

Andrew Arboe can be contacted by emailing arboea@planningacrossthespectrum.com. For more information, please visit www.planningacrossthespectrum.com.

## **Autism Spectrum News 2020 Editorial Calendar**

Spring 2020 Issue:

"Supporting Girls and Women with Autism"

Deadline: March 5, 2020

Summer 2020 Issue:

"Siblings and Autism"

Deadline: June 4, 2020

Fall 2020 Issue:

"Supporting Children with Autism"

Deadline: September 3, 2020

Winter 2021 Issue:

"Housing and Community Living"

Deadline: December 2, 2020

To Submit an Article or Advertisement, Contact David Minot at dminot@mhnews.org

College from page 27

#### **Projects**

The essence of the projects are geographic journeys on the Web forming from extensive interactions in learning the interests of the M/HS students, and from the interactions the undergraduate students are formulating the journeys on new personalized sites on the Web.

For example, the journeys are highlighting Asia, including China and Peking and Japan and Tokyo; Europe, including England and Italy; and the United States, including Boston, Massachusetts, Miami, Chicago, Los Angeles and San Francisco, California, for the M/HS students. The journeys to the locales are integrating museums, notable personalities, restaurants, recreations, and sports sites, and further integrating navigational options of transportation virtual tours. The journeys are informed by the interests of the M/HS students that are meaningful to them, apart from the special education teachers and the undergraduate students, such that they are being mostly researched by the M/HS students.

"The products of almost all of the projects, the journeys on the Web sites, are more innovative and more powerful in presentations of the results from both of the students – neuroatypical and neurotypical – involved on the projects than if the projects were only the results of the skills of one of the students," comments Professor Lawler.

The projects are being implemented annually in formal 12 2-hour sessions on Tuesdays and in informal 6 2-hour sessions on Fridays, in both fall and spring semesters of the university. The sessions on Tuesdays are involving 24 M/HS students paired with 24 undergraduate students, and the sessions on Fridays are involving an additional 8 M/HS students partnered with an additional 8 students of the university. The parents of the M/HS students are interfacing with the M/HS on involving the selection of students to be at the university. At the end of the semesters, the M/HS students are presenting their projects to their parents and to the M/HS staff and teachers in the auditorium of the university, and in fact, most of the M/HS students are presenting proudly their sites on the Web without the help of the undergraduate students. The privatized sites are being retained for the M/HS students by the M/HS after the presentations. The projects are being implemented in simplified tools, such as Google Maps, iMovie and Movie Maker, and Wix and WordPress, as in prior years.

These journeys of the M/HS students with ASD are essentially "I am finally here" sites on the Web being implemented by the students of Pace University, who are learning more of neurodiversity now in interpreting the interests and the skills (Baron-Cohen, 2019) of the M/HS students, most of whom they would not likely meet if they were not in this program.

#### Impact of Program

The impact of the program is being indicated in the reflections of the undergraduate students, in that they are indicating the importance of neurodiversity ("neuro-complex" and "neuro-unique" personalities (Muzular, 2018)), not having experienced interactions previously with such a frequently neglected segment of society.

"My experiences in the program have improved my perceptions of students with ASD, as I had no interactions with those with ASD until the program. I had stereotypes of them that were unfounded until the program. I learned a lot about them by talking to them when we were working on the projects with them," comments Elizabeth Byington, a program student at the university.

From the increased experiences and the increased research of these students from resources such as *Disability Scoop*, they are learning that students with ASD have interests and skills like them and are normal ("nothing about us without us" (Catapano, & Garland-Thomson, 2019)), and learning of the possibilities of those with ASD by undergraduate students is powerful in the setting of a university (Schwarz, 2006).

"The program is eye-opening in improving my perspective on the motivations and the skills of students with ASD. I have immense respect for the strengths of my M/HS student to be able to creatively work with me on the projects. I have been impressed the most that the disabilities of my M/HS student were not inhibiting his skills in working with me," comments Brittany

Schneider, another program student at the university.

Importantly, the undergraduate students, most of whom had not met those with ASD until the program, are reflecting interests to be advocates for those with ASD - interests that were not indicated until the program - with disability movement organizations, such as *Autism Speaks*, and sponsorships, such as *Advocacy Fairs* and *Disability Film Festivals* at the university.

Finally, the impact of the program is being indicated in the reflections of most of the M/HS students, as they are learning neurodiversity "not only in imaginative journeying possibilities on the projects, in partnering [with the undergraduate students], but also in improved self-advocacy and self-esteem skills," says Estefania Flores, Transitional Coordinator of the M/HS.

Most of the M/HS students in the program join new projects with new undergraduate students in subsequent semesters of the university.

The impacts of the program in the reflections of the M/HS students and the students of the university are narratives of positive results (Kroeger, & Kraus, 2017).

#### Conclusion

College students can be contributors to the field of neurodiversity. Engaging disability organizations can form a flexible foundation for involving other students with and without disabilities in initiatives of neurodiversity (Kroeger, Kraus, 2017) ("neurodiversity is good when it brings people together" (Muzular, 2018)), as in this program. The model of this neurodiversity program at Pace University, with the AHRC New York City Middle / High School, is definitely an opportunity to be pursued by other non-profit organizations and universities.

Elizabeth Byington is a junior undergraduate student majoring in psychology in the Dyson College of Arts & Sciences, Pace University; James Lawler, DPS, is Professor of Disability Studies and Information Technologies, Seidenberg School of Computer Science and Information Systems, Pace University; and Brittany Schneider is a senior undergraduate student majoring in arts & entertainment management in the Lubin School of Busi-

ness, Pace University.

For more information about the college neurodiversity program as practiced at Pace University, please contact Dr. Lawler at jlawler@pace.edu.

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#### Testing from page 24

Early Identification Could Lead to Earlier Intervention

"These findings add to a growing body of evidence that biomarkers might be helpful in identifying pre-symptomatic infants who are likely to develop ASD or other developmental challenges," says Dr. Lonnie Zwaigenbaum, Professor of Pediatrics, Stollery Children's Hospital Foundation Chair in Autism and Stollery Science Lab Distinguished Researcher at the University of Alberta.

"At this point, we can't fully determine the anticipated severity of a child's future symptoms. What we can say is that it's important to closely monitor their development and start therapeutic interventions early to support their skill development and address emerging functional impairments related to ASD."

The research team has confirmed similar findings in a separate group of 2,110 families having one child with, and a second child without ASD. Their next step will be to look beyond CNVs and determine how newer technologies – like whole genome sequencing – might increase the early ge-

netic detection rate.

You can download the entire study here: www.nature.com/articles/s41467-019-13380-2

The families who participated in the primary study are from the Baby Sibling Research Consortium (BSRC). Additional families that participated in replication testing are from the Simons Simplex Collection. This work was supported by Autism Speaks, Autism Speaks Canada, the Simons Foundation Autism Research Initiative, National Institutes of Health (NIH), National Institute of Mental Health (NIMH), Canadian Institutes of Health Research (CIHR), Canada Foundation for Innovation (CFI), Genome Canada, Ontario Genomics, Kids Brain Health Network. Canadian Institutes for Advanced Research (CIFAR), Stollery Children's Hospital Foundation through the Women and Children's Health Research Institute at the University of Alberta, Ontario Brain Institute, the Government of Ontario, the McLaughlin Centre at the University of Toronto, and SickKids Foundation.

About The Hospital for Sick Children

The Hospital for Sick Children (Sick-Kids) is recognized as one of the world's

foremost paediatric health-care institutions and is Canada's leading centre dedicated to advancing children's health through the integration of patient care, research and education. Founded in 1875 and affiliated with the University of Toronto, SickKids is one of Canada's most research-intensive hospitals and has generated discoveries that have helped children globally. Its mission is to provide the best in complex and specialized family-centred care; pioneer scientific and clinical advancements; share expertise; foster an academic environment that nurtures health-care professionals; and champion an accessible, comprehensive and sustainable child health system. SickKids is a founding member of Kids Health Alliance, a network of partners working to create a high quality, consistent and coordinated approach to paediatric health care that is centred around children, youth and their families. SickKids is proud of its vision for Healthier Children. A Better World.

About the University of Alberta Faculty of Medicine & Dentistry

The Faculty of Medicine & Dentistry at the University of Alberta is a lead-

er in educating and training exceptional practitioners and researchers of the highest international standards. The faculty's mission is to advance health through excellence in teaching, research and patient care. It is home to one of the top 100 ranked medical schools in the world. For more information, please visit www.ualberta.ca/medicine.

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#### Disclosure from page 12

The more that diagnostic closure happens, the more the stigma and misperceptions about ASD continue to be challenged to reflect a more valid and reliable picture of what it means to be an adult with ASD.

#### CONS:

- Research in college settings has found that neurotypical peers do not always understand ASD (Frost, Bailey & Ingersoll, 2019). This finding suggests that diagnostic disclosure might not always yield the desired results if the other party lacks understanding and awareness of ASD.
- There is no way to reliably predict the other party's response to your disclosure. When people lack awareness, they may meet this information with an attempt to understand and be supportive; however, they may also respond with dismissal and disbelief ("No way, you're too \_\_\_\_\_\_\_ to be on the autism spectrum!"). This kind of reply can feel invalidating and frustrating.
- For people who lack understanding, their behavior in response to disclosure might reflect misperceptions of what it means to be on the autism spectrum. For example, a person might respond by treating you in a more childlike manner based on these misperceptions.

**HOW** to Disclose Diagnosis

Liane Holliday Willey (2004) explains that she "chose long ago to have fun with my Aspieness" (p. 181). Liane details several approaches to diagnostic disclosure including hosting a gathering that is an ASD-friendly atmosphere and incorporates sensory awareness; focusing on the facts and communicating the information with this emphasis; use of various forms of writing; or finding an identified ally to disclose the information on your behalf. The takeaway from Liane's suggestions for disclosure is that use of self-awareness and insight regarding your needs, communication style, and knowledge of the other party with whom you are engaging in disclosure are all elements that determine how to go about disclosure. Again, there is no one size fits all, but there are a range of options that might work for reach person. Additionally, as Becca Lory indicates, "the 'how' changes based on the nature of the relationship; you wouldn't disclose diagnosis the same way to a family member as you would to a coworker" (personal communication, December 6, 2018). This is challenging, because there is not a single defining rule or single route to take in terms of how to disclose diagnosis.

#### AFTER Disclosure – Now What?

As Becca Lory, an adult autistic self-advocate, reports, many Aspies engage in the disclosure process, but then lack understanding or awareness of what to do next.

Becca recommends the following steps:

- Remember to Follow Up: You cannot just drop the information and leave it there. The point of disclosure is to access understanding or accommodations, so follow up is required.
- Actually Follow Up: Request your accommodations. Share materials to educate
- Answer Questions: Be open to answering questions about your experience of being on the spectrum. A person can do research, but that does not necessarily mean that they will understand YOUR SPECIFIC needs, challenges, differences, etc.
- Do the Self-Reflective Work: Disclosure is not useful if you have not done the internal work to know what your needs are. Internal work can be different for each person; for some it is meditation, for some it is therapy, for some it is exercise, and for some it is a combination of many different things. But without doing the work, effective self-advocacy cannot occur, because you do not know what to ask for!
- Don't Take it Personally: Disclosure of diagnosis is often new information to that person, and they need time to take it in and respond. It is usually not about you! Keep this in mind as you are going through the disclosure and self-advocacy process.

Ultimately, diagnostic disclosure is a significant component of navigating neurodiverse relationships and doing so has potential to result in benefits for all. Keeping these steps in mind as a starting point will assist with getting your needs met, improving relationships, and more accurately distributing information about ASD to the community at large.

Dr. Cody is a Professional Advisory Board Member for AANE. She can be found via her website www.spectrumpsychservices.com or via e-mail at drcody@spectrumpsychservices.com.

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#### Son from page 21

I always hang up my coat when I get home. I smile when you take selfies with me because you seem to like that. I continue to need your help, understanding, and support in many ways.

#### Fourth - Let Go of Your Anger

You've written about how the loss of the perfect son you dreamed of was difficult for you. You wanted to change me but I could not be fixed or cured. That made you angry. When you were angry around me, it did not feel good. I never wanted to be fixed or cured. It's not my fault that I wasn't the child you were expecting or waiting for. I am the only way I know how to be and like everyone, I am sometimes happy and sometimes sad. You didn't have a clue about how I felt. Once again that was about you because you wanted to fix me.

You finally learned to celebrate what I could do. This made a huge difference for me in our relationship. I was still a young child and it made me feel happier, when you seemed to truly enjoy me and accept me as I am. When you were constantly pushing me to do the things that seem 'typical', I was frustrated and cranky. When you played with me and followed my lead, I laughed and smiled because I felt happy.

#### Fifth - Accept and Appreciate Me

I know everyone has expectations. Please don't make yours too low or too high. When people's expectations of me are too low, it seems like they've given up on me, but I can do things. Yet, when expectations are too high and I cannot reach them, I become extremely frustrated. I have expectations too, you know. As your son, I expect you to love me and hang in



Tariq Naseef

there with me, no matter what. Some of my autistic peers make progress in leaps and bounds while others like me develop very slowly. There is a lot that I cannot do and will never do. While both of us work hard and persist in our own ways, I know that my outcomes did not always match your expectations.

Through it all, I have loved you and you love me. I know that your love for me is unconditional. When you were trying to change me, it sometimes felt like there were conditions. But I see and feel and know now that you love me unconditionally. Despite your best efforts, and mine, I have never learned to speak, read, or write. Thanks to your love and advocacy on my behalf, I live the safest life possible for me in a group home where I can live with support out in the world. I love our car rides and walks in the park when you visit.

These days, when you come to visit, I feel a calmer presence with you which brings me happiness as you have come to balance and live with acceptance and appreciation. Keep up the good work, Dad.

# Going Forward to a Deepening Understanding

Tariq has a cohort of autistic adults who are a growing chorus which contributes profoundly to understanding autism. Trailblazing Jim Sinclair wrote "Don't Mourn for Us" in 1992, https://www.autreat.com/dont\_mourn.html, While some amount of grief is normal, getting stuck there, according to Sinclair "is damaging for both the parents and the child, and precludes the development of an accepting and authentic relationship between them." The real grief in Sinclair's view is not autistic people themselves, but rather that our world

has no place for them (or you can say – does not create space for them. Parents are urged to get angry about that and change this situation

For anyone who wants to understand autism at a deepened human level, listen to and read the advice of autistic adults who are self-advocates, for starters:

- Temple Grandin proclaims that she is "Different but not less."
- Dena Gassner teaches, "You don't outgrow autism, you grow into it."
- Michael John Carley says, "Acceptance is a start not a finish."
- Jennifer O'Toole says "The face of autism is changing. And more often than
  we realize, that face is wearing lipstick."
- Stephen Shore says, "If you know one child with autism, you know one child with autism."

Keep listening to voices of autistic people that, unlike my son, have been able to communicate in ways you can understand, and keep reading the work of the Autistic Self Advocacy Network (https://autisticadvocacy.org/).

Robert Naseef, PhD, is a psychologist and father of an adult son with autism. His latest book is Autism in the Family: Caring and Coping Together (2013) by Brookes Publishing. He can be contacted at RNaseef@altenativechoices.com, and he blogs at drrobertnaseef.wordpress.com.

This article was originally published on November 17, 2019, and is reprinted with permission. The original article can be found at https://drrobertnaseef.wordpress.com/2019/11/17/if-my-son-could-speak/.



### **Greater Hudson Valley, NY, Support Groups**

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

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

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

For more information, visit the website www.aane.org or contact the facilitators: Bonnie Kaplan - Parenttalk@gmail.com | Judith Omidvaran - Judyomid@aol.com

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

This support group, Opening Doors, is now in partnership with the Asperger/Autism Network (AANE). This group is for adults who have an Asperger or similar autism spectrum profile. Learn, socialize and receive support from others who share common experiences. Focused on: Socialization, Mindfulness, Creativity, Self-Advocacy, Health and Well Being, Career Counseling, Relationships and Fun!

For more information, contact the facilitators:

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

#### Self-Determination from page 6

and actively take the initiative to pursue their life goals. This process often involves **self-advocacy** and **self-disclosure**. Young adults must be able to represent their own views or interests which may require them to reveal information about themselves. By recognizing one's unique talents, gifts and limitations, young adults will be more confident disclosing and advocating to attain the necessary support and resources needed to achieve their goals.

The goal is for young adults with ASD to progress through the continuum to the level that they are able to independently self-disclose and be self-determined to reach their full potential. Self-determination embraces freedom of choice and free will, without external control. For young adults to make it to this final step in the "Continuum of Growth" they must be able to demonstrate the following skills:

- Identify, develop and evaluate their own short-term and long-term goals
- Have the motivation to work towards achieving their identified goals
- Promote self-awareness and self-understanding
- Accept individual differences such as talents, strengths, and limitations
- Identify and advocate for resources and support as needed



CIP students enjoy collaborative cooking and learn independent living skills on their journey to self-determination

- Utilize problem-solving and decision-making skills
- Self-represent and appropriately disclose disability when needed

The journey to self-determination can be rocky for anyone, not just young adults with a diagnosis. Each year, CIP supports over 150 young adults with ASD and other learning differences as they

navigate their own path to living self-determined lives. These young adults face the challenges of progressing through the "Continuum of Growth." However, their dedication and motivation results in them achieving their goals.

If provided the right resources, opportunities, and support, young adults with ASD can exhibit self-determined behaviors. They can develop and achieve goals identified, including graduating from

college, obtaining employment and even renting, or buying their own home. We all play a role in aiding our young adults as they take the journey to self-determination. Our role, as supporters, will always be to provide opportunities and empower them to progress through the "Continuum of Growth" as they strive to live their unique independent lives.

Pilar Page, MSW, is the Program Director at the College Internship Program (CIP) in Berkeley. CIP is a national transition program for young adults with autism, ADHD and other learning differences. For information about their five year-round and summer programs across the US, visit www.cipworldwide.org or call 877-566-9247.

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#### Unity from page 4

entertainment, sports, or fashion (although a few autistics do manage to attain encyclopedic expertise in these areas when they are so inclined), finding situations where their talents can be put to use is an accommodation that costs very little yet can actually yield a substantial return, both to the individuals and to their communities.

Other peculiarities, such as sensory issues, can be accommodated with little more than a willingness to allow small deviations from established policies, rules, or norms. It certainly costs far less to provide an individual having sensitivities to certain sounds or visual stimuli with an environment that reduces exposure to such than it does to offer access for those with visual or mobility impairments, yet the latter have become accepted and commonplace in our society. In my own case, I have always had selective eating issues as well as clothing sensitivities. The first requires little more than awareness of its causes and acceptance of my only eating certain foods (mainly those typically found in a "children's menu"). People should not be offended that I do not tolerate many foods that might be served with the intention of pleasing me and, in the case of ethnic cuisine, that this in no way implies any prejudice against that culture on my part or, for that matter, criticism of the server's cooking. The second of my issues requires no more than minor relaxations in dress codes (if that), along with an understanding that I may not always conform to certain clothing styles. Once again, nothing more is needed here than awareness and tolerance of minor differences among individuals.

Issues of communications and social cognition are probably more challenging because they require greater appreciation, on the part of communities and society, of the challenges faced by those living on the autism spectrum. If an autistic person says or implies something deemed as inappropriate or is unaware of something in their social environment that they are expected to recognize, there needs to be complete understanding that this is in no way intentional, let alone done with any malicious intent. Yet again, all that is needed here is greater awareness on the part of the public and tolerance for differences that are relatively minor.

## Divisions Within the Autism Community

One of the greatest and most unfortunate barriers to neurodiversity, in my opinion, is the number and degree of divisions and disagreements that exist within the autism community itself. Among autistics, these are so many and so great that it does not pay to even try to enumerate them. This should not be a surprise, given that autistics are known for having strong individual preferences. These differences involve (among others) issues of treatments, practices, organizations, and many concern neurodiversity itself. This lack of unity can greatly undermine the progress that is desperately needed in moving towards greater acceptance and accommodation of autistics in our communities and throughout society.

Differences are also common among various organizations, all of which exist to serve the interests of the same autistic community. Even when there are legitimate disagreements over specific issues, there must still be greater unity if the needs of autistics are to be met. Also, coming as I do from a scientific background, I strongly believe that everyone in the autism community should support legitimate evidence-based science, as it offers the best hope that we have for attaining real and beneficial results. Ideas and treatments that have been repeatedly discredited need to be discarded by the community rather than defended.

The most significant, and perhaps most tragic, of these divisions, however, is the often hostile one between those concerned for the interests of severely impaired autistics and the community of less-impaired autistics (to which I belong). I find this especially disturbing because, even though there clearly are significant differences between the two groups, their needs are different enough that there should be little if any competition for resources among them. The more-impaired clearly need, by far, the greater share of benefits and services, and certainly should receive them. The less-impaired, however, often need little more than recognition, understanding, and acknowledgment of their condition; accommodations that require nothing more than small modifications of established policies: and services that can readily be provided by existing infrastructures such as school counselors, special-education teachers, and psychologists. In particular, early interventions have been shown to yield the greatest positive results, often reducing and even eliminating future need for benefits or services.

On a personal note, some individuals such as myself managed to "beat the odds" and achieve success in school, in employment, and in life. With some notable exceptions, most of these autistics are generally less impaired, and often succeeded despite not having been diagnosed until much later, let alone received any benefits, services, or special considerations. Many autistics of comparable (and even greater) talent were not so fortunate and had considerable difficulties in school and especially with employment for reasons that are all too well known by all of us, and their needs need to be addressed. The main reason that I identify so strongly with the autism community is that, even with my successes and lack of severe impairments, my eventual diagnosis came about as a result of having so many of the less-severe traits and difficulties associated with autism (sometimes nearly every one appearing on a list of these). Because of my experiences, I believe that there is much that unites the broader autism spectrum and no need for such great division in our community.

If the autism community is to attain the goals of neurodiversity, we will need to be as united as possible regarding the common objectives that we all want to achieve.

Karl may be contacted at kwittig@earthlink.net.

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