

AUTISM SPECTRUM NEWS

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Supporting Older Adults with Autism

By Karen Parenti, MS, PsyD
and Maggie Haag, MEd, BCBA, LSW
Melmark PA

Autism is a lifelong diagnosis, and as adults with autism age, many of the medical, physical, and mental changes they face are similar to those of typically aging adults. As adults with autism get older, it is extremely important for family members and/or professionals working with these individuals to understand the aging process. If professionals and family members learn as much as they can about both the person they support and what to expect as that person grows older, they will be better equipped to notice any subtle behavior or physical changes which may alert them that new interventions are necessary. It is important to note that changing physical needs may require home modifications; changing healthcare needs may require more specialized care; and changing psychiatric and neurological needs, such as dementia, may require constant monitoring.

Life expectancy rates are increasing in the United States, and that is no different for many individuals diagnosed on the



autism spectrum. According to Mukaetova-Ladinska & Stuart-Hamilton (2015), there continues to be much discussion about the limited research available on older adults with autism. In this study, researchers interviewed 45 adults who were either diagnosed with Autism or who pro-

vided care for an adult with autism. The authors found these participants to be deeply worried about the long-term care and management of autism in regards to aging, especially in relation to long-term support in their communities. Additionally, the researchers identified a number of

challenges that older adults with autism face including, but not limited to: social isolation, communication challenges, financial problems, not enough support with personal care, lack of employment options, inadequate health care, lack of housing and lack of advocacy.

Residential Model for Older Adults with Autism

One way to support older adults with autism is by living in residential community homes where care is provided consistently and regularly by qualified direct support professionals, along with a team of other professionals. All older adults with Autism do not require this level of care. However, many older adults need this level of support to navigate their environments and reach their maximum potential. This article highlights how one residential provider offers ongoing support to older adults with autism.

As adults with autism age, their group homes or living environments may need to be modified or adapted to their changing needs. Needed environmental modifications can sometimes be overlooked for

see Supporting on page 10

An Autism Spectrum News Interview with Temple Grandin

By David H. Minot, BA
Publisher
Autism Spectrum News

Temple Grandin has been at the forefront of autism awareness for the past 50 years. She has seen autism unfold from an unknown to a much better recognized diagnosis, yet she is keenly aware that gaps in understanding and unfulfilled priorities remain. This issue of *Autism Spectrum News* is themed "Supporting Older Adults," and so, appropriately Temple shares her unique perspectives as an autistic woman, now in her 70s.

What has surprised you the most over the years regarding autism awareness and scientific research?

Awareness has improved, but I'm concerned about the many young people who come up to me and say that all they want to do is to become autism activists. For me, career is my primary identity and autism is a secondary identity. I wouldn't want to change, I like the way I think but my



Dr. Temple Grandin

primary identity is career. Where people make autism their primary identity, I'm concerned. If I had diabetes, I wouldn't make that my primary identity. It's good to

be aware, but I'm seeing too many smart kids become too focused on the label.

A recent scientific article surprised me: [Genomic Trade-Offs: Are Autism and](#)

[Schizophrenia the Steep Price of the Human Brain?](#) This article basically says the same genes that make our brains big also are involved in autism and schizophrenia. With autism, you get extra growth in the back of the brain, which might account for art, math or music skills, but that then short-changes the social circuits. That paper was a mind-blower to me. Some other interesting studies that have surprised me scientifically, [Solitary Mammals Provide an Animal Model for Autism Spectrum Disorders](#). When you look at animals, some are more social than others. For example, in the big cats, lions are more social than panthers. One of the things I talk a lot about to the public is that autism in its mild forms may be just part of biological variation. Look at Silicon Valley, it is run by people on the mild end of the autism spectrum running fortune 500 companies!

You wouldn't have achieved the level of success in your career without the motivation your mother gave you, pushing you to try new things and discover the world.

see Temple Grandin on page 12

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"Autism and Neurodiversity"
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Spring 2020 Issue

"Supporting Girls and Women with Autism"
Deadline: March 5, 2020

Summer 2019 Issue

"Siblings and Autism"
Deadline: June 4, 2020

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Autism After 65 - Making the Most of the Golden Years

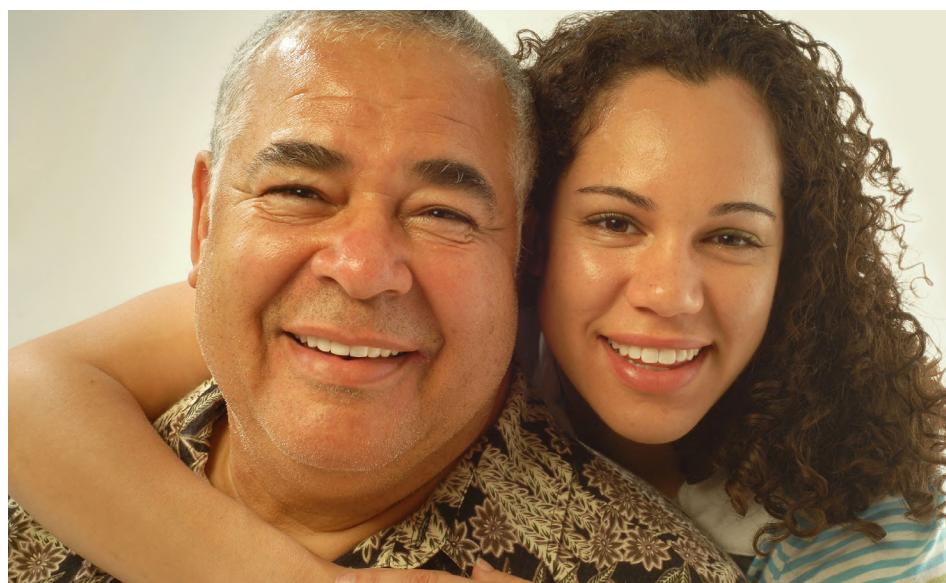
By Susan J. Moreno
Consultant
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For the most part, this article is not based on research. I am using personal life experiences and the reports of individuals with whom I have corresponded and/or personally known for many years through research for my previous book, *The Partner's Guide to Asperger Syndrome*. Many of the subjects covered here apply to all seniors. However, the extent and consequences are amplified when ASD is involved.

Aging is what we all hope for, but are still surprised when the associated challenges occur. There is no existing "list" of challenges for the aging process in individuals on the autism spectrum. The impact of aging, however, can be much more traumatic and/or challenging for the individual with ASD due to less flexibility (physically and mentally), more sensory issues, and decreasing social skills.

Many myths exist concerning those who become senior citizens or what many define as "old age." For the purpose of this article, I will consider senior citizen status as starting at 65. Just a few myths regarding the aging process are:

- Older people are less mentally stable.



- All older people become childish in their behavior and thoughts.

- All older people just want to sit back and watch the world go by.

Due to advances in medical care, people are living longer than ever in recorded history. Along with this, our focus on quality of life as a senior is ever increasing. Now that we recognize the vast number of individuals with ASD, we include them in our concerns about quality of life in old age.

Here are some things that those of us who love and/or care for a senior who has ASD need to do:

- Appreciate the gifts and skills of the older person with ASD. Many have a lifetime of experiences, talents, and expertise that can be shared with others. When they are asked to do this and enjoy the process, their feelings of being needed and important increase.
- Prepare for their eventual loss of skills. It is important for those who are aging and

have ASD to understand that it is perfectly natural to begin losing some acuity in sight, hearing, balance, and flexibility. Finding a caring gerontologist to be part of their care team can enhance this understanding. If they are in situations in which they can converse with others in their age group, it helps them to understand that they are not alone in these experiences.

- Preparing for eventual loss of health is not always possible. None of us can see what may be in store for us in terms of health challenges. Although some genetic testing is leading to more information on future health risks, it may be better to just focus on living a healthy lifestyle and keeping a positive attitude. Maintaining a balanced diet, regular exercise, attending to any medical needs, and seeking counseling and group support when necessary are ways to achieve this.

As the person with ASD loses their flexibility, we must strive to increase our flexibility in our interactions and plans concerning them. Here are some things we caretakers must learn:

- Allow more time for the person's speech processing, both expressive (speaking) and receptive (hearing and interpreting).

see *Golden Years* on [page 22](#)

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The Camouflage of Autistic Women

By Lukas Arnold
auticon

Women are diagnosed with autism 2-3 times less often than men. However, studies indicate that the number of unreported cases of women with autism is much higher than previously thought. Read here why women are so rarely diagnosed and why their daily work can be an immense psychological challenge.

Researchers Uncover Gender-Difference in People in the Autism Spectrum

A team of [researchers from Cambridge University](#) ⁽¹⁾ took a closer look at the compensation strategies of people with autism. People on the autism spectrum often find it difficult to assess social situations and interpret them “correctly.” In some cases, there is even a so-called facial blindness, i.e. the complete inability to interpret the other person’s facial expression. In order not to attract attention, many people with autism therefore develop certain mechanisms to conceal their gap - with devastating psychological consequences. For the continuous observation and imitation of their fellow human beings is associated with great cognitive effort. In this context, the researchers found that women with autism have a much higher discrepancy be-



tween externally observable behavior and inner experience than men. In other words, they can hide their social deficits better than their male counterparts.

Camouflaging in the Social Jungle

The compensation mechanisms described above are also aptly called “camouflaging.” Because those affected often try to hide their autism - for fear of not being accepted. There are several reasons why this becomes a challenge, especially for women. It is a foregone conclusion that

many women are not diagnosed at all in the first place. The majority of existing diagnostic criteria are designed for men. Even general practitioners and psychiatrists still have a widespread myth that autism does not exist among women. Closely interwoven with this is the classic role model of women: from an early age, girls are expected to give others a good feeling of being nice and social. From this perspective, it makes sense that autistic women inevitably develop increased camouflaging skills. A diagnosis, if one is made at all, can take years. One of the reasons is that these

women often learn to assume a neurotypical camouflage in their early childhood.

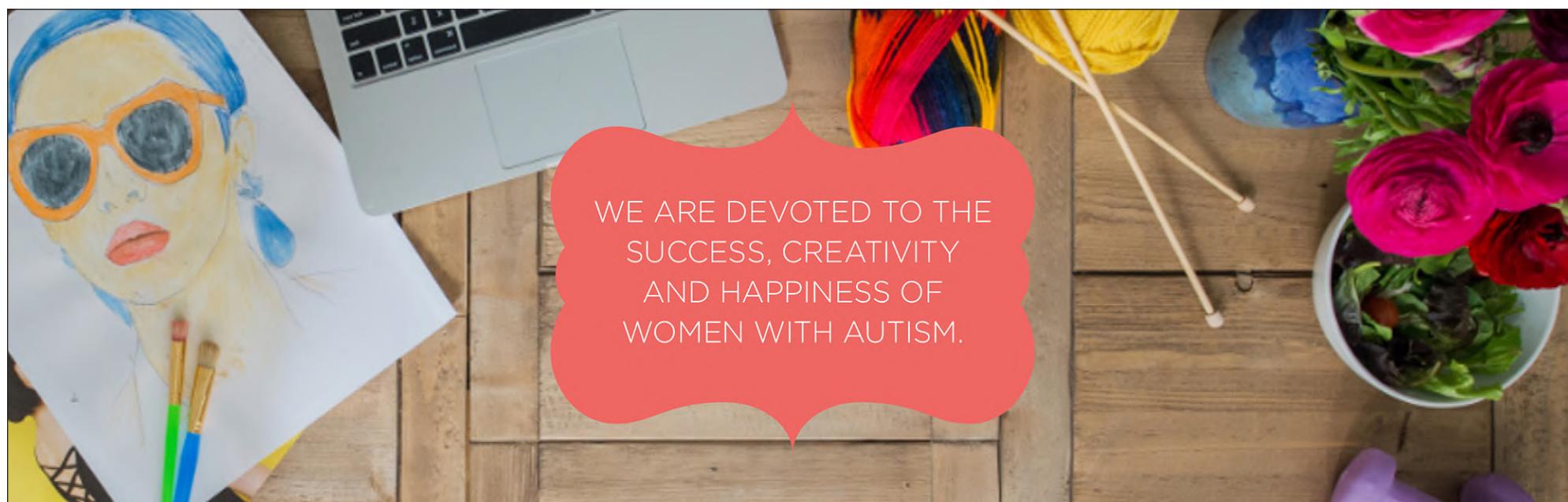
The Strain of Autistic Women at Work

Many people with autism, where unemployment is common among 90%, have great difficulties with the challenges involved. Small talk can be a stressful situation and a handshake can be awkward. It is the social surroundings, the profiling and self-expression with which autistic people have problems, not the work itself. For this reason, they are often unemployed despite their high qualifications.

Especially autistic women are under pressure to correspond to a gender stereotype. Relaxed conversation, understanding and courteous behavior as well as physical clothing are some of the unspoken expectations with which those affected are confronted. In order to master the unpleasant small talk at the coffee machine, many women in the autism spectrum learn corresponding phrases or sentences by heart at home, which they can recall in such situations. Many people with autism are not able to understand the complex social rules and consequently do not want to take part in discussions about the weather, fashion or the latest gossip.

It is also not uncommon to practice certain postures or facial expressions.

see Camouflage on page 24



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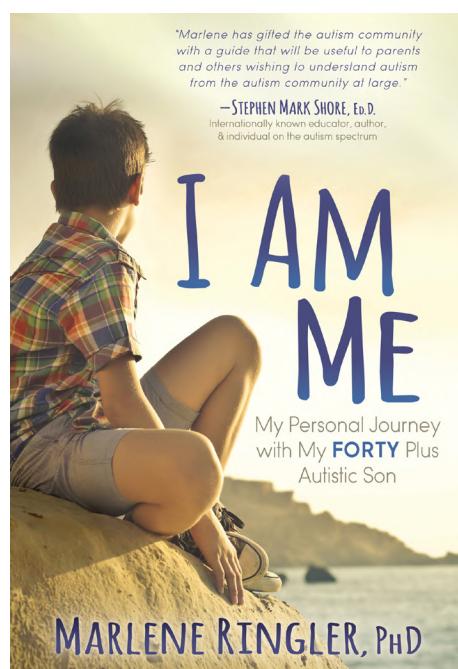


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Best Practices in Support of Aging Adults with Autism

By Marlene Ringler, PhD
Author, Consultant and
International Speaker

The DSM V which was released to the public in May, 2013, took the controversial decision to consolidate the diagnosis of Asperger Syndrome, or High Functioning Autism (HFA), under the umbrella of Autism Spectrum Disorder (ASD). The particularism of Asperger Syndrome had provided a framework with which families affected by an autism diagnosis could think about their children with perhaps a more specific notion of how the lives of their diagnosed children might unfold. In the mid-nineties during the period when there appeared to be increased curiosity about this mysterious neurobiological condition, my son at age 24 received the diagnosis of Asperger Syndrome. As the years passed and he matured, I began to search for more information about autism. But what I discovered was while there was interest in the development of children on the spectrum and discussions about interventions as applied behavior analysis (ABA) pioneered by the clinical psychologist Ivar Lovass, there was scant information about an adult on the spectrum. In fact, the lack of valid statistical data about an adult with autism may explain why lawmakers, policymakers, and decision makers rarely took into ac-



count their special needs (Robison, 2018).

As a Mother of a 45-year-old son diagnosed with high functioning autism (HFA) I live in a state of fear, worry and anxiety about just what will happen to my son when I am no longer around to provide daily guidance, support and love. When I speak at conferences such as the Jerusalem Professional Forum (in October, 2018), an organization of professionals interested in research on subjects related to an autism

spectrum diagnosis, about what motivated me to write my book: *I Am Me: My Personal Journey with My Forty Plus Autistic Son* (released in May, 2018), I describe what may be referred to as a “tsunami” - the nearly 50,000 children in the US alone who each year face an adult world so sadly unprepared to deal with the growing needs of the adult on the autism spectrum. I elaborate by commenting about the lack of empirical research, valid data, and ongoing resources committed to understanding the transition of care needs facing a growing aging autistic population: the senior citizen in our communities who is diagnosed with an autism spectrum.

We know that an increase in the prevalence rates of children diagnosed with autism indicate a trend which is unlikely to be reduced or even slowed down over the next decade (Halladay, 2018). When I was researching and writing my book, the generally accepted prevalence rate was one out of 68 children diagnosed as having an autism spectrum diagnosis. Today, nearly 5 years later, the Center for Disease Control, the federal agency in the US which supports health preparedness, charts the rate at 1 out of 59, a significant uptick in prevalence rates among children. It is interesting to note that global prevalence rates among children are being continuously updated, collected and analyzed; however, the data reflects the growth only among the young. No data to date exists on the

prevalence rate among the adult population though, fortunately, there does appear to be a growing awareness and interest in the subject of the aging adult on the spectrum. After all, yesterday’s autistic child is today’s autistic adult. Temple Grandin, for example, one of the most well-known and respected speakers, writer and advocate for those on the autism spectrum, writes with passion and candor about the obstacles she faces as a professional diagnosed at a young age with autism. Today, in her seventies, she challenges her audiences to think about the multiple and unique needs of the aging adult. Dr. Tony Attwood, too, addressing a Conference in May, 2018, at the Eretz Israel Museum, “ASD/Asperger Syndrome – Aspects of Practice and Research” sponsored by the Israeli Asperger and HFASD Association (EFFIE), laments the current state of lack of reliable research about the aging adult with an autism spectrum diagnosis.

We have seemingly come a long distance from the days when the movie *Rain Man*, released in 1988 and starring Dustin Hoffman as an adult on the spectrum, first brought to the attention of the world the plights and challenges faced by a family affected by an autism spectrum diagnosis. Credited as addressing a taboo subject while raising the level of awareness of what autism as defined in the early eighties

see *Best Practices* on page 26



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Supporting from page 1

these individuals, as many behavioral changes are assumed to be related to the biological factors of the aging process (Baker, Fairchild, and Seefeldt, 2015). However, changes or modifications made to the environment can have a positive effect on some behavioral changes (Baker, Fairchild, and Seefeldt, 2015). Residential providers need to assess the impact of the environment on behavioral changes, as well as assess appropriate behavioral programming. In addition to changing behavioral needs, physical needs for older adults with autism may change as well. For example, gait issues can appear or worsen as individuals age. Previously ambulatory adults may present as more of a fall risk, may exhibit decreased mobility, or even become non-ambulatory. Residential providers should be constantly assessing the accessibility and adaptability of their residential settings. In order for individuals to age safely in their residential homes, the homes must meet the physical needs of the older adults living in them.

This is also true for older adults with autism who live at home with family members or in apartment settings. Assessing the environment regularly is key to successfully supporting older adults diagnosed on the autism spectrum. While making these changes, it is also important to remember to keep the environment as familiar as possible, as many adults with autism enjoy routines and familiarity in their homes and bedrooms.

Highly-Qualified and Well-Trained Staff

There is a tremendous need for qualified and trained staff to work with older adults with autism. Staff who are trained in not only providing care, but in the aging process are better able to help these adults build and maintain skills. Highly-trained staff are essential to ensuring the greatest degree of independence is maintained through the lifespan.

Training of direct support staff in the proper care and teaching strategies for older adults with autism is a very important component of staff training. Training on all important job duties surrounding the aging process, providing personal care, teaching skills, and following behavior support plans should be done using a behavior skills training model (BST). BST includes a verbal description of the skill, a succinct written description of the skill, a demonstration of the skill by a competent trainer, and the trainee performing the skill with feedback from the trainer. This process continues until the trainee is competent with the skill (Parsons, Rollyson, & Reid, 2012). By training direct support staff on all necessary job duties utilizing this model, the residential provider can be sure that support staff are fully competent in the delivery of services. If needed, a provider can access expert speakers or consultants to provide additional training on Behavioral Gerontology or the aging process.

Additionally, residential programs that serve older adults with autism must have a specific model of service delivery for this population. It is of the utmost importance to have a collaborative interdisciplinary approach to care. These interdisciplinary teams (IDT) should include physical therapists, nurses, behavior analysts, psychiatrists, primary care physicians, program



Karen Parenti, MS, PsyD

specialists, supervisory personnel and, of course, the adult served and his/her guardian or representative if appropriate. By working as a team and reviewing the needs of the individual from both a medical and behavioral perspective, all appropriate and necessary interventions can be considered.

Ongoing Assessment by Credentialed Professionals

At Melmark, the ongoing physical and behavioral needs of older adults with autism are assessed and monitored regularly by professionals such as physical therapists, Speech and Language Pathologists (SLPs), nurses, primary care physicians, behavior analysts and psychiatrists.

Physical therapists regularly assess the person's ability to navigate their current environment, and make recommendations for environmental changes to increase safety and independence for each adult served. Since the research is limited on older adults with autism, it is imperative that primary care physicians and nurses assess the ongoing medical and healthcare needs to ensure the individual's current healthcare needs are continually being met. Similar to younger adults with autism, older adults diagnosed on the autism spectrum have difficulty communicating their healthcare needs and may not notice subtle changes.

SLPs can provide support in both feeding issues and communication strategies. The SLP will regularly assess individuals to ensure their current diet is appropriate, and will make recommendations for modifications to diets based on changes with the individual. SLPs also work on goals to promote or maintain communication skills. For example, if an older adult with autism who was previously using sign language to communicate can no longer use that means of communication, the SLP may have that person use an alternate mode, such as an electronic tablet with talking pictures or icons.

Behavior analysts are key to the IDT as they monitor and assess any behavioral changes, and may develop appropriate behavioral interventions, based on the principles of applied behavior analysis. These may include antecedent-based strategies, such as the implementation of a visual schedule for an individual who did not need that type of intervention in the past, and these may also include consequence strategies, such as appropriate reinforce-



Maggie Haag, MEd., BCBA, LSW

ment systems to improve or maintain positive behaviors. Behavior analysts will review data on behavioral changes and make updates to behavioral intervention strategies based on the behavioral data.

Since older adults with Autism may have other comorbid conditions, psychiatrists are an essential part of the IDT as they review behavioral data and medical changes for the individual, making appropriate medication recommendations based on this information. The behavior analyst shares information regarding any behavioral changes, as well as sleep information, and presents all relevant data in graph format so the psychiatrist can observe trends. All medication changes are

discussed with the individual and guardian/representative, as well as presented to a Human Rights Committee (HRC) to ensure the least restrictive interventions are being utilized.

Finally, program specialists along with other IDT and family members develop individualized support plans for the adults based on an assessment of likes, dislikes, strengths and needs, safety awareness, communication skills, medication administration skills, community skills, etc. These program plans include individualized goals to support the adult in skill acquisition or skill maintenance so the person served can continue to grow and thrive. These plans include the assistance and support needed in the community to ensure the person can maintain and/or build relationships with members of the community outside of their direct care team. This level of community integration and inclusion is very important for older adults with autism, as it allows for the highest degree of access to the person's local community.

Summary

Many aspects of care need to be considered when providing residential services and/or support to older adults with autism. While taking care of the person's physical health is vital, ensuring the environment in which they live is accommodating and accessible is just as important. As such, residential providers need to continually assess the environment of their residences in addition to the individuals who live in those homes.

see Supporting on page 20

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Housing for Adults with Autism: A Growing Crisis

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

This article will discuss the need for appropriate housing for adults with Autism. New and emerging programs will be explored. In full disclosure, this writer is the president and founder of Indie Living, Inc., a housing program currently in the early stages of development in New York.

Over the next decade, the CDC estimates that 500,000 teenagers with Autism Spectrum Disorder will age out of their school-based services and move into adulthood. As adults, the need and desire for person-centered housing opportunities is growing exponentially. An estimated 80,000 individuals sit on waiting lists that can be as long as 15 years. The number of individuals on waiting lists is expected to grow as the prevalence of Autism is predicted to increase by 15% over the next ten years. The discrepancy between availability and need is an ever-expanding chasm ([Autism, eParent Connect, 03/16/2018 03/12/2018](#)).

Michael H. is a 51-year-old man who lives with his aging parents. He is my brother and he has Autism. His housing options are limited by availability and appropriateness. It is likely that he, along with 69% of adults with Autism, will continue



Mandy H. Breslow, LCSW, MS Ed.

to live with parents or other family members indefinitely, unless dramatic changes take place.

In 1972, a young reporter named Gerardo Rivera managed to sneak into the infamous Willowbrook State School, which turned out to be, at best, a warehousing facility for individuals with intellectual and developmental disabilities. The reality that was exposed was that Willowbrook was a brutal, abusive and dehumanizing facility that cared nothing for the people who lived there. As a result of this expose, the

process of deinstitutionalization began. When Willowbrook's doors were finally closed in 1987, residents were placed in community-based housing. The options available were group homes, adult homes and supportive apartments. In the 33 years since, these models have not changed, despite the changing and growing needs of this population.

This begs the question: what happened? One theory is the unexpected, dramatic rise in prevalence. According to Science Daily, the rate of children diagnosed with Autism was 1 in 150 in 2000. Current estimates put that number at 1 in 6; nearly double in less than 20 years (Science Daily, 2018). As our understanding of Autism grows, we've become more adept at diagnosing the disorder at earlier ages and have realized that Autism occurs on a spectrum, rather than a static, one-size-fits-all disorder. Agencies charged with the task of providing housing for these adults were overwhelmed and underfunded. Salaries for professional and support staff remained low, further limiting agencies by creating staffing shortages, or hiring under-qualified workers. Rising rates, limited funding and poorly paid employees combined to create the perfect storm for today's housing crisis.

In order to meet the current and future demands for housing, we need to look outside the box at new and innovative concepts in housing models. The government, which has historically funded housing pro-

grams, proposed in its 2019 federal budget a cut of \$763 billion to Medicaid over the next ten years. People with developmental disabilities rely on Medicaid funds to pay for housing, education and vocational training, as do the agencies that provide these services (The Center for Public Representation, 2019). This will have catastrophic effects far beyond the crisis we have now.

Other issues affecting the availability of housing for this population include affordability, accessibility and discrimination. Average rent for a one-bedroom apartment is 104% of the average SSI benefit. This creates a real barrier to individuals in need. Lower income families often do not have the resources to access and navigate the system, which further precludes them from finding housing. Finally, there is the NIM-BY attitude that faces organizations and their participants. The fear and stigma of the disabled block real estate opportunities (Mary E. O'Byrne, Esq. and Stephen W. Dale, Esq., 2019).

In the absence of adequate government support, the private sector has started to step in and create new housing opportunities. The common thread between them is that they are developing programs that address the needs of the whole person. Current models are outdated. Community residences provide a sense of belonging

see [Housing on page 22](#)



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Temple Grandin from page 1

How did that shape you into the person you are today?

As a young child, my mother stretched and motivated me and gave me choices; there was always a choice. For example, I was afraid to go to my Aunt's ranch. Well, if I hadn't gone to my Aunt's ranch, I wouldn't have been in the cattle industry. My mother gave me a choice: you can stay for a week or you can stay all summer - not going was not one of the choices.

What is your view of sensory problems in Autism?

Sensory problems and anxiety are two things that really cripple some of these individuals. For research, I think a priority should be focusing on sensory issues. I often refer to a scientific paper titled [Environmental Enrichment as an Effective Treatment for Autism](#). Sensorimotor Enrichment is an adjunct to other therapies, not a replacement, where you stimulate two senses at the same time, with a lot of emphasis on smell and touch, and you get improvements for sensory issues. This can be done with simple, inexpensive household items like aromatherapy and carpet samples and warm and cold glasses, things like that. I want to work on practical ways to treat sensory problems. Like for example, if a kid is afraid of the vacuum cleaner (this is something I know works, even though it is not evidence-based), you give the kid the vacuum cleaner and let him play with it, where he controls it. Then, instead of being afraid, he now loves the vacuum cleaner. It is important for the kid to control the dreaded sound.

The problem with sensory issues is that they are so variable. In order to do a study, instead of assigning the subject to treatment by autism, you need to assign based on what their primary sensitivities are: Do they have visual sensitivities, touch sensitivities, sound sensitivities? Otherwise you just get a jumble of results that is like the average size dog. Let's say we are going to talk about dogs fitting on airplanes. Yes, on the whole they do fit on airplanes, but how about the Great Dane? That is one example of a dog that is an outlier - that is a subgroup out there that does not do well on planes simply because of their size.

What is your advice to parents who ask you about medications for their child?

A lot of parents and counselors are telling me their kids are so anxious that they can't do anything. Use antidepressants to treat the anxiety and if you get excitation, which is very common, you cut the dose and then it works fine. I have enough practical experience where probably 30 people have told me they cut the dose of the medication and then it worked fine.

Now, I've been on low doses of antidepressants for over 30 years - it saved me. What happens is that they put kids on a drug like Prozac and then they experience excitation as a side effect. Excitation keeps coming up in the literature that I've been reading. I'll tell you what's wrong - they are giving too high a dose. Forget the label, sometimes you need to go lower than the starter dose. I've seen this over and over again. Every time they do a research study,

they just use a set dose. If it's too high, it's a mess when dealing with the anxiety. For years I have been preaching the use of a lower dose - if they experience excitation, lower the dose. I've seen that work over and over again.

Can you comment on early intervention?

In a lot of states, we have a real problem with parents getting early intervention services. In some states, a child doesn't get into early intervention until age 4. In other states, they have early intervention, but when the kid turns 3, they are dropped from the earliest intervention program. All too often, they are waiting a year to get treatment, which is absolutely horrible.

How has your health changed as you moved into your older years? Have you had to make any changes?

I'll be 72 this summer. Well, I don't climb fences anymore, due to balance issues. I have quite a lot of chronic pain. I'm still taking the tricyclic antidepressant desipramine that I've been on since 1980 - I take 50 mgs, which is a starter dose, and I've never stopped taking it. I've heard too many horror stories about when people that were stable went off their meds, like a bipolar medication, and it was a complete mess.

In my early 30s when I started the antidepressants, it stopped the colitis I had. If you watch the movie, I was eating yogurt and Jell-O, and what the antidepressant did is it turned the volume control down on my fear responses and eased the panic attacks I was suffering from. It absolutely saved me, I don't think I'd be here today without it - I would have lost all of my innards to colitis.

I developed Meniere's disease and was losing my hearing about 15 years ago. I was able to get the Meniere's disease into remission - that's when I learned how to really surf the internet and read the scientific literature, so that I could educate myself. If I wasn't a trained scientist, I'd be in a lot of trouble. When I had the Meniere's disease, I had tinnitus which drove me nuts. I just had to find a solution to this and I knew the solution was going to be simple things. I learned this from reading patient message boards. What I did was play a wave machine and some classical music really softly, together at the same time. The tinnitus tuned out because the brain can't listen to three things at once.

I see a commonality in your approaches to addressing problems with simple, low-tech methods.

That's right, I do it because I want to offer alternatives for our low-income families. I have seen students where colored paper has saved college careers. I saw another student where pink sunglasses helped her to get an A on her Economics quiz because the print on the PowerPoint projector no longer looked like it was "jiggling." In this case, I don't care if it is evidence-based or not - you are talking about a \$15 pair of sunglasses saving a student's college education.

I met a woman at a conference who had a head injury and mentioned my book *Temple Grandin's Guide to Working with Farm Animals* because it has pastel paper in it. She looked at the yellow paper and exclaimed, "I can read, I can read, thank you!" Something in her brain caused white paper to make it impossible to read, and

a simple change to colored paper solved her problem. What I say is, if something is cheap, totally safe, takes a few minutes to try it, then yeah, we are going to go ahead and try it. But if something is expensive, possibly dangerous, and takes a long time to see if it's going to work, then I rely on evidence-based proven-effective approaches.

Have the challenges and impact of autism changed for you as you have aged?

I believe that some people with autism get better with age. For myself, I found my thinking got better with age, because as I read more and more, I have a bigger database because I'm a bottom-up thinker. I believe my thinking got better as I got into my 40s, because then you have enough knowledge, and it also gets rid of a lot of the black and white thinking. So, my brain has done just fine with age.

I'm still traveling a lot and keeping myself really busy, because I'd be bored - I have to stay busy.

I do 100 sit-ups every night, which I despise, but the sudden burst of energy they provide helps me sleep.

With depression and mental health issues often co-occurring with autism, could you speak to these issues and their impact in older adults.

In talking with people at conferences, I have been seeing depressed people in their 50s and 60s because the company which they have been employed at all of their lives has shut down and they don't know what to do next.

I would suggest all adults, regardless of their situation, start doing something new that is social.

For someone who is getting close to retirement, I would recommend that they start doing other things, so they have other things to do that they are already involved in by the time they retire. You need to replace the job with something else. In my generation, we had bowling leagues, golf - those are wonderful activities for socializing. Find others that have shared interests to participate with you.

For example, at the Kansas City airport, they've got stores and boutiques there and they have a huge model train exhibit. I bet you the person who's built that is on the spectrum. I look at that and think, somebody's having a good time, and he's probably an older adult.

Some people play video games online, but I think it's important that they get real people-to-people interaction in the activities they choose. Doing things with your church or other house of worship is another option - they can hand out programs and give out food.

Also, there's been some real problems in some older adults who refuse to try medication. I've talked to people who are very anxious about going to their doctor. I've talked some into trying one of the SSRI drugs at a low dose and it has really helped improve their mental health situation.

There is broad sentiment to both fund and provide adult autism services. What do you consider to be the most critical needs and supportive services for older adults?

People need decent health care, that's number one. There are many individuals who

end up on social security disability insurance because they need the health care. I've talked to some who would be happy to give up their SSI check as long as they still had the Medicaid. Without good medical care, I wouldn't be here today.

The other thing is transportation. Some people have health care, but they can't get to the services they need due to a lack of transportation. This is also an issue on getting to social and recreational events.

Transportation is also crucial for jobs. I talked to a very innovative woman in Colorado that has put together great jobs for people on the spectrum. Transportation is her number one issue and they are at the point where they are going broke on Uber cars.

Housing is another issue, we've got so many homeless people on the spectrum on the street. In fact, right now I've been communicating by phone with a homeless man who's autistic. He happens to have a very bad problem with saying inappropriate things to people - when he says them to me I just hang up on him. Well, I'm actually paying for him to stay at an inexpensive motel, so he's stabilized. And he's realizing that he needs to start changing what he is doing. I'm an academic, but I'm also a person out of the construction industry. In construction, you've got to get things done - you have to fix things. It's a very active approach. How can I get this man off the street, what do I need to do with him where I get him quality services that don't cost that much? We're doing quality, we're not putting him up in some slum full of rats, it has got to be quality.

Another issue is medication polypharmacy, where you are taking multiple medications to manage many different health problems. Often times a person is on ten different drugs and maybe they need to be on three. It's a big problem for Medicaid patients. Every time they throw a fit, they just throw another drug at it. All too often, no thought goes into medication management. Why did you start this drug, why are you still on that drug, do you even know about the drug interactions?

What are your hopes for future generations of autistic individuals?

I want to see kids get out there and be everything they can be. I don't want the person that should be doing the high-end skilled trade they love, such as plumbing, electrical, heating, mechanics, and instead, they are in the basement playing video games, I don't want that. These kids are not going into the video game industry, that's just not happening.

If you have a child who is more moderate, some could live in a group home - he could do a simple job. In other words, the attitude is to figure out what they CAN do.

Some of the more severely challenged individuals with autism often have other heavy-duty medical problems on top of autism like epilepsy you can't control, or some other problem. But it's still about figuring out what they CAN do, with less handicap mentality.

Where the parents really get stressed out is when you have an individual whose situation doesn't allow them to do typical activities like shopping, going to restaurants, going to the movies - they can't do with their child. By the time I was five, we were able to do normal activities like that.

see Temple Grandin on page 21

AUTISM SPECTRUM NEWS DESK

Autism Science Foundation Statement on the Use of Medical Marijuana for People with Autism

By The Autism Science Foundation

Medical marijuana is now legal in several states and the District of Columbia. According to the National Institute on Drug Abuse, the term “medical marijuana” means either the marijuana plant itself or one of its many extracts or compounds. Use of the marijuana plant is not approved by the FDA for any medical purpose. However, three marijuana-related compounds (nabilone, dronabinol and cannabidiol) are approved for specific indications.

To date, there is limited research, and no evidence, on the potential short-term, long-term or neurodevelopmental risks and benefits of medical marijuana or its related compounds in ASD.

What Scientists Know

The marijuana plant contains over 100 chemical compounds called cannabinoids. Of these, the compounds of greatest interest are tetrahydrocannabinoid (THC), and cannabidiol (CBD). THC is a psychoactive compound, use of which leads to a



“high” including symptoms of euphoria and memory loss. There are also effects on coordination and perception. CBD is not psychoactive, although it does have effects in the brain. The two compounds can be purchased and used independently of each other. The FDA recently approved a pharmaceutical grade of CBD as a treatment for seizures in two rare, genetically-driven, forms of epilepsy. This pharma-

ceutical-grade CBD, called Epidiolex, is a purified, highly concentrated formulation manufactured under strict safety and effectiveness standards.

The approval of CBD for rare forms of epilepsy has ignited interest in CBD and THC compounds for the treatment of seizures in autism, as well as for the core symptoms of ASD. The widespread use of CBD has generated claims that it is a pan-

acea, and it is now marketed by companies as a treatment for everything from infection to neurodegenerative diseases. There is tremendous interest in CBD with over 100 trials listed on the clinicaltrials.gov registry addressing a wide range of clinical indications. Research centers conducting studies are able to test their compounds for quality, but because CBD is classified by the FDA as a botanical, government agencies have limited oversight regarding the quality of CBD products sold online or in stores.

Why You Should be Concerned

The growing interest in CBD has spread into the autism community. Anecdotal reports tout improvements in anxiety, depression, and restlessness. In the absence of results from well-designed and carefully conducted studies there is no clinical guidance on the use of cannabinoids in people with autism spectrum disorder. For example, there is limited information on the dose schedule, adverse effects, target symptoms or treatment duration.

The psychoactive form of medical marijuana, or THC, has also been used by

see Marijuana on page 19

Using Gene Editing, Neuroscientists Develop a New Model for Autism

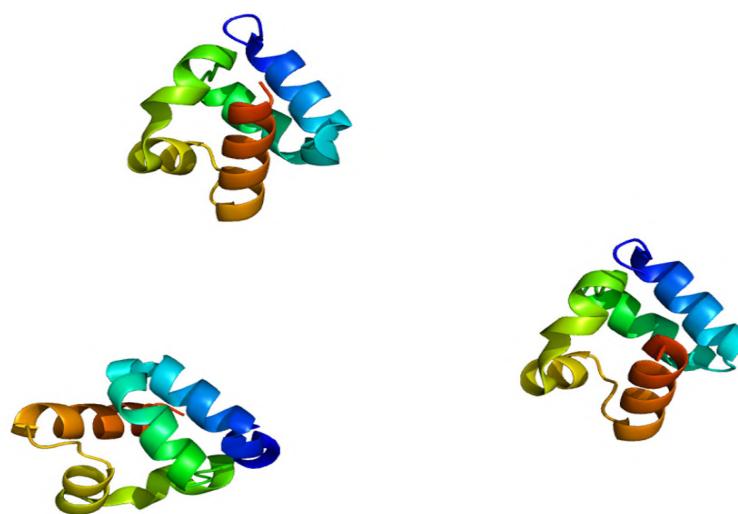
By Anne Trafton
MIT News Office

By introducing a gene variant associated with autism into monkeys, researchers hope to study treatment options for severe neurodevelopmental disorders.

Using the genome-editing system CRISPR, researchers at MIT and in China have engineered macaque monkeys to express a gene mutation linked to autism and other neurodevelopmental disorders in humans. These monkeys show some behavioral traits and brain connectivity patterns similar to those seen in humans with these conditions.

Mouse studies of autism and other neurodevelopmental disorders have yielded drug candidates that have been tested in clinical trials, but none of them have succeeded. Many pharmaceutical companies have given up on testing such drugs because of the poor track record so far.

The new type of model, however, could help scientists to develop better treatment options for some neurodevelopmental disorders, says Guoping Feng, who is the James W. and Patricia Poitras Professor of Neuroscience, a member of MIT’s McGovern Institute for Brain Research, and one of the senior authors of the study.



Credit: Emw, Wikipedia

Structure of the Shank3 protein, a gene with a strong association to autism spectrum disorder.

“Our goal is to generate a model to help us better understand the neural biological mechanism of autism, and ultimately to discover treatment options that will be much more translatable to humans,” says Feng, who is also an institute member of the Broad Institute of MIT and Harvard and a senior scientist in the Broad’s Stanley Center for Psychiatric Research.

“We urgently need new treatment op-

tions for autism spectrum disorder, and treatments developed in mice have so far been disappointing. While the mouse research remains very important, we believe that primate genetic models will help us to develop better medicines and possibly even gene therapies for some severe forms of autism,” says Robert Desimone, the director of MIT’s McGovern Institute for Brain Research, the Doris and Don Berkey

Professor of Neuroscience, and an author of the paper.

Huihui Zhou of the Shenzhen Institutes of Advanced Technology, Andy Peng Xiang of Sun Yat-Sen University, and Shihua Yang of South China Agricultural University are also senior authors of the study, which appears in the June 12 online edition of *Nature*. The paper’s lead authors are former MIT postdoc Yang Zhou, MIT research scientist Jitendra Sharma, Broad Institute group leader Rogier Landman, and Qiong Ke of Sun Yat-Sen University. The research team also includes Mriganka Sur, the Paul and Lilah E. Newton Professor in the Department of Brain and Cognitive Sciences and a member of MIT’s Picower Institute for Learning and Memory.

Gene Variants

Scientists have identified hundreds of genetic variants associated with autism spectrum disorder, many of which individually confer only a small degree of risk. In this study, the researchers focused on one gene with a strong association, known as Shank3. In addition to its link with autism, mutations or deletions of Shank3 can also cause a related rare disorder called Phelan-McDermid

see New Model on page 23

NYU College of Dentistry Honors Marco Damiani, CEO of AHRC NYC, with Kriser Medal

By Dylan Watton
AHRC New York City

New York University's College of Dentistry honored Marco Damiani, CEO of AHRC New York City, with its David B. Kriser Medal, the college's highest form of recognition at the school's 2019 graduation ceremony. Damiani was awarded the medal for "his extraordinary wisdom, counsel, and guidance throughout every phase of the planning and design of the NYU Dentistry Oral Health Center for People with Disabilities."

"It is truly a remarkable day when you receive an award for just doing your job!" Damiani said in his remarks at the ceremony recently. "When I first had the great fortune to meet with the leadership at the NYU College of Dentistry, I quickly saw and felt the passion, professionalism, commitment, and vision for not just providing a world-class dental education, but also for playing a part in creating a better world – in particular a better world for people who are perceived by society as 'different.'"

Throughout his career, Damiani has been steadfast in his commitment to finding innovative ways for people with intellectual and other developmental disabilities to build full, healthy lives as defined by each person with support from dedicated families, staff, and community partners.

The NYU Dentistry Oral Health Center



Presenting Marco Damiani, CEO of AHRC New York City, with the David B. Kriser Medal, are, Dr. Stuart Hirsch, left, Vice Dean for International Initiatives, and Dr. Charles N. Bertolami, right, Herman Robert Fox Dean, NYU College of Dentistry

for People with Disabilities has a number of innovations that set it apart. It is equipped with two sedation suites staffed by anesthesiologists, reducing the need for hospital referrals. It contains a multisensory room for those who may experience overstimulation or anxiety during a dental visit. The center offers a full range of dental services provided by highly experienced and engaged faculty, and a service

vision that underscores dignity, respect, safety, and coordination of care.

Damiani encouraged graduates to meet the ideals that helped build the oral health center. "While a core commitment at NYU Dentistry is to provide the best possible education, there is more at work here: striving to disrupt the cycle of low expectations," he said. "The low expectations of some providers and even academic institutions that

are comfortable either shunning or making token efforts to serve people with disabilities, when they should instead embrace the opportunity to broaden their clinical and academic perspectives and impact on these individuals. You can make a difference by disrupting the cycle of low expectations."

"Marco Damiani has led the way in providing innovative services for the intellectual and/or developmental disabilities community," said Charles N. Bertolami, DDS, DMedSc, Herman Robert Fox Dean of the NYU College of Dentistry. "It has been a privilege for all of us at NYU Dentistry to collaborate with him on behalf of expanded access to quality oral healthcare for people with disabilities, and it is our privilege to honor him for distinguished contributions to improved health and well-being for this large and especially vulnerable segment of our population."

Damiani was recognized along with Larry McReynolds, Executive Director of Family Health Centers at NYU Langone, who was also instrumental in the creation of the NYU Dentistry Oral Health Center for People with Disabilities.

Damiani concluded his remarks by encouraging the graduates to "always do more than what is expected, especially for those not as fortunate as you. Difference is the only thing we all have in common. Difference matters. Make a difference."

Dylan Watton is Communications Coordinator at AHRC New York City.

A Practice Run for Air Travel

By Lynn Uhlfelder Berman
AHRC New York City

Britney Lopez would not let go of her tablet before going through security at Newark Liberty International Airport as part of AHRC New York City's Wings for All® event.

Maria Aviles, Britney's mother, expected this would be as far as her daughter would go during a dress rehearsal for air travel on Saturday, May 18. But with a little coaxing and patience, Britney got through security and smiled with her tablet in hand as she boarded the United Airlines jet with her family. Britney, a 16-year-old with autism spectrum disorder (ASD) who attends AHRC Middle/High School, sat calmly on the plane tending to her tablet.

"Just a Special Experience"

Nearly 30 families participated in Wings for All®, hosted by AHRC NYC, The Arc, United Airlines and the Transportation Security Administration. Many parents admitted being nervous, not sure what to expect. But United's employees went out of their way to ensure this would be a smooth flight, even though the plane never left the gate. United volunteers cheered young passengers and their families as they boarded



Joanne Furstman with twins Teddy and Nicky settled into their seats

the plane. This was AHRC NYC's first Wings for All® in New Jersey. New Jersey has the highest rate of autism with one in 34 children; the national rate is one in 59.

Parents of young and adult children with ASD and other developmental disabilities have numerous concerns about traveling on a plane. How will their child react to the airport lights, crowds, and waiting in line? Will they be comfortable with airport security officers talking to or touch-

ing them? How will the engine noise affect their child?

United Captain Mike Neff met passengers as they waited at the gate. Once on board, he reassured Tom Wu and his wife, Zoe Zhang, that their son Eason, two-and-a-half-years-old, who was crying, would be OK. Eason calmed down once his parents showed a video on a phone and sang along.

"This was fantastic, uplifting, eye opening and just a special experience," Capt. Neff said.

Rewarding for Families

Wings for Autism®/Wings for All® also gives airport, airline, TSA professionals and other personnel the opportunity to observe, interact and deliver their services to people with disabilities in a structured, learning environment.

"Partnerships like this can remove barriers to travel for people with autism and other developmental disabilities and their families," said Marco Damiani, CEO of AHRC NYC. "This practice run makes a huge difference. We are empowering families, while educating and sensitizing airport personnel to the unique needs of people with developmental disabilities and their families."

John E. Goodson, Assistant Director, Educational Services & Program Develop-

ment for AHRC NYC, has seen the impact the programs have on families, having coordinated seven Wings for Autism®/Wings for All® events. "It's rewarding when you see families immediately book that trip they always wanted to," John said. "They become an airline's loyalist for life. They know this airline will support them."

While this was the first time many of the young passengers had been on a plane, they were all smiles as the flight attendants came around with snacks and beverages.

"We're Going to Fly to Disney!"

"Every customer deserves to enjoy and be comfortable throughout their travel experience and working with The Arc helps us ensure that thousands of families across the country feel welcome when they travel with United Airlines," Jill Kaplan, United's President of New York and New Jersey. "We are thrilled to bring this opportunity to Newark Liberty International Airport, our New York/New Jersey hub."

Maria Aviles was thrilled with the experience. "Britney did awesome, so we're going to fly to Disney! I'm excited," she said. "She liked it so much she didn't want to get off the plane."

Lynn Uhlfelder Berman is a PR/Media Relations Consultant for AHRC New York City.

Breaking Down the Barriers of Social Communication for Young Adults with Autism

By Braden Winslow, BA
and Samantha Feinman, MEd, TSHH
New Frontiers in Learning

The transition from adolescence to adulthood is an important and transitory juncture in the lives of modern young individuals. This exciting and oftentimes anxiety-inducing time brings with it a host of challenges: increased independence, heightened self-awareness, the taking on of more personal responsibilities, and a marked change in the expectations or practices of social engagement. This last area, however, potentially poses a greater threat to the development of positive self-identity for young individuals with Autism Spectrum Disorders (ASD) and related learning differences, as the pressure to navigate changing and varied social contexts yields many opportunities for, colloquially, putting one's foot in their mouth or engaging in a manner unbecoming of expected social practice. As Volkmar, Reichow, and McPartland note, "research does suggest that having good social skills and adequate social support relate to better quality of life in adults with ASD" (2014, pg. 64). Thus, it is important to consider how support systems can help supplement this crucial developmental opportunity by providing



Braden Winslow, BA

scaffolding for individuals to allow them to find social success beyond the scope and relative safety of their social program.

The effects of ASD-related social pragmatic deficits can play out in several ways, including lagging skills in social communication, social cognition, and the recognition or understanding of social cues. These can manifest in equally disparate ways person-to-person, from an individual talking



Samantha Feinman, MEd, TSHH

about only the topics that interest them, dominating a conversation and not allowing space for reciprocity, to apparent obliviousness to the interest levels of the other conversationalist(s) involved in an interaction. Breaking down these barriers of communication for young adults with ASD, while still encouraging growth, requires a balance of pushing individuals outside of their comfort zones, establishing accept-

ed boundaries for conversation, and using perspective-taking opportunities to draw attention to the response yielded by certain rhetoric or conversation topic. These approaches are only a small sample of strategies used by support networks to foster an individual's growth in their social skill set, but any utilized tactic for most situations should take care to be applied in a manner that seeks to meet the student where they currently are skill-wise, as opposed to attempting to fit square pegs into round holes. It is more advantageous for support networks to try and develop a positive self-identity for the individuals being supported as the starting point from which they achieve the desired social growth. Hence, this skill development should typically aim to be ecologically valid in its approach, concerning "those behaviors that are naturally exhibited by socially accepted adolescents or adults in a given social context" (Volkmar, Reichow, & McPartland, 2014, pg. 66). In so doing, support networks for ASD-related individuals strive to bolster the development of social communication in a way that doesn't negate or erase the importance of the individuals' self-identity, but establishes certain patterns of social behavior as existing closer to what we consider "typical" or "expected," which

see Communication on page 24



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Older Adults on the Spectrum Face a Variety and Number of Major Challenges

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

In spite of being fortunate enough to have avoided many of the challenges presented by aging on the autism spectrum, I nevertheless feel that I am in a position to write about these as an older adult on the spectrum who recently became a senior citizen. I was already a middle-aged adult (age 44) at the time of my initial diagnosis, and have since been involved in a number of areas concerning older adults and autism. In particular, I served on such initiatives as AFAA (Advancing Futures for Adults with Autism – www.afaa-us.org) and AASET (Autistic Adults and other Stakeholders Engaged Together – www.autistichealth.org, which deals with healthcare issues), in addition to attending and facilitating support groups for older adults over nearly a decade.

Aging presents numerous and varied challenges for many in contemporary society, but for older adults on the autism spectrum, these can be far greater and more significant. They can involve financial support, adequate housing, long-term care, daily living assistance, healthcare and health insurance, and finding viable communities, among other things. In many instances, the outlook is nothing less than



Karl Wittig, P.E.

dismal. Beyond the well-known limitation that, in most states, benefits and services for autistics end upon reaching adulthood (usually at age 21), many autistics are never able to live independently and depend on caretakers for most if not all of their lives. If these caretakers are parents or other older adults, they will find themselves without means of support or assistance with daily needs when their caregivers are gone. This is certainly true for more-im-

paired autistics who lack daily living skills, but can also affect less-impaired individuals who are nevertheless dependent on others because they were never able to find gainful employment; I have personally known a few with genius-level IQs for whom this is the case. Such autistics can find themselves in dire circumstances as middle-aged adults, even before they are senior citizens.

All of this is further complicated by the fact that, since there was virtually no public awareness of autism in their earlier lives, the vast majority of older adult autistics were never even identified, let alone diagnosed. This is true of almost everyone who was an adult by 1994, when the autism spectrum was expanded with the release of DSM-IV in which the new diagnoses of Asperger Syndrome and PDD-NOS were introduced. As such, it would be very helpful to identify older adults, especially senior citizens, who are on the spectrum so that their challenges can at last be properly addressed (that already being a “tall order” in our society). Because adult diagnosis of ASD is generally very difficult, and becomes even more so as a person gets older (since they have either “aged out” of some of their symptoms and behaviors, or else developed more and better coping mechanisms to mitigate their challenges), this presents a substantial problem for society as a whole which will need to somehow be addressed.

Health and Healthcare

Probably the most significant difficulties of aging involve the general decline in health to which all of us are susceptible. As we get older, we generally develop a wider variety of health problems, many of which require specialized care or treatment. Given the state of healthcare in the U.S., access to needed services is becoming more and more difficult for many. Whereas most health problems that affect younger adults are fairly routine and readily treated by primary-care physicians or in “walk-in” clinics and similar establishments, older adults are more susceptible to less-common problems that can only be treated by medical specialists with more extensive training and, especially nowadays, access to more advanced equipment and facilities. In the past several years, I have needed no fewer than three significant surgeries (prostate, sinus, and hernia – the first of these for a potentially life-threatening condition), and as such can speak to the reality of this situation. Access to such providers and services is often much more restricted than it is for routine medical care.

All of this is greatly exacerbated by the exploding complexity of our healthcare provider and insurance system, which becomes more and more difficult to navigate with every passing day. First of all, a patient

see *Challenges on page 22*

Youth on the Autism Spectrum: Jobs, College and BEYOND

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Housing from page 11

and acceptance in a communal living environment. However, they offer little in the way of independence. These programs are generally reserved for individuals with more significant needs. Supportive apartments offer varying levels of independence, but very little opportunity to be a part of a community. Newer housing models understand that in order for an individual to reach their fullest potential, they must incorporate community and independence into one program.

Disabled people need more invested in their education, housing, job training, transportation, assistive technology, and independent-living facilities. Governments earn back this investment - and more - by making people with disabilities economically productive citizens.

- Jesse Ventura

There are programs opening up throughout the country to address this need. Programs in California such as The Mission Project, Camphill, Sweetwater Spectrum and Legacy Homes are innovative models that seek to provide a person-centered alternative to typical housing. In other states, similar ventures are shaping the face of housing. In Arizona, Florida, Colorado, District of Columbia, Utah and New York, programs are also opening up. Many of these are already full, while others are still in the development process. The common goal is to allow adults with Autism to live full lives, while integrating into their communities.

Aside from the social and moral imperatives to create housing opportunities, there are financial benefits to it as well. Typically, the average cost to place and care for someone in a group home is approximately \$90,000 to \$140,000 per year. Independent living programs with on-site and community supports could save tens of thousands of dollars per year per person (Josh Kovner, Hartford Courant, 2018). This frees up resources in order to service more people for the same cost rather than operating at a deficit, or worse, leaving many sitting on waiting lists and causing economic hardship on families. In a report issued by Autism Speaks, it costs families an average of \$60,000 per year to care for a child with Autism. The majority of this cost is accounted for by the lost wage potential involved in providing care for the child (Autism Speaks, 2017).

With the clear economic, social and societal benefits of new and expanded housing communities for adults with Autism, why does there continue to be such a gap in need versus availability? While some of those theories have been discussed in this article, it remains clear that there are many factors that converge to create the current crisis we in which we currently find ourselves. And in order to meet the growing demands of a growing population of adults with Autism, we, as a society must step up our game while we embrace and support new housing initiatives that strive to create a more independent, self-determined and integrative life

see *Housing on page 22*

Why Autism Parents Say: “I Can Never Die”

By Susan Senator
Author, Journalist, and Public Speaker

The caregiving workforce shortage is and will be a crisis for so many Americans. “I can never die.” This is the rallying call of autism parents everywhere. Why do we feel that way? Because many autistic adults live with their parents—85%, according to autism researcher Peter Gerhardt. Autism most often comes with severe social deficits—a sometimes profound difficulty navigating the ways of people, the gray areas, yet so many do not get adequate care outside of what their parents can give. The parents are all they’ve got, the last protection in a very demanding, complex world.

Even autistic adults not living with parents, with lots of supports, face tremendous difficulties. Three years ago, my own adult autistic son came home from his supported living and day programs for a visit, with a fist-sized bruise in the middle of his chest. He has profound communication issues, so we could not learn how this happened. An X-ray revealed one set of broken ribs, in addition to an older, healed injury. My son, unfortunately, is one of many developmentally delayed adults who has been abused by someone in his community. Abuse by caregivers is rampant in the disability community. Across the country, according to NPR, “People with intellectual



Susan Senator

disabilities are sexually assaulted at a rate that’s seven times that of people without disabilities.” In the same story, one physician in New York City “has a practice just with people with intellectual disabilities. [This doctor estimates that] at least half the women that she sees have been the victims of sexual assault.”

Let’s face it: The world is just not ready for the droves of people who need—or who will need—intensive personal care in

the future. Reuters columnist Mark Miller interviewed MIT Sloan School researcher and author Paul Osterman about the caregiving workforce shortage. Miller quotes Osterman’s research: “in 2030 there will be a national shortage of 151,000 paid direct care workers and 3.8 million unpaid family caregivers. By 2040, the shortfall will be much larger: 355,000 paid workers, and the family and friends shortfall will be a shocking 11 million.” This severe deficit of care providers is because so many needy different populations are emerging at once. Another factor: new draconian immigration policies that reduce the potential workforce. And finally: the workers are generally paid minimum wage or less, despite having incredibly difficult jobs. The same Reuters piece Osterman says, “Caregivers earn very low wages - median income for CNAs in 2015 was \$20,000, and home care aides earned a median of \$15,000, according to Census data.”

There are often problems of oversight and staff shortages in residential settings and day programs. Again, funding is very thin, and so the ratios of caregiver or job coach to individuals can be inadequate. Poor supervision can lead to bad treatment or neglect.

What are parents like me to do to protect our disabled loved ones? How do we learn to trust caregivers if there is so much abuse out there? Often hidden cameras are not allowed, and even if they are, abuse captured

on video may not end in conviction. One parent in Massachusetts, Paul Joyce, has the evidence of his son being repeatedly beaten, on camera, and yet those responsible, even though found guilty, were given 18 months’ probation and “ordered not to work in this field again,” according to Joyce. The other perpetrator was simply ordered to write the Joyces a letter of apology.

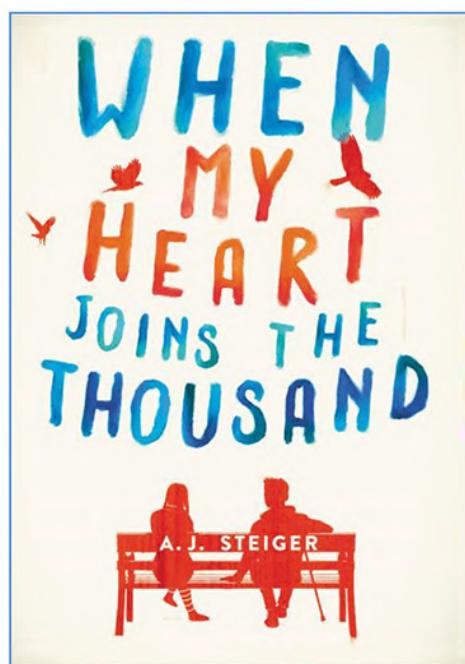
It is no wonder that the Joyces and a similar family, the Chans, have come together with many Massachusetts legislators to push for “Nicky and Dana’s Law,” which aims to create a registry of abusers, so that they may not be hired again in the field. Despite strong legislative support, the bill failed last session but is even more strongly supported now.

Parents like me are desperate to see laws like Nicky and Dana’s Law passed, at very least. But what can we do to prevent the abuse in the first place? I am a vigilant and very involved parent in my son’s life. I have made sure that all of his staff know him and me, and I’ve tried to connect with them and give them presents at the holidays, and also lots of support. I often take my son home for weekends to give more respite. But still, my son was injured. More than once.

My idea? Aside from funding caregiving jobs much better and dignifying the profession with licensing and training—

see Parents on page 26

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“Nutjob.” “Weirdo.” All of her life, 17-year-old Alvie Fitz has dealt with name-calling. This novel presents readers with a fully developed picture of a person with autism; she’s frank, observant, and funny. This is a gorgeous love story of depth and raw emotion that beautifully dismantles the ugly perceptions of autism.

Kirkus Reviews

This is one of those books that upon finishing it, I hugged it tightly to my chest. It was movingly beautiful and painfully heartbreaking.

Goodreads reviews

Alvie Fitz is a girl who loves animals. It’s people she has trouble with. Because of her unusual mind and way of thinking, some people tell her that she’s “on the spectrum.” Others just call her odd. As a result, she’s always considered human contact overrated — until she meets Stanley, a boy just as unusual as she is.

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Supporting Pioneers: Building Better Networks for Adults Aging with Autism

By Caitlin E. Coyle, PhD
and Danielle Waldron, MS
Gerontology Institute
University of Massachusetts Boston

Although traditionally understood as a childhood condition, autism is a lifelong disorder that presents in both children and adults. Many of the children with this disorder who were born during the last century and who are now reaching mid- and later-life did not receive formal diagnoses of autism. Further, increases in human longevity and the aging of the largest birth cohort (born between 1946-1964) in our nation's history suggest that although prevalence rates of autism remain around 1% of the population, the sheer numbers of these adults stands to increase dramatically in coming years.

These adults on the spectrum who live much or all of their lives without diagnoses, often struggle to develop their personal identities. Due to their difficulties with communication and relationship development, they work tirelessly to manage their disorder in order to assemble lives that include stable employment, intimate social relationships and families. As one adult aging with autism describes (his or her) life without an autism diagnosis, "...something basic was missing: Not knowing how to think about and appreciate ourselves."



Caitlin E. Coyle, PhD

We interviewed 30 adults over age 50 living with autism. From these life-course interviews, we uncovered significant barriers to successful aging that were related to social isolation. Seventy-three percent were unmarried, 50% lived alone, and we heard from many that friendships were few. As one adult with autism explained, "I don't know if I have close friends. I wish I did. I just have a hard time with crowds and I don't really know how to socialize. I don't really know how to make friends."



Danielle Waldron, MS

Additionally, challenges with relating to others and communication barriers resulted in varied work histories leaving these older people with financial consequences. An adult with autism shared that, "at one point, I lost my job and she lost her job. We just experienced this hideous, you know, financial insecurity." Individuals aging with autism also had regrets about their contributions to society, at least in part, attributable to issues with socialization. This sometimes manifested in underemploy-

ment despite high educational attainment; one woman with autism expressed, "I've been terrified of interviews. I've applied a couple places and oh my God, stress." She decided to remain in her current job, which was outside the scope of her graduate studies because it "felt more doable than meeting all the new people and stuff" at a new job. Given these consequences of social isolation, it was not surprising that the importance of nonprofit organizations, service providers and other structured social environments was revealed in these interviews. An older woman with autism shared that she was moving closer to her temple, stating, "I didn't find where I was living before very supportive. And I knew, I knew, I just knew there is a smaller community at the temple, a smaller temple that I feel like I would get more support and have more enjoyment with."

For adults with autism, getting older means an accumulation of limited social networks and the aging of their own family system (i.e. frailty or death of parents and siblings), housing instability, and financial insecurity due to varied work histories. Although many adults with autism live independently, many live without strong social relationships and persons on whom they can rely for support. Thus, a network of community organizations that provide information about available

see *Building on page 24*

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Challenges from page 16

having an unusual condition must be referred to the appropriate specialist. This does not simply mean the correct medical discipline (cardiology, gastroenterology, urology, etc.), but the precise specialty within that discipline; in modern medicine, this often is so specialized that identifying the appropriate provider to which a patient should be referred is not always trivial. To make matters worse, the health insurance industry has created a byzantine system of provider networks so complicated that it can be very difficult to determine if a provider is currently in your health plan. All of this can be daunting for just about anybody, but it is nothing less than a nightmare for autistics who usually require some semblance of systemic order, along with specific information, and the current system often provides neither. Clearly, this is a substantial problem even for autistics fortunate enough to have adequate health coverage (I purchase insurance from my state healthcare marketplace); for those not so lucky, the situation is dramatically worse. Most autistics will need considerable assistance with this problem.

As for maintaining good health, there are areas where common autistic traits may actually be used to good advantage. In particular, autistics are often very diligent at following instructions precisely and like

to maintain regular routines. If they can be successfully instructed in maintaining good health habits, there is a good chance that they will actually do so, as long as these are adequately taught (along with reasons for their significance) and compliance consistently encouraged and subsequently ascertained. In particular, following the instructions of medical providers precisely, which is essential to good outcomes in many situations, is something that many autistics will have little or no difficulty doing. The same holds for the management of medications: so long as they are explicitly told which ones to take, at what times, and in what doses (along with explanations of their purpose and importance, when appropriate), many autistics can be counted on to do so, and quite diligently.

At the same time, some aspects of health can often be more problematic for autistics, especially when they involve changes in long-held habits (which autistics famously have great difficulty with). One such case is with nutrition. Autistics often have poor eating habits for any number of reasons; in particular, many have very selective (as is the case with me) or otherwise peculiar food preferences which they will not deviate from, or at least will resist any attempts to change. While this may not be the case for most autistics, it is more common than most people realize

(I once attended a workshop on this issue for which the room was filled to capacity). One result of this is that excessive weight and obesity are very common in the autism community. When bad health habits cannot be changed, they should at least be managed such that the least harm can result. In the case of nutrition, this can be done by working within limitations to make the best choices possible, and perhaps use supplements to compensate for deficiencies in essential nutrients.

The Need for Community

As do most older adults, autistics have need for and greatly benefit from being part of a community. Unfortunately, they often have greater difficulty relating to contemporaries than do more typical adults. For these individuals, specialized interests and abilities can be of help – perhaps an unusual talent is of value to a wider adult community (e.g., electrical or mechanical repairs, computer help, categorizing items, preparing tax returns, etc.), in which they will thereby be more appreciated. An "obsessive" interest may also serve a similar purpose, if they are introduced to other adults that share that interest. Needless to say, these interests also serve as activities and hobbies for autistic adults to be engaged in.

One thing that may significantly help the

older autistic population is the availability of support and social groups. The idea of a peer-run support group for seniors on the autism spectrum was proposed in 2010 as an initiative of the Daniel Jordan Fiddle Foundation for adult autism (www.djfiddlefoundation.org) and instituted by GRASP (www.grasp.org). It started out as a group for 60+ adults facilitated by an older person on the spectrum, but the minimum age was soon lowered to 50 because of very low attendance (few individuals in the older age group had been diagnosed or identified) and to be consistent with the AARP age requirement. More recently, Aspies For Social Success (AFSS – www.nyautismcommunity.org) in New York has also offered an older adult group (with no formal age limit). I strongly believe that such groups, both support and social, and either professionally facilitated or peer-run, need to be made more widely available because they provide perhaps the only opportunities for older adult autistics to share about their challenges with others who have faced similar ones as well as socialize with those who perceive and process the world in a manner similar to their own. I have both attended and helped organize and facilitate these groups and, as with all other support and social groups, found

see *Challenges on page 22*

Five Tips on How to Best Support a Sibling of a Child with ASD

By Marlene Cuevas, LCSW
and Nicole Hadley, CCLS
The Center for Autism and
Neurodevelopmental Disorders
UCI School of Medicine

Being the sibling of a child with autism spectrum disorder (ASD) and other medical or developmental diagnoses can have its challenges, but it can also provide opportunities in building resiliency and compassion towards family members and others.

The Center for Autism & Neurodevelopmental Disorders had the unique opportunity to facilitate a 6-week sibling support series and have found both positive and negative impacts are shared among the siblings of children diagnosed with ASD. On the positive side, when siblings have the opportunity to form stronger connections and improve relationships with their parents or caregivers, they demonstrate increased empathy, an awareness of differences and resiliency. Alternately, some of the obstacles siblings shared were frustration, embarrassment, isolation, and lack of attention from parents to the siblings' needs. Here are five tips for parents on some approaches that can support a sibling of a child with ASD:

1. Connect in Shared Language: We encourage parents to make time with



their children to talk about their concerns, validate their emotions and find healthy ways to express them, like connecting with others who share in similar experiences. It is important to remind children that they are not alone and that every family is confronted with life's challenges.

2. Explain the Diagnosis: As parents, it is important to assess what your child understands about his or her sibling's diagnosis. Clarify misconceptions and explain what ASD is, the impacts ASD

can have on behaviors for the child with the diagnosis, as well as the impact the sibling may experience.

3. Understand that Different Age Groups Have Different Needs: As children develop, their understanding and needs will change. For example, preschoolers are going to be more observant of how the diagnosis will immediately affect them. Since some children can feel levels of guilt thinking they caused the sibling's autism, it is beneficial to acknowledge their fears

and explain they are not responsible for the disorder.

4. Create Open Communication: Information is the key component in supporting siblings and helping them cope with having a brother or sister with an ASD diagnosis. Incomplete information may create fantasies that are often worse than the real situation. As parents are coping, siblings are too. Parents and other caregivers should acknowledge that siblings could have the same concerns and worries as them. Limiting the amount of information provided will only lead to more misconceptions. Communicate information about the diagnosis as much as possible.

5. Provide Emotional Support and Coping Techniques: Siblings may experience an array of emotions. Caregivers and parents should focus on helping siblings express these emotions in a healthy manner. For example, stress balls, yoga, talk therapy, support groups and approaches that support each sibling's unique perspectives, experiences and needs.

Parents who had their children participate in The Center's 6-week sibling support series felt it was an overall positive

see Sibling on page 24

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Marijuana from page 13

families in the autism community. When Colorado legalized recreational marijuana there were reports of families moving there to obtain it legally. There are many known adverse effects of THC, such as increased anxiety, psychotic thinking and cyclic vomiting. Because of its psychoactive properties parents should be very cautious about giving THC to their children. It should not be smoked, as there is evidence that smoking marijuana is linked to lung cancer. Some parents have reported giving their children THC-containing "edibles". However, THC may have serious side effects in children and should be ingested only under strict medical supervision.

Before you decide to embark on any new drug treatment for yourself or your child, we highly recommend you talk to your

doctor and ask about potential benefits and risks based on your own or your child's medical history with a full understanding of both evidence-based and non-evidence based treatments for ASD. Parents and autistic adults should carefully consider the costs, risks and benefits of a drug that has not been proven effective or safe.

What Should Be Done
in the Future of Research

Autism Science Foundation strongly concurs with the American Academy of Pediatrics and urges further study on the safety and efficacy of medical marijuana in ASD and other conditions of childhood. While the FDA has eased some regulatory requirements to study CBD, the legality of CBD is still in question making human-based research highly

challenging. We urge the DEA to move medical marijuana from a Schedule I to a Schedule II compound to expand future research possibilities. The Autism Science Foundation has provided funds to study the biological mechanisms of cannabinoids in rodent models of ASD and we look forward to continued research in the pre-clinical and clinical domains to inform the debate on the risks and benefits of these compounds.

Readings of Interest

<https://www.drugabuse.gov/publications/drugfacts/marijuana-medicine>

<https://www.fda.gov/news-events/press-announcements/fda-approves-first-drug-comprised-active-ingredient-derived-marijuana-treat-rare-severe-forms>

<http://extras.denverpost.com/stateofhope/index.html>

Lihi Bar-Lev Schleider, et al. (2019). Real life Experience of Medical Cannabis Treatment in Autism: Analysis of Safety and Efficacy. nature.com/scientific-reports.

pediatrics.aappublications.org/content/135/3/584

<https://www.taxpolicycenter.org/taxvox/high-hopes-and-altered-states-choices-marijuana-and-tax-revenue>

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Supporting from page 10

The older adult's individual support plan needs to be robust and completely individualized with achievable goals built in that support access to the local community, skill acquisition and maintenance, and comprehensive goals to address communication skills and mobility, if and when needed.

It is equally as important to have a high-

ly-qualified team of professionals working collaboratively to ensure that exemplary care is being provided at all times. This, in addition to well-trained direct support staff working with individuals, will help ensure the greatest outcomes for the older adults can be achieved.

Karen Parenti, MS, PsyD, is Executive Director and Maggie Haag, MEd., BCBA, LSW, is Senior Director of Adult Services

at Melmark PA. For more information, visit <http://www.melmark.org>.

References

Baker, J. C., Fairchild, K. M., & Seefeldt, D. A. (2015). Behavioral gerontology: Research and clinical considerations. In *Clinical and Organizational Applications of Applied Behavior Analysis* (pp. 425-450). Academic Press.

Mukaetova-Ladinska, E.B., & Stuart-Hamilton, I. (2015). Adults with Autism Spectrum Disorder (ASD): Service user perspective on ageing transition(s). *American Journal of Autism, 2*(1): 1-11.

Parsons, M. B., Rollyson, J. H., & Reid, D. H. (2012). Evidence-based staff training: A guide for practitioners. *Behavior analysis in practice, 5*(2), 2-11.

Autism Spectrum News 2019-2020 Editorial Calendar

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Golden Years from page 4

- Keep in mind that their misbehavior is seldom intentional. The playing field of life is changing for them. Assume the best unless you are certain that a behavior or mannerism is intentionally negative.
- We must change our resources for helping them cope. Have suggestions for solutions ready before addressing problems with the person who has an ASD. Be sure to stay upbeat in your discussions and dealings with the senior you are helping.

Individuals with an ASD often experience old age differently than non-spectrum seniors. Despite gradual transitions, their realization of body changes may be very sudden. Although they are at an older age, they may still be “stuck” in the interests and behaviors of a younger era in their lives, such as liking and even obsessing on music, movies, games, dress of past decades (e.g., disco music or hippie clothing).

It is common for seniors with ASD to have difficulty explaining states of health. For instance, they may not tell you they are experiencing stiff joints, leg cramps, or heart arrhythmia. Or they may not realize they are losing their hearing, until one day they panic about it. This can also be true of diminishing sight. These phenomena can lead to disagreements or fear. Suddenly, they are making proclamations or accusations, such as:

- “The TV isn’t loud enough.”
- “You aren’t using 100-watt bulbs in the lamps.”
- “Stop taking me to doctors I don’t need to see.”
- “I don’t walk slowly, the rest of you

walk too fast.”

Proactive plans are crucial at this turn of events. Remind the senior with ASD of the good points of their appearance. This can be a good way to encourage grooming and hygiene (e.g., “My body can change, but I can still dress well”). Encourage regular exercise to help them stay as fit as possible. This is where programs for typical seniors may work just fine, such as YMCA water fitness, Tai chi programs, yoga, and community center exercise events. Contact your state office of aging for more information. This can also be a time of opportunity for the caregivers to take a small break at predictable intervals.

Another great proactive plan is to make a morning schedule or “to do list” for the ASD senior. Always remember the “not about me, without me” philosophy when attempting such a schedule or list. No one wants to be forced to do things that they don’t like. Therefore, your positive and creative skills will be essential in working with them to develop a daily list and then add in items for appointments or special events. A good place to begin is with breakfast. Choose something they like to do or eat in the morning and make that a part of the checklist. Depending on their living situation, other items may have to take place before breakfast, such as grooming, medications, and checking the checklist. For example, if you live in a communal setting, you may not be able to go to breakfast in your pajamas. In grooming, it may help to select an outfit the late afternoon before their next morning routine. This is a great awareness check time:

- What is the weather forecast?
- Am I doing something in the morning that will require activity-specific clothing?
- Is what I want to wear clean (beware of spots, as they often don’t see them) and pressed? (Using a laundry service can

be very helpful if the ASD senior can afford this expense. If not, friends and family may volunteer to help.)

- Will I be comfortable in what I’m choosing to wear?

Taking medications is very time-specific, as some should be taken before eating, some during meals, and some afterwards. Seniors can use segmented pill dispensers that not only delineate the day of the week, but the time of day, such as a.m. and p.m. For our seniors, using different colored pill dispensers before, during and after eating may be helpful. In some cases, it may be necessary to have a separate pill container cluster that is given out each day. Vera Bradley makes a pill container set that can be kept inside a small, zipped bag. Using colored tape or indelible markers can indicate which meal and whether before, during, or after eating that meal. For those who will accept the accommodation, there are now pill dispenser wristbands that can be used as well.

Diminished hearing and sight, increasing aches and pains, and feeling more isolated can lead to a grumpy disposition. This can be seen in critical comments about those with whom they interact, being very picky about food and entertainment, and negative facial expressions. Some seniors on the autism spectrum can become very paranoid, suddenly distrusting those who help and/or are friends with them. Informing others of their health challenges and using distraction techniques may help with this.

Prepare a “training list” to share with auxiliary helpers. Likes and dislikes, daily routines, and health issues are important to include on this list. Entertainment preferences and areas of interest should be followed by cautions about what they don’t like in these areas. For routines, include exercise, diet, and social routines. Be sure to be specific as to what they like and dislike in each area. Health issues to be covered can be a list of medications and allergies, meth-

ods of persuading them to take their meds that have been successful, and an emergency medical call list. If the senior with ASD has repetitive verbal arguments, phrases, or other repetitive verbal behaviors, list ways to respond to these situations. Most important on your training list is explaining ways to calm and soothe this individual.

The most dramatic change that aging brings about is a greater need to access medical care. This involves everything from routine tests to management of chronic medical needs to sudden trips to emergency care caused by falls or deterioration of body functions. Being proactive with the ASD senior’s health care providers will be immensely helpful. The senior with autism may still have problems with waiting their turn for service and accurately explaining their aches, pains, and concerns. Informing those personnel working in intake positions at places that will be regularly visited about their possible stressors may help. Also, ask for an estimate of how long the wait will be. This will help you to advise the senior in question about how to cope with the wait.

Visual supports can help with explaining areas and levels of pain, if necessary. When accessing emergency care, keep a sheet of information about the senior in a handy location, such as the refrigerator door, your wallet, or by the telephone. This can include keys to communicating with that person, and understanding the difference in their expressive language. Understanding the impact of other phenomena such as claustrophobia or hospital psychosis, or “sundowners” syndrome will be important.

Hospital Psychosis occurs when someone enters a structured living situation such as hospitalization or a skilled care facility. They suddenly may become disoriented and paranoid, often blaming their primary caretaker or care staff for their confinement, and distrusting the people upon whom they rely for care. They may engage

see *Golden Years* on page 22

How Do I Fund My Child's Applied Behavior Analysis?

By Marci Wheeler, MSW and
Dr. Cathy Pratt, BCBA-D
Indiana Resource Center for Autism
Indiana University – Bloomington

Your son/daughter has just been medically diagnosed with an autism spectrum disorder (ASD) by their primary care physician or by a psychologist. It has been recommended that you pursue Applied Behavior Analysis (ABA) therapy. ABA is endorsed by the American Academy of Pediatrics as an evidence-based practice. The challenge then becomes locating a provider and funding for the program. A list of providers can be found on our website at <https://www.iidc.indiana.edu/pages/where-and-how-to-find-an-aba-provider-or-center>. ABA programs should guide you on identifying and accessing funding sources. This article is written so that you can better understand your options. Do not be overwhelmed.

Insurance Coverage

Indiana is fortunate to have a strong autism insurance mandate. Understanding if and how you are covered under your insurance plan should be the first step. Your child is eligible to be covered via insurance, because ABA is considered a medically necessary part of your child's



treatment program. There are a variety of medical coverage programs available to families. These may include employer-based health coverage, private purchase of health insurance, and state and federally subsidized programs.

If you have private employer based insurance, check to see if ABA is covered. You can determine if your plan is covered by Indiana's or another state's autism insurance mandate by checking with your company's Human Resources Department. Ask if your plan is fully funded and if it was issued in Indiana or another state. If your insurance was issued in another state, check with that

state's Department of Insurance and ask if that state has an insurance mandate or parity law for autism. Your insurance covers autism treatments if it is fully funded and is issued in Indiana or another state that has an autism insurance mandate.

If your employer-based insurance is self-funded (also referred to as self-insured), the policy is regulated under federal law and exempt from any state regulation. Your employer-based self-funded plan may still voluntarily cover autism, so you should ask if they do. Self-funded companies that are required to comply with the federal Mental Health Parity and Addiction

Equity Act (MHPAEA) must cover ABA and autism treatment. Coverage cannot be limited unless the same limits apply to substantially ALL medical surgical conditions in the same category of service (inpatient, outpatient). Some self-insured plans are exempt from MHPAEA and would not have to cover autism or ABA. Any self-insured plan that does NOT offer ANY mental health services does not have to cover autism or ABA.

If you have an Affordable Care Act Plan (ACA) purchased from the federally facilitated Indiana ACA marketplace, ABA is included in the "Essential Health Benefits" package and required to be covered in Marketplace plans because they must follow the Indiana Autism Mandate: <https://www.healthcare.gov/get-coverage/>.

Beginning in 2017, ALL federal employee health care plans must cover medically necessary autism treatment. This includes ABA therapy and other therapies (e.g., speech therapy, physical therapy) generally accepted by the medical community and written into the treatment plan by the child's treating physician.

Medicaid

All Medicaid Health Plans cover medically necessary ABA. Medicaid Health Plans must be full coverage plans and include: Medicaid Disability, also referred

see Fund on page 25

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What do you say to parents in that type of situation?

It's a very difficult situation. Those parents really need some respite, they need some help. I'm thinking of a case in Texas where every month a church put on this big respite function to give parents a short break from child care. One family had a very severe child with autism who also had many other major medical issues. They brought their child to this church respite function and the parents just went out in their air-conditioned car, laid the seat back, and played the stereo for four hours. They were completely fried because they couldn't get any sleep, they couldn't do normal stuff like go out to dinner, go to church, just normal stuff. It can be very stressful being a parent and respite opportunities are very important.

What advice would you give to parents of children with autism?

We've got to work on early intervention. If you can't get services, then make your own early intervention. My book, *The Way I See*

It: A Personal Look at Autism & Asperger's, is one way to learn.

For older kids, parents need to be motivating them and figuring out what the individual CAN do. Let's say it's a person with more severe challenges. Well, parents are often too quick to dress them. Instead, take the time to teach them how to dress themselves – motivate! If the child is good at math and is bored with "baby" math, then give them college math books if they can do it. If he has art skills, enhance those skills.

I've also seen way too many kids ending up in the basement and going nowhere. What makes me crazy is one smart kid who ends up in the basement playing video games, and another one just like him has a cool job out in Silicon Valley. One day I'll be visiting a big name Silicon Valley company, and the next day I'm at an autism meeting and a mom comes up to me and she'll say, "He's 12 and I can't get him out of the basement" or another mom will come up and say, "I pushed my child, I got him out doing things, he's got a job and he's loving it!"

There are two kinds of moms, there's really a fork in the road for the fully verbal adult with autism: One that will have a child in the basement playing video games

(gaming disorder is now an ICD 11 designated disorder) and one that will have a child that can get out and have a life with a career, because they were motivated by the parents. This is what I'm seeing. Then another day I'm down in the maintenance shop at a meat packing plant and they can't hire people for skilled trades right now because nobody introduced these skills to different kids in their school. There is a gigantic shortage of workers for skilled trades.

I like what Stephen Hawking, the famous astrophysicist, has to say about disability: "**Concentrate on things your disability doesn't prevent you from doing well....**" He could do math in his head - about the only thing he could do well, and that's what he did. There is a tendency to develop a handicapped mentality. I see too many parents who have a smart kid and they don't push them enough.

The other thing to tell parents who have a younger child who isn't talking is that children can look very severe when they are little - I was one of those kids. So, you do your early intervention, and then you'll know after a few years what his level is. I'm having lots of parents still coming up and telling me, "Well, the doctor says he's

going to go nowhere." Can you believe they are still saying things like that?

There is a tendency for parents to try all types of crazy alternative treatments. For example, people trying hyperbaric oxygen chamber therapy and finding out it doesn't work. Well, I never promoted that because I never could find even anecdotally that it worked when I asked the family a lot of questions. It's the same with early intervention, it should be started as soon as possible. Parents need to stick with the science from the very beginning.

I talk to low-income families in the southeast where there are little to no services. I tell them to get the grandmothers from your church and suggest they read [these books](#). Start working with this child and you start working with them now, because the worst thing you can do is do nothing. Don't wait. You've already received a diagnosis - it's called "He doesn't speak, and his behavior is a mess." Start working on him now.

The viewpoints expressed in this article do not reflect the opinion of the Autism Spectrum News Editorial Board or the Publisher, Mental Health News Education.

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and living environment for our children. Because, as stated by Mahatma Gandhi, "The true measure of any society can be found in how it treats its most vulnerable members."

About the Author

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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

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References

Autuori, Donna M., "Building Supportive,

Person-Centered Communities for Adults with Autism" www.eParent.com, 2018

CDC Data and Statistics, www.cdc.gov, 2018

Reimann, Matt "Willowbrook, the institution that shocked a nation into changing its laws", June, 2017

Johns Hopkins University Bloomberg School of Public Health. (2018, April 26). U.S. autism rate up 15 percent over two-year period: Researchers say racial and ethnic disparities are narrowing. *ScienceDaily*. Retrieved May 9, 2019 from www.sciencedaily.com/releases/2018/04/180426141604.htm

O'Byrne, Mary E. Esq. and Stephen W. Dale, Stephen W. Esq., 2019 "Getting Creative: Models for Filling the Housing Gap, 2019

Jesse Ventura. (n.d.). AZQuotes.com. Retrieved May 08, 2019, from AZQuotes.com Web site: <https://www.azquotes.com/quote/302218>

Kovner, Josh. "Bill Would Encourage Housing Options for Group Home Clients". Hartford Courant, 2018

Autism Speaks, www.Autismspeaks.org

Mahatma Gandhi. (n.d.). AZQuotes.com. Retrieved May 12, 2019, from AZQuotes.com Web site: <https://www.azquotes.com/quote/877037>

Golden Years from page 20

in nonsensical arguments when asked to take medicine or agree to tests. Escape often becomes their top priority. If the senior with ASD is showing signs of this behavior, be sure that his or her caregiver team consults psychiatric care in case antipsychotic drugs may be needed. Often elopement safeguards may need to be put in place. In some elders, this confusion may become a daily occurrence, regardless of a new setting or one that is familiar. This may occur most often in the late afternoon or early evening.

Don't offer props or strategies when they are not needed. Over-anticipating their challenges can further their reliance on others.

Remaining a healthy caregiver is key

in making the aging experience optimal. Whether a paid or volunteer non-family member or someone who is related by genetics or love, you will need knowledge and encouragement as you take this important journey into the new frontier of aging.

Work at establishing regular intervals to take breaks from being the main caregiver as much as you need, and/or as much as is possible. Find friends and/or a counselor with whom to share concerns and frustrations. Talk to others in similar situations. Sometimes a social worker may be available to link you to others facing similar challenges. If not, consider forming a support group locally or online. Stay aware of what makes you a mentally and physically healthy caregiver. Stay physically as strong as possible by regular exercise, yoga, or other forms of meditation, or just taking a daily walk.

Finding effective "relief valves" will be important, whether that is physical, spiritual, or intellectual. Knitting, reading, drawing or other art endeavors, computer activities such as Caring Bridge (for those facing potentially terminal illness) or Facebook can help. If you are the spouse or partner of the aging person with ASD, this stage of life can be highly stressful. A strong faith can be helpful in this or any time of great stress and worry. Most religious denominations have group activities that often involve spouses with aging or ill partners.

I encourage you to stay in touch with others who are involved on a daily basis with ASD and aging, whether caregivers or clinicians. Though each path will be unique, many circumstances will be similar. Keep collaboration your key to success.

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Sources of Information on Aging and Elder Care

Indiana Long Term Care Insurance Program: www.in.gov/iltcp/

AARP: www.aarp.org

National Institute on Aging: www.nia.nih.gov/search/site/aging

National Council on Aging: www.ncoa.org

American Society on Aging: www.asaging.org

Administration on Aging: www.aoa.gov

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them to be of great value to our community.

Looking to the Future

One possible bright spot in all of this is that, because many of us develop countless coping mechanisms throughout our

lives, not to mention acquire knowledge and skills over many years, autism itself is usually not considered a degenerative condition, even as many other aspects of aging are; the former can perhaps be taken advantage of to help mitigate the latter whenever possible. As bleak as the present situation may be for many, it can be addressed, first and foremost, by identifying as many

older adults on the spectrum as possible, and at the same time improving awareness about the common behaviors and traits of and challenges faced by these individuals, especially among those who provide any form of care or services for them. Some individuals will require intensive long-term care, whereas lower-level supports will be sufficient for others (who in some

cases may otherwise live independently). In many instances, little more than minor accommodations will be necessary. For society as a whole, appropriate resources and accommodations, where necessary, need to be provided or otherwise made available.

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Syndrome, whose most common characteristics include intellectual disability, impaired speech and sleep, and repetitive behaviors. The majority of these individuals are also diagnosed with autism spectrum disorder, as many of the symptoms overlap.

The protein encoded by Shank3 is found in synapses — the junctions between brain cells that allow them to communicate with each other. It is particularly active in a part of the brain called the striatum, which is involved in motor planning, motivation, and habitual behavior. Feng and his colleagues have previously studied mice with Shank3 mutations and found that they show some of the traits associated with autism, including avoidance of social interaction and obsessive, repetitive behavior.

Although mouse studies can provide a great deal of information on the molecular underpinnings of disease, there are drawbacks to using them to study neurodevelopmental disorders, Feng says. In particular, mice lack the highly developed prefrontal cortex that is the seat of many uniquely primate traits, such as making decisions, sustaining focused attention, and interpreting social cues, which are often affected by brain disorders.

The recent development of the CRISPR genome-editing technique offered a way to engineer gene variants into macaque monkeys, which has previously been very diffi-

cult to do. CRISPR consists of a DNA-cutting enzyme called Cas9 and a short RNA sequence that guides the enzyme to a specific area of the genome. It can be used to disrupt genes or to introduce new genetic sequences at a particular location.

Members of the research team based in China, where primate reproductive technology is much more advanced than in the United States, injected the CRISPR components into fertilized macaque eggs, producing embryos that carried the Shank3 mutation.

Researchers at MIT, where much of the data was analyzed, found that the macaques with Shank3 mutations showed behavioral patterns similar to those seen in humans with the mutated gene. They tended to wake up frequently during the night, and they showed repetitive behaviors. They also engaged in fewer social interactions than other macaques.

Magnetic resonance imaging (MRI) scans also revealed similar patterns to humans with autism spectrum disorder. Neurons showed reduced functional connectivity in the striatum as well as the thalamus, which relays sensory and motor signals and is also involved in sleep regulation. Meanwhile, connectivity was strengthened in other regions, including the sensory cortex.

Michael Platt, a professor of neuroscience and psychology at the University of Pennsylvania, says the macaque models should help to overcome some of the lim-

itations of studying neurological disorders in mice, whose behavioral symptoms and underlying neurobiology are often different from those seen in humans.

“Because the macaque model shows a much more complete recapitulation of the human behavioral phenotype, I think we should stand a much greater chance of identifying the degree to which any particular therapy, whether it’s a drug or any other intervention, addresses the core symptoms,” says Platt, who was not involved in the study.

Drug Development

Within the next year, the researchers hope to begin testing treatments that may affect autism-related symptoms. They also hope to identify biomarkers, such as the distinctive functional brain connectivity patterns seen in MRI scans, that would help them to evaluate whether drug treatments are having an effect.

A similar approach could also be useful for studying other types of neurological disorders caused by well-characterized genetic mutations, such as Rett Syndrome and Fragile X Syndrome. Fragile X is the most common inherited form of intellectual disability in the world, affecting about 1 in 4,000 males and 1 in 8,000 females. Rett Syndrome, which is more rare and almost exclusively affects girls, produces severe impairments in language and motor skills and can also cause seizures and

breathing problems.

“Given the limitations of mouse models, patients really need this kind of advance to bring them hope,” Feng says. “We don’t know whether this will succeed in developing treatments, but we will see in the next few years how this can help us to translate some of the findings from the lab to the clinic.”

The research was funded, in part, by the Shenzhen Overseas Innovation Team Project, the Guangdong Innovative and Entrepreneurial Research Team Program, the National Key R&D Program of China, the External Cooperation Program of the Chinese Academy of Sciences, the Patrick J. McGovern Foundation, the National Natural Science Foundation of China, the Shenzhen Science, Technology Commission, the James and Patricia Poitras Center for Psychiatric Disorders Research at the McGovern Institute at MIT, the Stanley Center for Psychiatric Research at the Broad Institute of MIT and Harvard, and the Hock E. Tan and K. Lisa Yang Center for Autism Research at the McGovern Institute at MIT. The research facilities in China where the primate work was conducted are accredited by AAALAC International, a private, nonprofit organization that promotes the humane treatment of animals in science through voluntary accreditation and assessment programs.

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Thank You & God Bless!

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will ideally lead to more success for these individuals in navigating the milieu of interaction in academic, extra-curricular, or professional contexts.

We have found through our Summer and Winter in the City group programs, which take participating students on a series of day-trips and outings around New York City for two weeks, that New York City serves as a uniquely rewarding locale for developing social skills organically. Participants have the chance to develop authentic and translatable social skills in a city that provides many opportunities for various activities, cultural immersion, differing sensory inputs, and a unique element of randomness. Unforeseen challenges and teachable moments supplement the students' social skill-building. "The person who has heightened sensory sensitivity may perform well in a low-stimulation environment but become physically uncomfortable... in an environment that has too many irritants. The problem and the solution are not within an individual, but rather in the person-environment fit" (Gobbo & Shmulsky, 2010, pg. 3). Additionally, "a person who is taking public transportation from one point to another has to read the schedule and signs around him or her, provide payment for the use of the transportation, maintain safety while interacting appropriately with others, and observe their community to identify their stops. All of these activities involve

academic skills that are embedded in functional tasks" (Volkmar, Reichow, & McPartland, 2014, pg. 45). Thus, individuals have the potential to develop authentic social skills by testing their boundaries and building skills around navigation, decisiveness, regulation, budgeting, and more in addition to those that occur in the social context.

Before any skill improvement can occur, there must exist buy-in from individuals at the center of any ASD skill development support group. To help spur engagement and interaction, participants should be encouraged to take an active role in planning out which activities, sights, and experiences the group explores. This should be achieved collaboratively by the entire group, which provides participants the opportunity to be confronted with differing opinions, disparate interests, and disagreements on what the group should do. Navigating these common social occurrences in the context of a group that shares similar social obstacles enables participants to learn in a judgment-free space that helps define for how they choose to fit into the mold of expected social behaviors. Furthermore, as participants begin to deepen their relationships with their peers, they may begin to self-impose the decorum of social interaction and spur that process in each other, yielding a dynamic that further allows for social skills development in consideration of the aforementioned ecological approach: "If the goal is to teach social-

ly motivated adolescents and adults with ASD how to interact effectively in a neurotypical world, then understanding the ecologically valid social customs of the dominant peer group is essential" (Volkmar, Reichow, & McPartland, 2014, pg. 67). Thus, by manufacturing a peer group for participants, they may obtain the necessary social skills development outside of the vacuum of simply talking about or practicing skills one-on-one. This gives the opportunity to bolster that development in context of a larger group that can establish its own accepted and expected behaviors, as well as providing social feedback in real-time, ideally avoiding the "square peg, round hole" conundrum.

The larger context of group-driven social programming allows students to improve their social awareness via interaction with each other, providing the potential for social "hiccups" that students learn to navigate. For example, a participant may insist upon not talking about politics or religion at all, as she has perhaps compartmentalized these topics as being inappropriate for social engagement, since they oftentimes lead to disagreement or conflict. Another participant, however, may *only* want to talk about politics or religion, which presents a clear opportunity for skill-building for both students. An effective approach to getting around this potential social obstacle is to challenge the latter participant to not talk about politics/religion at all, and to try and find other topics that don't alienate certain members

of the group. Conversely, the politics/religion-averse participant learns to regulate her reactions to the politics/religion-centric participant's choice of conversation topic. Subsequently, both individuals can come to a greater understanding of their unique social perspectives in the context of the group (and perhaps society at large), ideally walking away with a deeper appreciation for themselves and their capacities. Suffice to say, if ASD support networks can provide the scaffolding for individuals to develop positive self-identity and social skills, then we will have done our part to foster their growth and ease their eventual integration into society, in turn giving them the tools necessary to find success in the long-term.

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References

Gobbo, K., & Shmulsky, S. (2010). Autistic Identity Development and Postsecondary Education. *Disability Studies Quarterly*, 36(3). doi:10.18061/dsq.v36i3.5053

Volkmar, F. R., Reichow, B., & McPartland, J. C. (Eds.). (2016). *Adolescents and Adults with Autism Spectrum Disorders*. Retrieved February 25, 2019, from <https://www.springer.com/us/book/9781493905058>



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Camouflage from page 6

These are often borrowed from the behavior of their colleagues in order to radiate self-confidence to the outside world. Since many autistic people also react extremely sensitively to tactile stimuli, they find it unpleasant to wear tight-fitting clothing. Therefore, it is especially difficult for autistic women to correspond to the dress codes in the

workplace. All these factors can lead to a so-called "autistic burn-out." The constant psychological and cognitive peak performance eventually leads to a breakdown. The fact that more autistic women suffer from the problems described does not mean, however, that their male counterparts are free from these problems - female autistic women are only better at playing the nerve-wracking game of hide-and-seek.

About auticon

auticon is an IT and compliance consulting business and the first enterprise to exclusively employ adults on the autism spectrum as IT consultants, providing quality assurance testing on software and web-based applications. auticon employs more than 100 IT consultants on the autism spectrum in the UK, Germany, France, Canada, United States and Switzerland, and is the

first social enterprise to scale this model across Europe. For more information, visit www.auticon.com.

References

I. Meng-Chuan Lai, Michael V. Lombardo, Amber Ruigrok "Quantifying and exploring camouflaging in men and women with autism" *Sage Journals*, November 29, 2016 <https://journals.sagepub.com/doi/10.1177/1362361316671012>

Building from page 18

services, peer-support opportunities, and social opportunities for adults aging with autism can be crucial to the successful aging of older persons with autism.

As gerontologists, we are calling on the

aging and disability service networks to work collaboratively to develop appropriate and attractive models of community support for older adults with autism. The needs of older persons to remain living independently (housing, transportation, access to care, and opportunities for

meaningful social engagement) are not unique to those living without a disability. However, to understand the preferences of persons with autism for how community support services are provided and to explore how these preferences are tied to their goals for later- cross-disciplinary

partnership is crucial.

Caitlin E. Coyle, PhD, is a Research Fellow at the UMass Boston Center for Social and Demographic Research in Aging and Danielle Waldron, MS, is a PhD candidate at the UMass Gerontology Institute.

Sibling from page 19

experience for both the caregivers and siblings. Siblings shared that the support group helped them feel connected with others who had similar feelings and frustra-

tions, and that it helped them understand ASD and how the diagnosis impacts their brother or sister. Additionally, siblings said the series helped them develop more compassion towards their siblings with an ASD diagnosis.

The Center is grateful for the siblings who participated in this series and is looking forward to providing more opportunities like this to continue making a positive impact in the life's of those who have a loved one with ASD.

The University of California, Irvine School of Medicine Center for Autism & Neurodevelopmental Disorders is a non-profit entity within UCI Health. For more information, please visit www.thecenter4autism.org.

Fund from page 21

to as Traditional Medicaid; Hoosier Care Connect; Hoosier Health Wise; and MED Works. Medicaid carriers include Anthem, MHS and MDWise. These are insurance companies that are contracted by the State of Indiana to manage some Medicaid Health Plans. You do not have to “switch Medicaid types” to access ABA coverage. You do have a choice of Medicaid carriers.

Not all ABA providers accept Medicaid insurance. They may choose to participate in all Medicaid plans, some plans, or none. It will be important to ask the ABA provider about what Medicaid options they accept. An ABA provider must be a participating provider with Medicaid, AND be a participating provider who is credentialed by the insurance carrier who may be managing the Medicaid plan. For example, if you have Medicaid managed by MHS and your ABA provider is a participating provider in Medicaid, but NOT with MHS, they cannot be paid by MHS Medicaid managed plans. They must be “credentialed” by MHS and be in the MHS network.

Effective August 1, 2018, if individuals under age 21 are deemed appropriate for Applied Behavior Analysis (ABA) therapy, providers should access funding under Early and Periodic Screening, Diagnostic and Treatment (EPSDT). Visit the website at (<https://www.iidc.indiana.edu/pages/medicaid-epsdt>; <https://www.medicaid.gov/medicaid/benefits/epsdt/index.html>) for more information on EPSDT.

To learn more about Indiana Medicaid options, visit: <https://www.in.gov/medicaid/index.html>. If you are unsure which type of Medicaid you have, call the Division of Family Resources at 1-800-403-0864.

If your family receives military health care benefits (US armed services “TRICARE”), the TRICARE Comprehensive

Autism Care Demonstration (Autism Care Demo) covers applied behavior analysis (ABA) services for all eligible TRICARE beneficiaries diagnosed with an autism spectrum disorder.

Family Voices Indiana provides a helpful Fact Sheet regarding purchasing insurance for all children with special needs. This information can be found at http://www.fvindiana.org/wp-content/uploads/2018/01/FS_Guide-to-Purchasing-Insurance-1.pdf.

Note: Know your insurance policy and follow the appropriate procedures. Submit your child’s Care Plan that your ABA provider and you have developed to the appropriate person or department within your insurance carrier. Keep organized and thorough records of all dealings with your insurance carrier, especially paperwork sent and received.

Other Options

You may have insurance but find that additional coverage and services are needed for your child. Eligibility for the three programs and services listed below varies and may be dependent upon family income, and/or the diagnosis, age, and level of care needs of your child. Supplemental funding for services may be available from one or any of these programs. Families are encouraged to apply for the following programs:

In Indiana, there are two Medicaid waivers designated for people with developmental disabilities. These are the Family Supports Waiver (FSW) and the Community Integration and Habilitation Waiver (CIH). ABA is not a specific service of either the FSW or the CIH waiver. However, the waivers can be a funding source for non-medically necessary behavioral supports. ABA is not an available service for individuals 21 and older through the FSW and CIH Medicaid Waivers. They can have access

to other behavior support services. Realize there is a waiting list for the Waiver, so do not expect it will happen right away.

The Children’s Special Health Care Services (CSHCS) Program helps families of children ages 0-21 with serious chronic medical conditions get treatment related to their child’s medical condition. Autism is a CSHCS eligible medical condition. CSHCS is the payer of last resort. This means that the program may pay only after your private health insurance and Medicaid have been billed. CSHCS is not an insurance program, but can provide supplemental funding. This program is federally and state funded, and features care coordination services that help children and their families get medical care that can include ABA. If eligible for ABA coverage through the CSHCS program, coverage is limited to \$10,000 per child, per calendar year and the ABA provider must be enrolled with CSHCS.

United Healthcare Children’s Foundation (UHCCF) purpose is to help fill the gap between what medical services and equipment a child needs and what their health insurance benefit plan will pay. UHCCF grants provide financial assistance for families with children, ages 16 and younger that have medical needs not covered or not fully covered by their health insurance plan. Award amounts are up to \$5,000 or 85% of the fund balance, whichever amount is less, within a 12-month period. The grant is paid directly to the health care provider. For more information and to apply, see the UHCCF website <https://www.uhccf.org/>.

In addition, you may want to check out a limited number of grants that are listed on the Indiana Resource Center for Autism website. The article, Grant Funding Opportunities: For Families and Professionals is found here: <https://www.iidc.indiana.edu/pages/grant-funding-opportunities>. Look

under the section for parents and families. Your local library may also be able to assist you in finding grants to apply for to cover some therapy costs.

If either your ABA provider or funding source provides information that seems confusing or contradictory, contact:

Indiana Arc- Insurance Advocacy Resources Center: <https://www.arcind.org/our-programs/insurance-advocacy-resource-center/>. Michele Trivedi is an INARC Manager and health advocate with many years’ experience. You can contact Michele at 317-977-2375 or toll free 800-382-9100. Her email is mtrivedi@arcind.org.

Family Voices Indiana- Indiana’s Family to Family Health Information Center: <http://www.fvindiana.org/>.

Call their toll-free number, 844-323-4636 and ask to speak to a specialist in your area. You can also email them at info@fvindiana.org. Spanish speaking specialists are also available.

Marci Wheeler, MSW, is Social Work Specialist and Dr. Cathy Pratt, BCBA-D, is Center Director at the Indiana Resource Center for Autism at the Indiana Institute on Disability and Community at Indiana University, Indiana’s Center for Excellence on Disabilities. For more information, visit <https://www.iidc.indiana.edu/pages/irca>.

This article is reprinted with permission. You may view the original article, published on January 15th, 2019, at <https://www.iidc.indiana.edu/pages/how-do-i-fund-my-childs-applied-behavior-analysis>

References

Wheeler, M. & Pratt, C. (2019). How do I fund my child’s applied behavior analysis (ABA)? Retrieved from <https://www.iidc.indiana.edu/pages/how-do-i-fund-my-childs-applied-behavior-analysis>.

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

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

For more information, visit our website www.FAAHFA.com or contact the facilitators:

Bonnie Kaplan - Parenttalk@gmail.com | Judith Omidvaran - Judyomid@aol.com

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Parents from page 17

like special education teachers—I want to unite autism parents worldwide to help each other. To this end, we should start a network I'm calling GHOST, which stands for "Giving Help from the Other Side, Together." In this imagined organization, autism parents would provide another set of eyes for someone else's adult autistic loved one. We would trade off checking in on one another's adult autistic loved one.

We would spy on their care providers. We would make sure our comrades' dependent loved ones are safe and happy. We would be a group committed to having each other's back. We would recruit younger parents who will need this help as they age. Our motivation would be simple: to have a community of truly invested people to keep our guys safe.

I am not joking about GHOST. Who better to check up on things than another parent in the same boat? Because really, living

forever or becoming actual ghosts is hardly a plan for this very complicated world our vulnerable loved ones. Parents, neighbors, citizens: we need to take back the night and push our legislators to do better and engender a qualified, caring, and well-paid workforce before more lives are shattered.

Susan Senator is the author of numerous autism books including *Autism Adulthood: Insights and Creative Strategies for a Fulfilling Life*. Her writing has appeared in *The New York Times*, *The Washington Post*, *Sa-*

lon.com, and *The Boston Globe*. For more information, visit <http://susansenator.com>.

This article is reprinted with permission. You may view the original article, published on April 27th, 2019, at www.psychologytoday.com/us/blog/all-families-are-not-alike/201904/why-autism-parents-say-i-can-never-die.

The viewpoints expressed in this article do not reflect the opinion of the Autism Spectrum News Editorial Board or the Publisher, Mental Health News Education.

Best Practices from page 8

might look like, this movie received outstanding reviews. Hoffman won the Oscar for best actor for his dramatic portrayal of an autistic adult.

The process, then, of introducing the subject of autism to the general public by exploding myths and taboos and taking a serious, sensitive and reasonable approach to educating persons unfamiliar with an ASD requires time and commitment. I call this the 5 A's process or 5 Steps, based on Stephen Shore's paradigm presented in a paper he delivered at a conference in Bahrain, April 2, 2019. The model provides a framework which can help us understand the multiple challenges facing an autistic adult, while providing a basis to support and inform critical decisions about the future of the adult on the spectrum.

1. Acknowledging a diagnosis of autism as a lifelong disability
2. Accepting the limitations as well as the strengths
3. Accommodating to the needs of the autistic adult
4. Appreciating their potential to contribute to our society
5. Applying what we know today about the autistic spectrum population to our aging population

With the concomitant limitations of solid research about this population, what must we do to apply what we do know today in an effort to ensure a smooth transition from adolescence to adulthood and from adulthood to aging? I suggest that transition of care topics include leisure and social opportunities, medical issues, housing options, employment and volunteer choices, and legal and ethical considerations. In addition to these transition of care needs, I suggest that there are 5 critical and overarching principles which might influence our best practices.

The first principle is to worry less about trying to cure them, fix them, and heal them or to make them neurotypical. They are not as adults and were not as children. Let us rather try to understand the experiences this population faces each and every day and to see beyond their sometimes strange and unconventional ways.

With the support systems in place, including family and communities, we can guide our aging autistic adult population to appreciate and apply the best they have to offer as older, more experienced autistic adults. For example, mentoring younger autistic adults, as Dr. Tony Attwood has suggested, is one

wonderful way our aging adults can contribute to the world around them.

Second, we know that as this population ages, there is a tendency toward social isolation and loneliness (Hickey and Crabtree, 2018). Lowered life expectancy may also be an outcome of lack of social involvement (Vaillancourt, 2016). Dwindling financial support and community interest at the very time when it may be most needed to support the needs of the adult on the spectrum is a subject which Gottlieb (2015) addresses in his well-articulated NY Times editorial "Adult, Autistic and Ignored." Life is fluid for us neurotypicals as well as for our autistic adults and change, something that those on the spectrum struggle with constantly, brings with it very human and predictable events such as sickness, loss and grieving. How to cope with these potentially overwhelming changes and emotions means we need to boost psychological services which must be made available and must be seen as simply one more treatment - planned and prepared in advance - so that our adult children are more able to adjust to the realities as they transition into adulthood and aging (Mazurek, 2014).

Third, in addition to boosting psychological services, we should deepen and extend social services to include regular visits from professionals associated with the social welfare system. The infrastructures for such services exist. Now we have to adapt and modify the infrastructure taking into account the special needs of this special population including research on topics of autism and ageing (Charlton, 2017).

A formalized, systematic and organized plan such as the private, for pay service proposed by The Asperger/Autism Network, AANE (2019) called the LifeNet Program promotes the awareness of the needs of the adult with autism by recognizing that the family may not be available when the aging autistic adult may be most needy. The program appears to hold promise as a creative solution to the question I raised about who will look after the needs of my forty+ son when I am no longer here.

Fourth, based on evidence-based studies beginning to emerge in the scientific community (Halladay, 2018), we now understand that there is reason to believe that the aging adult with autism may suffer from higher incidences of conditions as schizophrenia and Parkinson's, as well as possibly a twenty times greater risk of anxiety and depression. We need therefore, to reach out to the caregivers, medical staff, and support service providers by initiating a campaign to educate, train, and prepare them so they are more comfortable and able to deal with the challenges that lie ahead as our autistic children become adults and then transition

to senior citizens. An Adult Autistic Clinic at Mt. Sinai Hospital in Miami, Florida for example, is impressive in its scope, dedication and commitment to providing a full comprehensive service offered by professionals who understand adults with autism.

As the prevalence rate continues to increase in children, this trend clearly affects future support of our adults with autism. My fifth principle, then, is based on a reality that there needs to be an increase in resource allocations reflecting this upward trend of diagnosis. I am heartened by the push toward a greater commitment of resources as promoted by the Autism Collaboration, Accountability, Research, Education, and Support Act (Autism CARES), a primary source of federal funding for autism research, services, training and monitoring. Under the CARES ACT, lawmakers are looking to secure an additional \$1 billion to ensure that for the first time, this allocation places an emphasis on the needs of adults with autism by adding the phrase "across the life span."

To summarize I propose that these 5 principles serve as guidelines to help us plan for transition of care in a responsible, thoughtful and reasonable manner. Keeping in mind that an estimated 1% of the world population has been diagnosed with autism, it is essential that civil societies accept responsibility for their future well-being. We should worry less about fixing our adult children and concentrate more on recognizing their strengths; boost interventions such as psychological and social services; prepare those people tasked with taking good care of our aging children by enriching their knowledge base; and finally, work to influence decision makers to ensure that a proportionate increase in funding allocations reflects the clear and current increase in the prevalence rates of both children and adults. Our aging children deserve no less.

Dr. Marlene Ringler is a Ph.D. in English Language and Literature as well as a trained and certified teacher, CEO and founder of the international Ringler English Language Institute. Her company was recognized as a lead vendor for global training for multinationals including Toyota, Intel, IBM and Microsoft. She pioneered the concept of in-house training specifically in business settings. When living in the United States, Marlene was the co-coordinator of the English for Specific Purposes and English as a Second Language adult training programs for refugees and immigrants for Montgomery County Public Schools in Maryland. Her program was nominated for special recognition by the White House for its work in adult literacy. An advocate for persons with disabilities, Marlene encouraged peo-

ple in school systems in the US and in Israel to develop programs for students who might not otherwise be able to function in a typical classroom. She counseled and guided teachers, administrators and parents to recognize the needs of the disabled population.

Today, Marlene works closely with service care providers to maximize the potential of the autistic population in a work setting. In addition, she counsels and advises parents about resources, opportunities, and the legal aspects of raising an autistic child to adulthood. Marlene and her family currently reside in Israel and sponsor, host, and organize conferences, social events, and gatherings in order to promote awareness about the needs of autistic adults.

For more information, please visit <https://www.marleneringler.com>.

References

- Attwood, T. (1998). *Asperger's Syndrome: A Guide for Parents and Professionals*. London: UK. Jessica Kingsley Publishers.
- Charlton, R. (2017, September). Researching Autism and Ageing, Network Autism, UK.
- Donvan, J and Zucker, C (2016). *In a Different Key: The Story of Autism*. New York, New York. Crown Publishers.
- Gillot, A., and P.j. Standen. "Levels of Anxiety and Sources of Stress in Adults with Autism." *Journal of Intellectual Disabilities* 11.4 (2007): 359-70. Web.
- Gottlieb, E. 2015, September 5. Adult, Autistic and Ignored. *The New York Times*, Opinion.
- Halladay, A. (2018) A 2018 Year of Review of Scientific Research. *Autism Science Foundation*, December 23, 2018.
- Hickey, A. and Crabtree, J. (2018, February 2). Autism and Ageing: Loneliness and Isolation, National Autistic Society, Network Autism.
- Mazurek, M. (2014, April 22). Loneliness, Friendship and Well-being in Adults with ASD, Interactive Autism Network (IAN).
- Robison, J. (2018, September 2). Life, Love and Happiness for Autistic Adults-What Happens to Autistic People as they Age? *Psychology Today*.
- Silberman, S. (2013) *Neuro Tribes: The Legacy of Autism and the Future of Neurodiversity*. New York, New York. Penguin Books.
- Vaillancourt, M. (2016, April 2). It Is No Surprise That People with Autism Have a Low Life Expectancy. *Independent Minds*.

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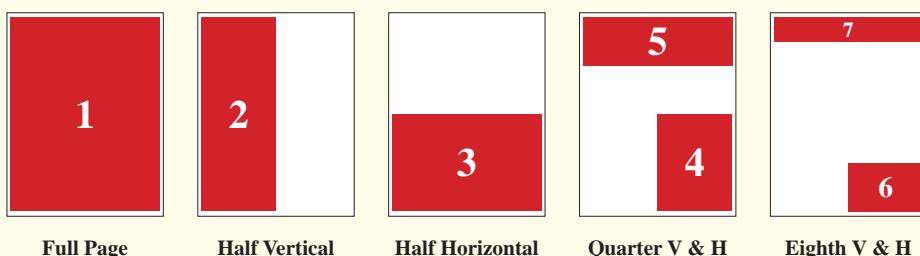
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