

AUTISM SPECTRUM NEWS

YOUR TRUSTED SOURCE OF SCIENCE-BASED AUTISM EDUCATION,
INFORMATION, ADVOCACY, AND COMMUNITY RESOURCES

SPRING 2021

VOL. 13 NO. 4

Housing and Community Living

Five Key Issues to Explore When Considering Housing Options

By Desiree Kameka Galloway,
Autism Housing Network
and Denise D. Resnik,
First Place AZ

Finding the right home for you or your loved one with autism or other intellectual and developmental disabilities (I/DD) can be daunting. While today's marketplace is finally beginning to offer more options, several important issues should be considered to find the optimum housing environment once the momentous decision is made to move out of the family home. Individuals and their families can contemplate which of these and other options best fit their lifestyle interests, support needs, location preferences and finances.

A great place to start is [A Place in the World: Fueling Housing and Community Options for Adults with Autism and Other Neurodiversities](#). The 2020 report includes more than 150 terms and several examples designed to guide individuals and their families and developers alike. The first resource of its kind focused on supportive housing options, it aims to provide a consumer-friendly resource that advances



Residents of The Arc Jacksonville Village, one of various national properties listed in the Housing Market Guide, enjoying new friendships

a broad and more robust marketplace where individuals can better express their housing needs and preferences in terms understood by those prepared to deliver from the private, nonprofit, philanthropic and public sectors.

Co-authors include Arizona State University Watts College of Public Service and Community Solutions and its Morrison Institute for Public Policy, the First Place Global Leadership Institute and its Daniel Jordan Fiddle Foundation Center for Pub-

lic Policy, Autism Housing Network, and pioneering leaders from all sectors across the U.S. and around the globe.

Just as home options for seniors have evolved and expanded over the past 50 years, individuals with autism and other I/DD should also be able to describe and access a variety of supportive housing choices offering a broad spectrum of services and amenities, diverse locational and lifestyle preferences and funding streams.

The five key issues shared in this article - and much more - can be explored in greater detail in [A Place in the World](#). Consider the following as you build your vision of "home."

1. Alignment with Life Goals and Lifestyle

When it comes to housing options, individuals and families may consider how their own lifestyle fits with a particular property or community. Whether it's the ideal studio apartment or sharing a home with friends, a group home or a planned community setting, the type of property is the first step in determining where to live. For some, the energy and connectivity of

see Options on page 22

Leaders of the Autism and Behavioral Health Communities To Be Honored at May 12th Virtual Leadership Awards Reception

☆☆☆ You Are Cordially Invited! ~ See Page 20 for Details ☆☆☆



Marco Damiani

Chief Executive Officer
AHRC New York City
Excellence in Autism Award



Tony Hannigan

President and CEO
Center for Urban Community Services
Lifetime Achievement Award



Hillary Kunins

Exec. Deputy Commissioner of Mental Hygiene
NYC Department of Health and Mental Hygiene
Healthcare Hero Award



Allison Sesso

Executive Director
RIP Medical Debt
Behavioral Health Advocacy Award



Ian Shaffer, MD, MMM, CPE

VP and Executive Medical Director
Healthfirst - Behavioral Health (Retd.)
Corporate Leadership Award

NON PROFIT
ORGANIZATION
U.S. POSTAGE PAID
MONROE, CT
PERMIT NO. 137

Mental Health News Education, Inc.
460 Cascade Drive
Effort, PA 18330

Table of Contents

Housing and Community Living

- 1 [Five Key Issues to Explore When Considering Housing Options](#)
- 4 [A Scaffolded Approach to Supporting Individuals with Autism](#)
- 6 [How Executive Function Skills Aid in Daily Living](#)
- 8 [Community Living and Inclusion for Individuals with I/DD](#)
- 10 [How Preparing Early Improves Independent Living in Adulthood](#)
- 11 [Improving Interactions Between Police and People with Autism](#)
- 12 [Increase Neuro-Inclusive Housing in Your Community: Here's How!](#)
- 13 [Teaching Community Skills to Prepare for Independent Living](#)
- 14 [Organizational and Individual Change: The Road to Inclusion](#)
- 15 [Finding Home: Creating a Home that Supports the Individual](#)
- 18 [Perspectives From Two Adults Living Independently at Chapel Haven](#)
- 19 [Community Living Skills Opportunities for Independent Living](#)
- 24 [Parents are Vital to Positive Post-Secondary Outcomes](#)
- 26 [Tenants Celebrate Two Years of Independent Living in New Housing](#)
- 27 [Accessory Dwelling Units Offer More Housing Options](#)
- 27 [A COVID-19-Inspired Housing Solution for Our Autistic Daughter](#)
- 29 [Community Living in the Era of COVID-19](#)
- 31 [Suitable Housing and Community Living: Challenges for Autistics](#)

Supporting the Autism Community

- 16 [AHRC NYC Artists Dive Deeper Into Art and Self-Expression](#)
- 17 [How Robots Can Be Used in Special Education](#)
- 23 [Your Child's Right to an Appropriate Transition Plan](#)
- 25 [Compassionate Care is a Missing Piece in Behavior Analytic Training](#)
- 28 [My Child with Autism Needs Anesthesia - What Should I Know?](#)
- 29 [A Parent Advocate's Hard-Fought Journey](#)
- 31 [AHRC New York City's Educational Advocacy Guides Parents](#)
- 33 [Smart Home Technology and Autism](#)

Autism Spectrum NewsDesk

- 3 [MHNE Welcomes David Minot as New Executive Director](#)

2020 MHNE Leadership Awards Reception

- 3 [Leaders To Be Honored at May 12th Virtual Leadership Awards](#)
- 20 [Event Registration Form](#)
- 21 [Slate of Honorees and Event Details](#)

Editorial Calendar

Summer 2021 Issue

“Autism and Employment”

Deadline: June 3, 2021

Fall 2021 Issue

“Challenging Behaviors and Autism”

Deadline: September 2, 2021

Winter 2022 Issue

“Improving Lives with Technology”

Deadline: December 3, 2021

Spring 2022 Issue

“Education and Autism”

Deadline: March 3, 2022

For more information, visit

www.AutismSpectrumNews.org/submit

or email dminot@mhnews.org

Stay Connected with ASN Online

Over 1,000 articles and 50 back issues at

www.AutismSpectrumNews.org



#YourTrustedSource

Since 2008, *Autism Spectrum News* has been providing a trusted source of science-based autism information, education, and quality resources in the community.

Please Support the Resources Advertised in This Issue!

AHRC New York City	Daniel Jordan Fiddle Foundation	Moving Forward
Behavior Therapy Associates	Devereux Advanced Behavioral Health	MSR Legal Consulting Services
Berklee Institute for Arts Education & Special Needs	First Children Services / Exceptional Learning	New Frontiers Executive Function Coaching
Center for Career Freedom	First Place AZ / Autism Housing Network	Potential, Inc.
Chapel Haven Schleifer Center	Melmark	Threshold Program at Lesley University
College Internship Program (CIP)	MOVIA Robotics	Westchester Jewish Community Services (WJCS)

AUTISM SPECTRUM NEWS DESK

Mental Health News Education, Publisher of Autism Spectrum News, Welcomes David Minot as New Executive Director

By Staff Writer
Autism Spectrum News

The Board of Directors of Mental Health News Education (MHNE), the nonprofit organization that publishes *Behavioral Health News* and *Autism Spectrum News*, announces important changes in Executive leadership and launches a planning initiative with an eye toward future development.

In a move designed to reflect the increase in technology and strengths of the leadership at MHNE, the father and son team of Ira H. Minot, LMSW, and David H. Minot, BA, will assume new titles effective immediately with Ira becoming *Founder* and David becoming *Executive Director*.

Since the creation of MHNE in 1999, Ira Minot, a survivor of mental illness, was the face and sole leadership of the organization. In 2008 Ira's son David Minot came on board to help launch *Autism Spectrum News* and develop the organization's website in its earliest form.

Times have changed and so has the technology driving MHNE and the website of [Behavioral Health News](#) and [Autism Spectrum News](#). At the January 27th meeting, the MHNE Board of Directors conferred on Ira the permanent title of Founder and resolved to redefine Ira's role so that he would continue as the publisher of *Behavioral Health News* and continue to contribute his exceptional vision to the organization. Simultaneously, the Board elevated David Minot to the position of Executive Director.

"For the past year I have suggested this change in our titles because David has be-



**Ira H. Minot, LMSW, Founder and
David H. Minot, BA, Executive Director**

come the face of the organization and taken on new responsibilities including the redesign of both of our websites, developing our social media strategy, and recently launching webinars, which provide our readership direct access to leaders in the autism and behavioral health communities," Ira stated. "I am not retiring any time soon and will still be publishing *Behavioral Health News* while David continues to publish *Autism Spectrum News*."

"What most people don't know is that my father and I make up the entire staff of MHNE. Running this organization is a labor of love, and we couldn't do it without our wonderful Board of Directors," acknowledged David Minot. "Over the past few years, it became clear that we needed to modernize our content delivery strategy. Our websites have been completely redesigned from scratch, and now visitors are greeted by a media-rich experience that is

much more accessible with thousands of articles now available to read, search and share on social media. We are now also able to publish additional website-only content that can address timely issues such as COVID-19 and better serve the needs of our readership. I am excited to lead the organization into our next phase as a growing media presence providing vital information and education to the autism and behavioral health communities."

Debra Pantin, MSW, MS-HCM, MHNE Board Chair and President and CEO of Outreach, remarked, "We applaud Ira for the effort it took to create an organization and run it almost singlehandedly for over 20 years and at the same time recognize David as the new face of the organization to support his new roles in technology and networking."

About MHNE

Mental Health News Education (MHNE), publisher of *Autism Spectrum News* and *Behavioral Health News*, is a 501(c)(3) non-profit organization that provides a trusted source of education, information and community resources on mental illness, substance use disorders, and autism spectrum disorders to consumers, families, and the professional community. As one of the nation's leading evidence-based publications for the behavioral health and autism communities, both publications provide an affordable and cost-effective opportunity to reach a large, targeted audience now estimated at over 200,000 readers. For more information, visit [AutismSpectrumNews.org](#) and [BehavioralHealthNews.org](#).

Leaders of the Autism and Behavioral Health Communities To Be Honored at May 12th Virtual Leadership Awards Reception

By Staff Writer
Autism Spectrum News

Mental Health News Education, Inc. (MHNE), the nonprofit organization that publishes *Autism Spectrum News* and *Behavioral Health News*, will be honoring five outstanding champions of the autism and behavioral health communities at its Virtual Leadership Awards Reception on May 12, 2021 from 5:00 pm to 6:00 pm.

For more information and to register, visit [BehavioralHealthNews.org/Awards](#).

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

David Minot, Executive Director of MHNE, added, "We are so pleased to have this opportunity to recognize these champions who have dedicated their careers to making a difference in people's lives."

Ira Minot, Founder of MHNE, remarked, "Due to COVID-19, this will be our first Virtual Leadership Awards Reception. This year's event will be an evening to remember as we pay tribute to our distinguished honorees. We cordially invite all colleagues, friends and family members to join in the celebration."

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

Visit [www.BehavioralHealthNews.org/Awards](#)

For Event Details, Honoree Details, Event Sponsors, and Registration Details

A Scaffolded Approach to Supporting Individuals with Autism in the Community

By Ernst VanBergeijk, PhD, MSW
and Krista Di Gregorio
The Threshold Program
at Lesley University

The outcomes for young adults with ASDs are well-known and well-documented. Without intervention young adults with ASD fail to reach basic young adult milestones in terms of independent living, employment, and social and romantic relationships. “Research suggests 70% of individuals with ASD will be unable to live independently, that the cost of supporting each person may exceed 2 million dollars over their lifetime, and that the cost of autism services in the U.S. exceeds \$236 billion dollars annually” (Buescher, et al., as cited in Bruyere et al., P.14216). The unemployment rate among this population is staggering. It was estimated that approximately 85% of individuals with ASD are unemployed (Shattuck, 2012). Roux et al., (2013) found that only 53.4% of young adults with autism ever worked outside the home for pay since leaving high school and this was the lowest rate among disability groups. Further, the team found that young adults with an ASD earned an average of \$8.10 per hour, significantly lower than the average wages for young adults in comparison groups; and held jobs that clustered within fewer occupational types.

Data from the [National Transition Longitudinal Study-2](#) (NTLS-2) indicate that the proportion of young adults with ASDs employed was comparable to young adults with deaf-blindness or multiple disabilities. In fact, individuals with ASDs earned only 86% of what other young people with other disabilities earned. Not only are these young people more likely to be unemployed, but they are also more likely to be underemployed. Half the young people with ASDs worked less than 20 hours a week. That rate is 4 times lower than all other disabilities. On average they worked 23.3 hours per week versus 35.8 hours per week for all other disabilities. This is 36% of the hours that young people with other disabilities work. The proportion of young adults with ASD working full-time is about 1/3 of all other disabilities (26% vs.71%) (Standifer, 2012).

What do we know about encouraging employment and thereby fostering independence among ASD young adults?

Pillay and Brown (2017) identified 4 predictors of employment for individuals on the autism spectrum. Those predictors were: (1) A supported workplace, i.e., a workplace that provides supports such as job coaching in order for the individual to succeed; (2) ASD traits and behaviors (the more significant the autistic traits or externalizing behaviors, the less likely the individual is to be employed); (3) Functional independence; and (4) Family advocacy.

Miligore et al. (2012) found the odds were greater for employment if the individual received job placement services from state offices of Vocational Rehabilitative



Threshold students, staff and alumni enjoying a Red Sox game at Fenway Park. They are able to choose among several special events offered at Threshold each week.

Services. However, they found only 48% of ASD youth received such services. Furthermore, post-secondary college services were the best predictor of better earning which is critical for independent living. Yet, only 10% of individuals with ASDs in the data set received college-based services. Carter, Austin, & Trainor (2011) found six predictors significantly increased the odds of employment after high school for individuals with severe disabilities: (1) Paid community-based employment while in high school; (2) Being male; (3) More independent in self-care; (4) Higher social skills; (5) More household responsibilities during adolescence; and (6) Higher parental expectations for future work.

Do post-secondary programs work?

The research on the efficacy of these programs is preliminary and limited. Wehman et al., (2013) conducted the first research study where post-secondary vocational training was randomly assigned to students with ASDs. The control group were students who received services through the school district and Vocational Rehabilitative Services Offices. The results showed that 87.5% of the students in the post-secondary vocational training group were employed 6 months after training compared to only 6.25% of the control group who found employment. Moore & Schelling (2015) looked at a group that was not exclusively on the autism spectrum, it did include some individuals with ASD and an Intellectual Disability (ID). Their study found 9 out of 10 students (with ID who graduated from a post-secondary program) were employed within 2 years of the study. This was compared to the respondents to the NTLS-2 study where only 1/2 of the high school graduates with ID were employed.

Independent living and employment skills are complex interconnected skills that are comprised of more simple building blocks that can be learned sequential-

ly with scaffolded levels of support. College-based transition programs seek to teach those skills to students with ASDs as well as other kinds of disabilities. The curriculum of these transition programs varies. Parents along with their young adults must explore these programs together to ensure that the program will meet the student's needs and help him or her reach his or her ultimate goals. A key factor is whether the transition program is more academically oriented and leads to a college degree, or whether the program focuses upon life skills including employment and independent living skills. The acquisition of a college degree in and of itself does not guarantee that a student with an ASD will be gainfully employed and be capable of living independently in the community. Transition programs explicitly teach employment skills through classes as well as internship opportunities that are supported with seminars which help the students decipher the social rules of the workplace. Likewise, independent living skills are first taught in the classroom and then are applied to real life settings. Social skills are also taught in the classroom in transition programs and are further reinforced in the residence halls through social programming and in the moment interventions by residence life staff.

The Threshold Model of promoting employment and independent living:
A scaffolded approach

The Threshold Program's two-year core program focuses on developing social skills, living independently and career training. During the two-year residential program, students participate in pragmatic classes including personal finance, computer applications and food lab and participate in multiple internships tailored to their individual interests and goals. Students live in student dorms and learn to navigate on public transportation and explore their local

neighborhoods safely. Lesley University offers an inclusive experience where Threshold students have access to undergraduate courses and can choose to participate in all university activities and athletics.

Threshold graduates have two post-graduate options: the Bridge and Transition programs. A small number of students each year choose the Bridge program. In Bridge, students continue to live in the dorms and further explore their internship opportunities during a school calendar year. Bridge Year strengthens work, independent living, and social skills in a structured setting. Most students opt for a Transition year, taking a next step and move into local apartments. Threshold staff assist students to find paid employment and they also remain supported by Independent Living Advisors. Transition students live independently, and Threshold staff meet with them regularly to provide guidance with cooking, budgeting, apartment upkeep, employment strategies, social interactions and accessing local resources.

At the completion of the Threshold Program, all alumni are entitled to a myriad of free services and support from our Alumni Center. Alumni frequently access employment-related support, such as writing résumés or searching for jobs. We also organize workshops and courses. If alumni just want to find something fun to do, we offer consistent social activities with other alumni. Many of our alumni choose to live in the local area to access the Alumni Center but during the recent pandemic we have expanded our virtual services and opportunities to many out-of-state alumni as well.

Our scaffolded approach to independent living has produced exceptional outcomes. In our most recent independent alumni survey, Threshold graduates reported an 85% employment rate. This is drastically higher than the national average. Seventy-seven percent of our graduates are living independently and 38% pay their own rent or mortgage themselves without additional family support. Happily, many of our alumni continue to enjoy Threshold social opportunities and 50% report being in a long-term relationship or marriage.

Ernst VanBergeijk, PhD, MSW, is a professor at Lesley University in Cambridge, MA and is the Director of the Threshold Program which is a post-secondary transition program for students with a variety of disabilities. www.lesley.edu/threshold. He also oversees the Lesley University Threshold Alumni Center which provides life-long support for graduates of the Threshold Program. Beginning Summer 2022 the Threshold Program will be offering a 6-week summer program focusing upon the acquisition of pre-employment, independent living and social skills.

Krista Di Gregorio is the Director of Alumni and Employment Services at Lesley University Threshold Program. The Alumni Center she oversees offers life-long support to all graduates of the Threshold Program. She and her staff also coordinate services for all post-graduate Bridge and

see Scaffolded on page 35



Lesley University's College-Based Transition Program

THRESHOLD PROGRAM

Here, they'll find their potential.

The Threshold Program is a two-year program preparing young adults with diverse learning challenges for independent living. As part of the Lesley community, our students gain the training and confidence needed to succeed in the workplace, and the real world. They learn how to budget, pay bills, use transportation, engage in their community, and a lot more. And best of all—they make friends they'll keep for life.

- Learn how to live independently
- Explore employment interests
- Gain experience through internships
- Live on campus and become part of the Lesley community
- Graduate with a certificate of completion and six college credits
- Option to continue on to our Transition Year or Bridge Year programs
- Gain lifetime access to our Alumni Center's programs and services

lesley.edu/learning

OUR GRADUATES

95% are happy with their level of independence

85% are employed in at least one paying job

89% are satisfied with their social lives

64% spend time with friends at least once per week



Lesley
UNIVERSITY

The Care and Keeping of Home: How Executive Function Skills Aid in Daily Living

By Alissa Cappelleri, MAT
Program Coordinator
New Frontiers Executive Function Coaching

Navigating independent living requires balancing responsibilities and monitoring oneself. All individuals must strike that balance that makes the most sense for them and their lifestyle regardless of neurodiversity. To execute daily living tasks, one must self-start and sustain motivation throughout despite various distractions and competing priorities. Across the board, this is a difficult ask. There is an inherent lack of external structure to use as a unit of measure and there are limited natural occurrences that lead to true positive reinforcement. The question of “why?” is brought to the table while an individual defines what purposeful action looks like for themselves. Those on the autism spectrum may encounter some challenges establishing a system to conduct a self-sufficient life. Meaning making can serve to be an arduous process as there is much that is open ended and left to be constructed independently. That being said, figuring out how to organize time and prioritize household tasks can be difficult when they do not have the same “fixed” deadlines of school or work. Supporting individuals on the autism spectrum in further developing executive function skills enables goal-directed behavior and promotes accountability.

Executive functions allow for the execution of day-to-day tasks while keeping an eye on what lies ahead. They encompass all the cognitive processes that allow one to move from point A to point B with various amounts of focused effort. Executive functions guide behavior and direct course for problem-solving (Dawson & Guare, 2016). When considering the management of one’s living space, there are various multi-step tasks that are being completed in a sometimes simultaneous fashion. Laundry can be done while dinner cooks in the oven and one engages in another responsibility. This juggling between activities requires a lot of starting, stopping and picking up where the previous was left off. In any capacity, there is a certain amount of potential chaos that brews below the surface.

When providing attention to the following executive function skills, an individual can be better suited to manage day to day responsibilities.

Prioritization and Planning

It is easy to push off tasks that are not tied to external responsibilities. Through focusing attention on the structure of time, seemingly “backburner” items are given a place so that living spaces remain optimal. When looking at one’s roles and responsibilities in a variety of contexts, all can be sorted into the categories of “fixed” and “flexible.” Those components that are fixed are firmly situated within a time constraint or external involvement that create an impetus for completion. Deadlines or hours of operation forced these tasks into a set space on the schedule where the rest



of one’s day is planned around. All that remains flexible are subject to adjustment. Being mindful in this is crucial as it can be very easy for these tasks to fall by the wayside.

Creating structure allows for all to be accounted for and given a designated time to attend to those things that can easily be ignored or have their avoidance justified. While it is important to focus on what is essential, developing blinders to tasks that are not bound by external accountability is not advised. There is no true dire consequence of letting dishes pile up in the sink or forgoing laundry for the third week in a row, but day to day functioning is impacted, thus they are tasks that must be prioritized. For those that struggle with expectations that are not governed by rigid rules, enacting a system to follow can be helpful. A set plan that makes the space for the maintenance of one’s living space builds routine and situates one in a productive habit.

Time Management

Once tasks have been prioritized and a plan to carry them out have been made, it is essential to evaluate the time that will be dedicated and the pacing one needs to move through a schedule. Visual and auditory prompts are helpful here to aid in the transitions from one activity to the next. Making a list of each responsibility that includes the time needed to execute a given task and that is easily accessible serves as a tool of reference. Conceptualizing the passage of time can be difficult so alarms may be increasingly valuable. It is not unusual for ten minutes to feel like seconds or even hours depending on the nature or interest level of a task. Those who struggle with grounding themselves in time can benefit from external markers to help guide through the day. This allows for urgent tasks to be situated within the necessary confines while still making space for the essential but maybe not immediate household needs. Here is where it is possible to make good use of structure in order ensure all bases remain covered. Supporting someone on the autism spectrum may look

ing for a pot to boil on the stove. Having a menu of options of small activities that can be executed within the waiting required of others allows for an individual to be most judicious with the day.

Metacognition

“What is working?” is a question that should be asked frequently when extrapolating the efficiency of one’s system of keeping track of daily living responsibilities. In order to best foster independence, it is essential to provide opportunities to engage in thinking that determines whether or not given methods best serve a situation. Though specific steps are parceled out for each task and can be represented in whichever manner is most suitable for an individual, opportunities to engage in discourse about process allow for increased independence and proactive problem-solving skills. Taking moments to establish the efficacy of systems can ground one in the “Why?” behind a procedure and opens the conversation to determining if present means of being are ideal and where they may be entry points for intervention. It can be that expectations are being met, but the ways to go about it may be a bit roundabout. Exercises in evaluating present productivity and other options help to keep one constantly aware that there has been a commitment to an activity but it is subject to change. The idea here is to build routines but to also pay attention to the need that there may need to be alterations made to those routines over time. While the process for cleaning the bathroom may remain largely untouched, there can be small variances depending on availability of resources and time permitting. Rather than abandoning a task because it seems as though it cannot be completed, being aware of one’s thought processes explores which aspects are possible.

Response Inhibition

There are tasks that one has to do and then there are those that an individual may want to do. An ideal schedule accounts for both. However, it can be hard to find motivation to complete these “have to’s” when the “want to’s” are so tempting. The executive function skill of response inhibition is one that plays a key role in managing adult responsibilities and meeting the expectations of daily living. The self-imposed guidelines needed to care for one’s living space can be difficult to follow independently. Seeking out external systems of accountability can be beneficial so that pace can be kept and commitments remain in place. Setting up times to communicate with an individual at the start of tasks can serve as a prompt that it is now the moment to be engaged in a focused activity. Tying seemingly small tasks to larger picture concepts can help to establish exigence and motivation as well. For example, wiping down the counter as an end of day ritual is one that can be easily abandoned but may serve the purpose of preventing the

like assisting in the crafting of such time-tables or providing prompts in the form of questions to help transition. Knowing there may be some adaptations is necessary as there will be times where tasks may take longer than expected. The creation of buffers between activities can help with the discomfort of moving on and abandoning a task that may not have been completed entirely. It is good to be prepared for when there are moments where the washing machine is not done running so it is not yet possible to move on to putting the clothes in the dryer. Sometimes the timing is off, and flexibility is needed.

Cognitive Flexibility

Unexpected obstacles arise despite how ironclad a plan appears. A dish gets dropped or the timer on the oven shows 5 more minutes, but it is necessary to leave for an appointment at this given moment. Navigating these situations can be difficult due to the nature that they were unplanned and require time that was not accounted for. While it is not necessary to insert time in the schedule for suddenly emergent tasks, one must be able to adjust as new priorities present themselves. In these instances, it can be helpful to model “taking stock” to see what aspects of a set schedule can no longer be adhered to and where flexible items on the agenda can be redistributed to a later time in order to address the new-found item. Attention to self-monitoring skills and cognitive modeling is helpful here as acknowledging the discomfort or inconvenience can validate the frustration that comes along with making room for the unknown. Noting that priorities have changed and walking through the reasons why begins to reconcile the situation and switch between tasks.

Moving from one activity to the next is essential when executing daily living responsibilities. Not every activity requires rapt attention at all times and there is a waiting game that is played. Being able to move from chore to chore in incremental ways makes the most of time. That being said, though it may be time to make dinner, there are tasks that can be done while wait-

see *Executive Function* on page 38

Help us, help you.

Academics • Career • Life Skills
...and beyond!



New frontiers has helped hundreds of clients just like you by providing customized additional support. We work with children through adults on the skills needed to succeed in life.



Executive
Functions



Academics &
Tutoring



Social
Coaching



Life
Skills



Professional Skills
& Development

HUFFPOST

blogtalkradio 


ImpactADHD.com
Helping Parents Help Kids

We're a featured and
trusted organization.



The coaches at New Frontiers have been an amazing help with my son Jordan. Since we moved to a new area he's been having issues meeting new friends and socializing. The coaches helped build his confidence and learn ways to comfortably interact with new people.

- Michael, Parent

Community Living and Inclusion for Individuals with Intellectual and Developmental Disabilities

By Karen Parenti, MS, PsyD,
Krystina Cassidy, MEd,
Kimberly Duhanyan, MEd, BCBA,
and Mary Jane Weiss, PhD, BCBA-D
Melmark

It was not long ago that individuals with intellectual and developmental disabilities were cared for in settings quite separate and isolated and were deprived of full integration into their communities. Thankfully, in recent decades, the entitlement to community living and learning opportunities has become clear, and the integration of individuals with intellectual and developmental disabilities into their communities has steadily improved. Still, much work remains in understanding what components of community involvement matter, in identifying how to enhance these opportunities, in understanding how to increase community acceptance, and in ensuring that individuals with disabilities experience the full range of community immersion experiences.

Individuals with disabilities deserve to become an integral part “of” their communities, and not just go on outings “in” their communities. A goal for community living and full integration should be to achieve meaningful joining with the community, and to ensure that the integration is multidimensional and includes a wide range of activities that enhance quality of life. Ideally, individuals should be engaged in the community not just for errands and essential tasks, but for leisure activities, volunteer events, employment, and social activities. For example, individuals should be encouraged to the extent possible to participate regularly in various activities offered by the local YMCA, church, or community center. Additionally, individuals should be encouraged to participate in neighborhood activities and events, and when possible, get to know and have regular engagement with their neighbors. Activities for engagement can be geared towards individuals’ various likes and preferences, which may differ amongst individuals.

Individuals should also have outreach and maintain connections with their local community liaisons, police officers and community figures. This, in turn, will help individuals with disabilities build meaningful and sustainable relationships with people who are not paid to care for them. Finally, to the extent possible, individuals with disabilities should be given ongoing choices of what community activities they want to be a part of including their level of involvement. This gives them more control over their life and also increases their overall independence and satisfaction.

Community Integration and Quality of Life

Community inclusion and engagement are closely related to the concept of quality of life, which has also been increasingly discussed as an essential outcome for individuals with disabilities. Quality of life is difficult to define, but is related to the



individual’s capacity for contacting fulfillment and joy in everyday pursuits (Ayres et al, 2016; Biggs & Carter, 2017; Parsons et al, 2012). Experiential components that impact quality of life include: housing, employment, leisure interests, and social connections (Schalock, Bonham & Marchand, 2000). Fortunately, there is some agreement on which elements of quality of life are most important (e.g., Bramston, Pretty, & Chipuer, 2002; Plimley, 2007). These include:

1. Emotional well-being, often considered synonymous with happiness
2. Social well-being, associated with connection, engagement, and relationships
3. Physical well-being, associated with general health, level of physical activity, and overall wellness
4. Self-determination, as evidenced by the degree of control and choice
5. Social inclusion, as indicated by community immersion and engagement
6. Personal development, focused on skill development and the attainment of independence
7. Personal rights, including the preservation of dignity

It is interesting to look at this list in the context of community engagement and inclusion. High levels of community engagement lead directly to these indices of quality of life, allowing for social inclusion, enhancing social well-being, and increasing happiness. Being a true part of one’s community also provides for many more opportunities for choice, control, independence, and self-determination.

In addition, meaningful, sustained community engagement provides for much more embedded instruction, as individuals can learn tasks and navigate environments naturally, in real contexts. This is a strong advantage over historic reliance on teaching skills in analog settings, where generalization to the natural environment

is always a concern. Indeed, as more community-based instruction can occur in situ, much less generalization training needs to be conducted. Instruction can be more efficient, effective, and overall enriching.

Community-based instruction also allows for the provision of more specific supports embedded into the community, to create the scaffolded support needed to help the individual succeed. This is a significant advantage over the provision of external supports, and allows for naturally available supports to be provided. Recent explorations of contexts, in which individuals with autism succeed as employees, point to several factors including an increased level of the community’s understanding of autism and the provision of supports within the environment (Dreaver et al, 2020). These supports might be tangible (e.g., visual supports), social (e.g., frequent informal check ins), or formal (e.g., presence of a coach). These same themes of increasing community members’ understanding of autism and individuals with intellectual disabilities and providing multiple environmental supports can enhance success in any community integration context, and can increase the overall success of immersion in community activities.

Dreaver et al (2020) discuss the importance of “match” between the individual and place and/or type of employment, and this concept can be extended to all aspects of community integration. Indeed, individualizing tasks, activities, and environments that are best aligned with an individual’s preferences leads to more success, whether it is a leisure or an employment context. Successful employment experiences also benefit the individual with disabilities in obvious ways, building their skills and confidence, and increasing their quality of life. It also benefits the employer, and the other individuals who work at that site, widely impacting the broader community and creating a diverse and inclusive environment for all.

Summary

The involvement in all aspects of community living serves as a critical quality of life indicator in a variety of ways for

those with intellectual and developmental disabilities. This involvement also enriches the community as a whole.

All human beings should have the opportunity to pursue relationships, employment, and preferred leisure activities. Individuals with disabilities are no exception to this, and when provided with individualized support(s), they can be successful. When a person’s dignity is promoted and care is shown for their well-being, their chance for happiness is increased as is their independence with future undertakings. The level of fulfillment and happiness that can be obtained within the community setting for those individuals can be paramount to their success in all areas of their life.

Karen Parenti, MS, PsyD, is Senior Director of Program Quality Assurance and Family Services for Melmark PA. Krystina Cassidy, MEd is Director of Melmark PA’s Children’s Residential Homes. Kimberly Duhanyan, MEd, BCBA, LABA, is Senior Director of Residential Services for Melmark NE. Mary Jane Weiss, PhD, BCBA-D, is Senior Director of Research at Melmark. For more information, please visit www.melmark.org.

References

- Ayres, M., Parr, J. R., Rodgers, J., Mason, D., Avery, L., & Flynn, D. (2017). A systematic review of quality of life of adults on the autism spectrum. *Autism*, 1362361317714988.
- Bramston, P., Pretty, G., & Chipuer, H. (2002). Unravelling subjective quality of life: An investigation of individual and community determinants. *Social Indicators Research*, 59(3), 261-274.
- Biggs, E. E., & Carter, E. W. (2016). Quality of life for transition-age youth with autism or intellectual disability. *Journal of autism and developmental disorders*, 46(1), 190-204.
- Dreaver et al 2020. Success factors enabling employment for adults on the autism spectrum from the employer’s perspective. *Journal of Autism and Developmental Disorders*, 50, 1657-1667.
- Parsons, M. B., Reid, D. H., Bentley, E., Inman, A., & Lattimore, L. P. (2012). Identifying indices of happiness and unhappiness among adults with autism: potential targets for behavioral assessment and intervention. *Behavior analysis in practice*, 5(1), 15-25.
- Plimley, L. A. (2007). A review of quality of life issues and people with autism spectrum disorders. *British Journal of Learning Disabilities*, 35(4), 205-213.
- Schalock, R. L., Bonham, G. S., & Marchand, C. B. (2000). Consumer based quality of life assessment: A path model of perceived satisfaction. *Evaluation and program Planning*, 23(1), 77-87.

Melmark

Mission First. *Every Individual, Every Day.*[®]

Melmark is a multi-state human service provider with premier private special education schools, professional development, training, and research centers.

We are committed to enhancing the lives of individuals with autism, intellectual and developmental disabilities and their families by providing exceptional evidence-based and applied behavior analytic services to *every individual, every day*.



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



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



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

NEW ENGLAND

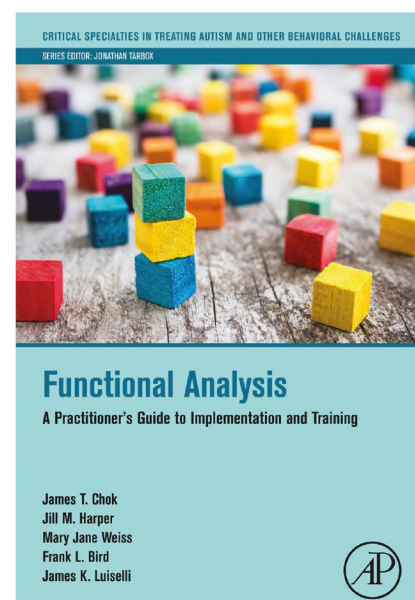
461 River Road
Andover, MA 01810

PENNSYLVANIA

2600 Wayland Road
Berwyn, PA 19312

CAROLINAS

Pineville Church of the Nazarene
8614 Pineville-Matthews Road
Charlotte, NC 28226



Melmark clinicians have published the textbook, *A Practitioner's Guide to Implementation and Training*, now available in hard copy and e-book versions.

WWW.MELMARK.ORG

How Preparing Early Improves Independent Living in Adulthood

By Samantha Smith, MEd, BCBA, LBS-PA, Rebecca Miller, MS, RBT, and Julia Robertson, MS Ed, QASP-S, RBT
Exceptional Learning, LLC

It is never too early to prepare for any skill, but especially skills needed to live independently. Many young adults feel that moving out on their own is a rite of passage, whether that be attending college to live in a dormitory, renting their own apartment, buying their first home, among many other independent living situations. Individuals with Autism Spectrum Disorder (ASD) are far less likely to participate in this rite of passage and sense of accomplishment as reported by Anderson, Shattuck, Cooper, Roux, and Wagner (2014). The cases of Autism Spectrum Disorder are rising at an alarming rate. The Center for Disease Control and Prevention (CDC) reports 1 in 54 cases in America as of 2016, rising from 1 in 150 in 2000. The ability for our country to adapt and guide these individuals to be productive members of society and live a quality life is a tremendous task. With diagnostic evaluations starting in infancy, the ability for qualified professionals, working alongside families, to assist in learning functional living skills is paramount. The earlier we can begin strengthening their communication, social, and adaptive living skills repertoires, the better prepared



they will be for their adult life. In their study on post-high school living situations among adults with disabilities, Anderson et al. (2014) found that strong functional living skills and conversational abilities correlated with independent living situations for individuals with ASD. This resonates with what the autism and behavior analytic communities know to be true about adult living. Think about the expertise most self-sufficient, independent adults should have to live in the community: finding and keeping employment, managing time and money, purchasing and preparing food, keeping a healthy hygiene routine, and completing regular chores to maintain a home, to name just a few. Not to mention the need for developed conversational and social skills for healthy friendships, roommates, professional relationships, and even romantic connections. For a person with autism, this repertoire of behaviors may be

no easy feat to master. If a team waits until late adolescence, potentially 16 or 17 years of age, to begin teaching interventions on these daily living skills, there may not be adequate time for a young adult to successfully master these skills to then transition to independent living arrangements. Additionally, at the age of 21, the availability of support dramatically declines. Expecting a young adult to learn the necessary skills in just a few years is unrealistic and potentially harmful to their future success. The intricacies associated with true mastery of adaptive living skills, social skills, and community skills requires an individual to begin practicing the basics at an early age. For example, someone learning to create a budget must first understand monetary values, how to use cash or cards at the store, how much common items cost and even using a banking app on their cell phone or an ATM. Thankfully, ABA programs use assessments such as the Assessment of Functional Living Skills (AFLS) and Essential for Living (EFL) to inform treatment teams of these crucial aspects of adult life: toileting, health & safety, housekeeping, social awareness, money, living with others, requesting, acceptance, and following directions (Partington, J.W., 2012; McGreevy, Fry, & Cornwall, 2014). Appropriate programming based on community participation and home living

see *Preparing on page 32*



Fanwood, NJ • Maple Shade, NJ • Montgomeryville, PA • Pottstown, PA

Offering the STRIVE Autism Care Continuum

STRIVE is an interdisciplinary continuum of care to diagnose, treat and achieve positive outcomes for children with autism and their families. STRIVE integrates diagnostic services, interdisciplinary behavioral health treatment and other therapeutic services under one roof. Services take place in center, home, and community settings.

We offer a range of services including:

- Autism Screening & Diagnostic Clinic (2 years and older)
- Applied Behavior Analysis (ABA)
- Psychological Counseling
- Social Skills Groups
- Support Groups for Parents & Siblings
- Behavioral Parent Training

☆ Immediate openings at our brand-new STRIVE Clinic, located just off Route 422 in Pottstown ☆

☆ Easily accessible for families in South Eastern Berks County and Western Montgomery County ☆

☆ Join us for our Grand Opening on April 17, 2021 from 11a-2p ☆

500 Creekside Drive, Suites 511-519, Pottstown, PA



For further information please contact Dr. Jeff Selman, VP Clinical Services of First Children Services at jselman@firstchildrenservices.com or visit www.firstchildrenservices.com

Improving Interactions Between Police and People with Autism

By Kristine Quinby, MEd, BCBA, LBS
Founder, President and CEO
Potential, Inc.

A man stands among an aisle at a store. He doesn't talk with anyone or interfere with their shopping, but he's making the store's employees uncomfortable, nonetheless. He picks up a product from the shelf, examines it closely, and returns it to its original place. He repeats the process again and again over the span of an hour, maybe even longer. It's clear he won't be buying anything. What's he doing then?

The longer he remains, the larger the questions looms.

Eventually, an employee will approach the man and ask him to leave the store. The interaction will escalate rapidly, and the police will need to be called. Now, what began as a strange but innocuous situation threatens to unravel and put multiple lives at risk.

The man in question has autism spectrum disorder, unbeknownst to the employee or anyone else in the store. He has the profile of someone who might receive services at my nonprofit, [Potential Inc.](#), which works with people of all ages who have autism and other developmental disabilities to improve their communication, behavior, and social skills, among other basic needs.

In scenarios like the one I've just shared,



it's no fault of either party. Police are trained to respond a certain way, and people with autism don't look any different from anyone else.

By age 21, one in five young adults with autism had been stopped and questioned by police and five percent were arrested, according to a 2017 [study from the A.J. Drexel Autism Institute](#) at Drexel University.¹ And according to [research at the Children's Hospital of Philadelphia](#), people with disabilities, including those on

the autism spectrum, are five times more likely to be incarcerated than people in the general population. Also, "civilian injuries and fatalities during police interactions are disproportionately common among this population."

Growing Awareness

In 2006, as part of a larger effort to address jail overcrowding and reduce the rate of incarceration among people with behav-

ioral health conditions in the county where I live and operate Potential, the commissioners charged the county's Department of Behavioral Health with "leading an effort to develop a more effective response to individuals in crisis whose behaviors bring them in contact with police officers." Two years later, a task force was created with the aim of implementing a Crisis Intervention Team (CIT) model among the county's municipal police departments.

There are many similar models in use today across the country and around the world, but over the last two decades, CIT has become "[one of the dominant paradigms in the United States](#)"² for police interactions in crisis situations involving people in the community with mental, emotional, or developmental challenges.

Through CIT training, police officers learn how to identify these conditions and how to effectively de-escalate a crisis, theoretically avoiding injuries to all involved. The officers also learn how to link people with the appropriate treatment, if necessary, which is intended to reduce arrests and recidivism.

"The overall goal of the CIT training program," as the [Bucks County CIT Task Force webpage](#) says, "is to treat mental illness as a disease, not a crime."

As of 2019, the University of Memphis CIT Center reported that there were

see Police on page 33

We Need You to Reach Our Potential

Potential offers a stable, nurturing work environment that allows Board Certified Behavior Analysts to grow personally and professionally.

BENEFITS INCLUDE:

- ✓ Opportunities for professional growth
- ✓ An organizational culture built on respect, integrity, compassion and teamwork
- ✓ A chance for mentorship by industry leaders in our field (such as Greg Hanley)
- ✓ Collaborative, multi-disciplinary environment
- ✓ Opportunities to present at regional and national conferences
- ✓ Paid professional development opportunities, both internally and externally
- ✓ Medical and dental benefits
- ✓ Competitive wages and guaranteed salary employment
- ✓ Starting salary based upon experience and education
- ✓ Annual performance evaluations and salary increases
- ✓ 403b retirement savings plan with employer match
- ✓ A safe and healthy work environment



WE TREAT AUTISM
POTENTIAL

As a preferred ABA provider, Potential offers individualized programs in the home, school, or our center for people of all ages.

Join our team! Apply at www.potentialinc.org/careers.

POTENTIAL | 170 Pheasant Run, Suite 100 | 215.579.0670 | 888.AUTISM-0 | www.potentialinc.org

Follow Us! [Facebook.com/potentialinc](https://www.facebook.com/potentialinc) | [YouTube PotentialInc](https://www.youtube.com/PotentialInc) | [Instagram Potential.Inc](https://www.instagram.com/Potential.Inc) | [LinkedIn linkedin.com/company/potential-inc-](https://www.linkedin.com/company/potential-inc-)

Increase Neuro-Inclusive Housing in Your Community: Here's How!

By Desiree Kameka Galloway,
Autism Housing Network
and Denise D. Resnik,
First Place AZ

For most people with autism, housing is not affordable. It is a myth that Medicaid pays for housing (unless the individual lives in an institutional setting). If a person with autism can access Medicaid Long-term Support Services (LTSS) that pays for staff, transportation or programs necessary to be part of their community but cannot afford housing, they will potentially be displaced into the “next empty bed” of a group home or host home potentially multiple counties away.

While some may prefer a group home or host home, without planning these crisis placements leave little room for choice of preferred service provider. This displacement can be traumatic and dismantles the significant work and energy invested in finding the right support and ecosystem like friends, faith community, jobs, day programming, healthcare providers and more.

In the U.S., there are no federal programs that provide housing assistance specifically to people with autism. Pooja Paode, a Daniel Jordan Fiddle Foundation Adult Autism Public Policy Fellow, has brought to light the following important findings in her recently published policy review, [Housing](#)



Local leaders stand together as April 21 is declared
“Autism After 21 Day” in Montgomery County, Maryland.

for Adults with Autism and/or Intellectual/Developmental Disabilities: Shortcomings of Federal Housing Programs¹:

- Housing assistance is set aside for people with disabilities in general. This means “disability units” are most often interpreted as being wheelchair accessible, not necessarily neuro-inclusive or incorporating amenities that make housing more accessible to people with autism.
- Currently, fewer than 120,000 people with disabilities benefit from disability-

ty-specific federal housing assistance to live in their own home (Non-Elderly Disabled Housing Choice Vouchers or Section 811 units). This is critically inadequate considering the CDC estimates nearly 5.5 million adults are on the autism spectrum.²

- Even if someone can access housing assistance that is not disability-specific, options are mainly rental units in urban areas. While more easily accessible to public transportation, healthcare, jobs and more, some autistic individuals may

feel overwhelmed with the people, sights and sounds of urban life.

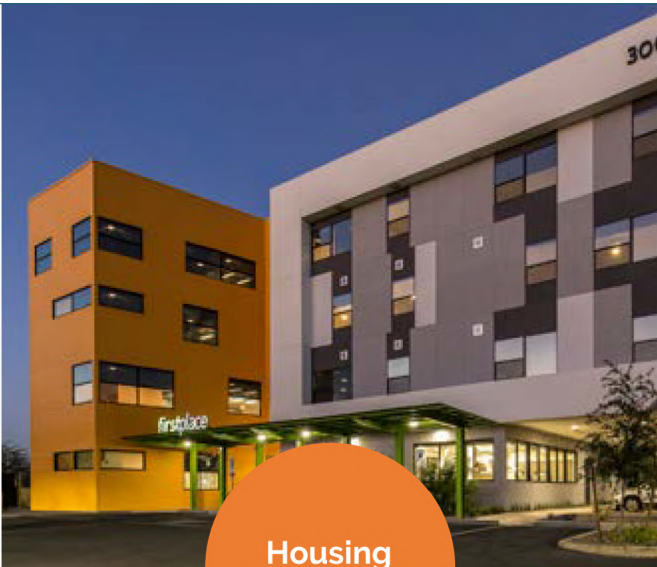
- People with autism living with senior caregivers are not counted in statistics as being at risk of homelessness even though they will likely lose their home when their caregiver passes away or can no longer support them.
- The majority of Fair Housing Act complaints sent to the Department of Justice are for discrimination on the basis of disability.

This may come as a surprise, but local community leaders and the housing industry in general are not aware that people with autism need housing. The reality is the public face of autism is often either a child or an autistic savant like the Good Doctor or Rainman - none of whom are interpreted as needing deeply affordable housing. Unless a housing developer or local official has a child with autism or other intellectual/developmental disability (I/DD), most people assume that they live with family or the government takes care of everything. Unfortunately, these assumptions mean that the future of adults with autism or other neurodiversities is not being considered in general community development. For these reasons, it is imperative that the

see Neuro-Inclusive on page 24



Nomenclature



Housing
Market Guide



Promising
Practices

Developing a New Generation of Housing Options

A Place in the World is a comprehensive housing guide with essential terminology expressing what individuals with autism and other neurodiversities and their families need and want from a marketplace that can deliver. This groundbreaking report defines residential opportunities, informs best practices and helps drive crucial partnerships to address pressing housing needs for special populations.

Join us for the [First Place Global Leadership Institute Symposium Webinar](#) April 7 & 8 and hear from pioneering developers, researchers and healthcare leaders. And visit the Autism Housing Network to find additional resources for creating more neuro-inclusive communities!

aplaceintheworld.org

autismhousingnetwork.org

firstplaceaz.org



Teaching Community Skills to Prepare for Independent Living

By Todd Merritt, PhD, BCBA-D
and Jessica Basir, MS, BCBA
The Arc Westchester

Independent living may be conceptualized as a philosophy of individual control, peer support, self-help, self-determination, equal access, and individual and system advocacy, in order to maximize the leadership, empowerment, independence, and productivity of individuals with disabilities, and the integration and full inclusion of individuals with disabilities into the mainstream of American society (Rehabilitation Act, 1973). Federal regulations mandate that people with intellectual and developmental disabilities (I/DD) have a right to live as independently as possible and that providers help a person reach this goal through the supports and services provided throughout their lifetime (Developmental Disabilities Assistance and Bill of Rights Act of 2000, P.L. 106-402; IDEA, 2004). These supports and services are required to begin in school programs as part of a student's Individualized Education Program (IEP) and continue to be required in adult services through the Home and Community Based Services Waiver's final rule (Home and Community Based Services, 2014). Although these guidelines seek to enhance the level of autonomy and independence experienced by people with



I/DD, DiGennaro Reed et al. (2014) identified a variety of variables that may continue to pose barriers to an individual's ability to live independently. These researchers conducted an anonymous survey of 152 senior citizens, paid staff (e.g., professionals, paraprofessionals, advocates), and family members of individuals with disabilities who identified personal safety, assistance with household skills, assistance with medications, assistance with daily living skills, fire safety, loneliness, and severe weather safety as some frequent barriers to independent living.

Although previous research has identified some barriers to independent living, it is the responsibility of the person's team to identify individualized skills that will address these barriers and better promote independent living. The team responsible for designing and implementing the supports and services must follow a person-centered planning approach, which includes the individual with I/DD and their natural supports (e.g., friends and family members). The first step in identifying the skills to target for instruction is to conduct an assessment to identify a person's current level

of performance and develop supports that will enhance skills that are needed.

There are a variety of assessment approaches that a team may use. A publicly available criterion-referenced assessment that is often used to identify skill deficits, including community skills, is the Assessment of Functional Living Skills (AFLS) (Partington & Mueller, 2012). The AFLS consists of six protocols, all of which focus on fostering independence for adults. While these publicly available assessments provide comprehensive breakdowns of various skills, they must be purchased, require training to effectively conduct the assessment, and may not capture individualized details of a person's skills.

If these publicly available assessments are not appropriate, the team may assess a person's skills using individualized task analyses. A task analysis breaks down any complex skill or a series of behaviors into smaller, teachable units (Cooper, Heron and Heward, 2007). Task analyses can be one of the simplest and most individualized ways to assess community skills related to independent living. Once the team has identified the person's skill deficits, the next step is to develop the supports and services that will be provided through formal or naturalistic teaching opportunities.

Formal instruction is seen most often within school and in-home support

see Teaching on page 30

This is what success looks like...



This is what an adult living with autism looks like!

Building successful futures for adults living with autism takes innovative program development, advocacy, funding – and a belief in their strengths, talents and promise.

The Daniel Jordan Fiddle Foundation Signature Programs provide the blueprints that create opportunities for the diverse population of adults living with autism to build rewarding futures.

To learn more about
The Daniel Jordan Fiddle Foundation
visit: www.djfiddlefoundation.org

To contact us, email:
info@djfiddlefoundation.org

Become a **FAN** of
The Daniel Jordan Fiddle Foundation
on: [facebook](https://www.facebook.com/djfiddlefoundation)



Organizational and Individual Change: The Road to Inclusion

By John Bryson, MS Ed, CESP
and Brad Walker
NEXT for AUTISM

People with disabilities face many documented barriers to full inclusion in society. According to Article 3 of The United Nations Convention on the Rights of Persons with Disabilities, one of the primary barriers is the general public’s attitudes towards people with disabilities. (Merrells, Buchanan & Waters, 2018). Discrimination experienced by individuals with Autism Spectrum Disorder (ASD) limits their access to social and recreational activities, employment opportunities, living accommodations, and community resources. Social stigma may also contribute to co-occurring depression, anxiety, and other mental health conditions (Botha & Frost, 2018). It is also important to note intersectionality of race, ethnicity and disability. The impact of discrimination is even higher for these groups (Hassiotis, 2020).

To improve public attitudes and reduce stigma change must occur at the personal and organizational levels (Fisher & Purcal, 2017). Every community member can promote inclusion by taking steps at the individual level. Self-reflection is the first step in addressing individual bias. That requires awareness of attitudes that guide thoughts, behavior, and feelings. An example of indi-

Simple Strategies to Encourage Inclusion		
Inclusive Strategy	Individual Example	Organizational Example
Evaluate biased attitudes toward people with ASD	Engage in self-reflection focusing on changing biased attitudes	Conduct comparative analysis of employee demographics and community demographics
Address systemic barriers to full inclusion of people with ASD	Ensure your faith communities’ children’s and adult learning programs are inclusive of people with ASD and those with learning differences	Implement inclusive hiring practices that focus on attracting, supporting, and retaining talent with ASD and other disabilities
Increase personal contact and build relationships with people with ASD	Reach out and offer to have lunch with a colleague with ASD, be comfortable with being uncomfortable	Launch disability-specific employee resource groups that share goals with a variety of business operations

vidual bias is social avoidance: community members avoid a person with a disability because of their social discomfort. For many, that is the result of having no previous contact with people with disabilities. (Slater, 2020). Developing interpersonal relationships with individuals with ASD is essential to redress these biases. Only through personal contact with a neighbor,

a colleague, a family member, or through the development of a friendship can social avoidance be mediated and these biases be confronted and changed.

Stereotypes stigmatize people with ASD. For example, it’s falsely believed that people with ASD need to be taken care of, they drain society resources, they are weird. Sadly, these beliefs contribute to the lack

of equitable options for employment, housing, and social engagement for many individuals with ASD. Confronting stereotypes through self-reflection is an uncomfortable but crucial step in the process of promoting inclusive communities (Slater, 2020).

The stereotype that people with ASD prefer to perform repetitive tasks at work has negative effects too. If an employer believes an employee with ASD only has an aptitude for repetitive tasks, they’ll be overlooking that person’s full potential. For example, Charles, an academic, most apt at conducting complex analyses of literature, accepted a job he was offered because he needed to work. The job involved the completion of repetitive tasks. He was not successful at the job he was hired for and eventually lost the job due to poor performance. His next employer understood his specific interests and abilities, and took the time to meet and listen before forming an opinion on how he would fit into their organization. In his current job he provides analyses of research and academic literature to team members. He has never been happier. People with ASD can thrive when people confront personal bias and value diverse backgrounds, choices, preferences, skills, and abilities of people with ASD.

Personal attitudes and beliefs are not the only barriers to inclusion. Change must also occur at the organizational level (Fisher

see Inclusion on page 30

Building Your Career is Personal.

1 on 1 Online Instruction at home!

Convenient, stress-free, private.

Free/no tuition/gov’t paid. Free loaner laptops.

Your choice of your own personal NYSED licensed Instructor.



1hr classes, 8am-8pm, 7 days/week
Rolling enrollment. Start anytime.

Earn your Certificate in Microsoft Word, Excel, Outlook, PowerPoint, Keyboarding & other work skills demanded by most Employers (Indeed.com)

Learn at your pace, take 3-7 months, no deadlines.

And, the Center, in Partnership with Jawanio, Yonkers, will make sure you get a well paying job; PT/FT, close to your home.

Call/text/email Lizzie to arrange for an interview:

914-557-1318 cell, lizzie@freecenter.org

Start your career path today!



The Center for Career Freedom

185 Maple Ave, White Plains, NY 10601

• 914-288-9763 • Freecenter.org •

14yrs & up

We love
Students
with
Special
needs!

Devereux
ADVANCED BEHAVIORAL HEALTH

UNLOCKING
HUMAN POTENTIAL™



Devereux Advanced Behavioral Health positively impacts the lives of tens of thousands of children, adolescents and adults – and their families – every year. We change lives by by unlocking and nurturing human potential for people living with emotional, behavioral and cognitive differences.

devereux.org | (800) 345-1292

Finding Home: Creating a Home that Supports the Individual

By Becky Lipnick
Communications Lead
Vista Life Innovations

Many young adults dread being asked, “What are you going to do after high school?” And this is especially true for those with autism and other disabilities. For many individuals with autism or other disabilities, it can be a big step to leave their family home. Some choose to attend a post-secondary program away from their families, learning the life skills that they will need to manage their own household, establish and keep meaningful relationships with peers and in general live life to the fullest...but even after attending a post-secondary transition program, it can be hard to imagine what comes next. A program like **Vista Life Innovations** knows this firsthand, having guided members for over 30 years. While not always straightforward and smooth, by utilizing and supporting a range of housing types and opportunities, there is a housing answer for everyone.

As a way to test community living, after being in a dormitory setting where teaching and training occurs 24 hours day, Vista offers a “middle step” to independent living through the use of a condominium setting. In these transition condominiums, students are afforded the opportunity to



Patrick and his housemates about to share “family dinner” together at their home

test their independence. Living with up to three housemates, students receive limited (but always available if needed) support from Vista’s staff. Jordan Shamas, a member of Vista’s programmatic leadership, explains, “The transition condominiums allow the students to get a feel for living independently. They get to practice taking care of their home and organizing their schedules using whatever strategies work for them.” Getting used to life outside of

the dormitory can be especially valuable for those with autism and other disabilities who struggle to adjust to change (National Autistic Society, 2020).

Abigail, a student who recently moved into the condominiums, has hung chore checklists around her condo with pictures and notes to remind her to complete tasks, especially the ones that she must do more frequently now that she is living in her own space. One of the great benefits of

the condominiums is that Life Skills Instructors (LSIs) support individuals like Abigail as they adapt to handling everyday tasks. Abigail is also learning to schedule plans with her friends from the dormitory, something which will help her stay social when she moves into her own home in the community. Once students are ready to live independently, many decide to find homes along the shoreline because of friendships made while at Vista.

Following a successful stint of “condominium living” under Vista’s guidance, students graduate from our core training program and move into the community in a variety of settings. Currently, Vista supports nearly 100 homes along the Connecticut shoreline, each of them person-centric and unique in their design. In Patrick’s case, as an adult with autism in Westbrook, he is glad to be living with his four housemates during the pandemic. Particularly during this time of social distancing, the housemates are enjoying spending time together for birthdays, board games, movies at home, and their regularly scheduled family dinners. “One of my favorite memories with my housemates is a water balloon fight we had over the summer,” Patrick says. “It was really, really hot. Oh yes, cooling off was the thing to do, and it was fun to have everyone join in!” The housemates each contribute to taking

see *Finding Home* on [page 37](#)



Vista Life Innovations
Imagining Possibilities ... Empowering Lives

Vista Life Innovations is a post-secondary, residential program located along the Connecticut shoreline dedicated to providing services and resources to assist individuals with disabilities achieve personal success and transition into adulthood.

WESTBROOK • MADISON, CONNECTICUT
www.VistaLifeInnovations.org

Providing services and resources to assist individuals with disabilities achieve personal success

A TRUE COMMUNITY EXPERIENCE


Moving Forward
Towards Independence

Moving Forward Towards Independence is a residential program offering transitional and independent living support to post secondary adults with developmental, learning and autism spectrum disabilities.

Moving Forward Offers Unique Advantages:

- Graduated support levels
- Community life to support the growth of the whole person
- A lifelong community
- A safe, small town location in beautiful Napa Valley

To learn more visit our website at
Moving-Forward.org or call (707) 259-1125

Moving Forward Towards Independence • Napa, California

AHRC NYC Artists Dive Deeper Into Art and Self-Expression With Guidance From MoMA Educators

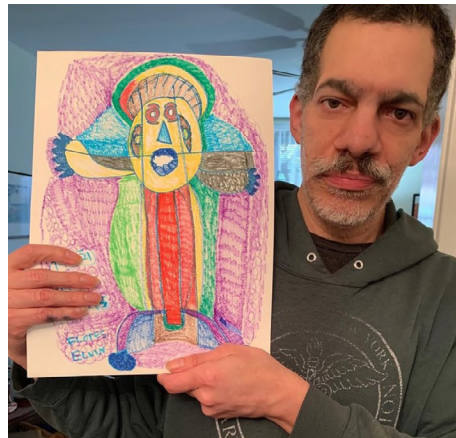
By Lynn Uhlfelder Berman
AHRC New York City

With Autism Awareness Month just beginning and Developmental Disabilities Awareness Month just ending, AHRC New York City is proud to recognize The Museum of Modern Art, just one of our wonderful community partners, which is raising the profiles and enriching the lives of artists throughout AHRC NYC.

The pandemic is bringing out the best in some artists with autism and other intellectual and developmental disabilities (I/DD). Talents are emerging where parents never imagined. The inspiration comes from AHRC New York City's partnership with The Museum of Modern Art (MoMA) Educators.

Carrie McGee, Assistant Director, Community and Access Programs with MoMA's Department of Education, and Theresa Rodewald, Assistant Educator, Community and Access Programs, remotely share pieces from the MoMA collection. They engage the artists, asking what they see and how it makes them feel. Each week they provide a MoMA Challenge, providing a new level of expression for many artists.

Cory Tyler, 41, of the Bronx, has ex-



Elvin Flores with one of his pieces

celled during several challenges. "I drew birds watching TV on the beach," he says. "If I can accomplish one challenge, I know I can accomplish other things."

Another challenge asked artists to create a work that reflects the way you feel. Tyler, who is soft spoken, drew a mountain with eyes in it. He titled it "Silence," reflecting the feeling of always being watched without finding solitude in this space.

Before working with MoMA, Pola-Ana Mora, AHRC NYC's ArTech Manager, said the group would only explore art on the surface. "They're asking how artists

feel when working and how it can relate to practices in their own lives," she said.

MoMA Focuses on Adults with I/DD

Prior to COVID-19, McGee, who has been with MoMA for 18 years, has worked with many different groups, including people with disabilities. The museum strives to make the museum accessible to everyone. Once COVID-19 spread, the team could no longer work off-site with every partner. "One audience we identified as a priority was adults with I/DD," McGee said. "Adults with I/DD could use that social connection and engagement with the museum."

AHRC NYC's Jonathon Epstein, Transition Developer in Adult Day Services, is a Steering Committee Member of the [Museum, Arts and Culture Access Consortium](#), which strives to increase people with disabilities' access to New York City's cultural institutions. Jonathon connected MoMA Educators which led to regular sessions with artists supported at ArTech.

The powerful impact of the partnership is apparent. "Making art and connecting with others over it can be really meaningful over time," McGee said, adding that engaging with art offers the artists an opportunity to express themselves intellectually and emotionally.

Some individuals who never have participated in art programs are creating beautiful work and sustaining it, Darinka Vlahek, Director of Arts and Community Outreach, said. "They may not express themselves verbally, but they are expressing themselves with art. That's part of the value of creating art in COVID."

Artist Takes Matters Into Own Hands

You can hear empathy, as Tom Gambaro describes the pandemic.

"When I saw what was happening during this crisis, it felt really bad," Gambaro said. "Most of the patients in the hospital could be relatives of other people or even old friends. So that's when it hit me. I decided to take matters into my hands."

The Brooklyn artist, inspired by MoMA Educators and the AHRC New York City art staff, has molded 20 clay figurines of doctors and nurses. He works on his own, but the feedback, delivered through remote sessions, has provided an additional spark. He has sold 11 figures on his Instagram page: [@thomastheamazingartist](#). He will donate a portion of the proceeds to a local hospital.

"I'm awfully glad they love it," he said with a smile. "I kind of feel amazed."

Virtual Art Sessions "A Blessing"

Millie Santiago's son, Elvin Flores, calls the virtual art sessions "a blessing." "For over 15 years, Elvin has been an artist who never wanted to draw or paint at home," she said. But that changed when AHRC NYC's programs went remote. "He



Tom Gambaro, of Brooklyn, with one of the hospital staff figurines he molded out of clay

is expressing himself every day through art - with or without the actual sessions. This is new."

"The difference that I have been able to see in his pre-pandemic world view artwork is that he seemed to be able to draw energy from those around him and somehow put that into his work. I believe that is why it was more difficult for him to draw at home. At home now, he takes what is in front of him - a smaller world view - and interprets it."

Making people happy with his art is important to Flores. "As a person, he is always looking to see how he can help others," Santiago said. "As an artist, I believe he wants to do the same thing."

Art Changes a Life

Art has changed Claudia Danies daughter, Sydney. "She's not the same person," Danies said. "I think art has taught her that if you do something positive, you get the attention."

Sydney is calmer and more attentive, Danies said. She has no trouble sitting for a 90-minute Zoom session with MoMA or the AHRC NYC arts staff.

"Sydney has so much more confidence in herself," said AHRC NYC's Vlahek. "Asking her how she feels about something helps her think and puts her in a position to see she can do things."

The walls in Danies' Queens home are covered with art. She has many artist friends. Her daughter never expressed interest in going with her to a museum or creating her own art. But even that has changed. Since participating in AHRC NYC's art program, Sydney has joined her mother on two museum visits. She asks questions and expresses interest in different exhibits.

When Sydney showed her mother her interpretation of Van Gogh's *Starry Night*, drawn on notepaper, Danies was impressed, as was Sydney. She asked how she knew the drawing. "It's a very good interpretation," Claudia said. "Kudos to AHRC NYC for raising the bar," she added.

Lynn Uhlfelder Berman does Public/Media Relations for [AHRC New York City](#).



RECOGNIZING POTENTIAL.

Even in a year unlike any other... Every day, in every program offered by AHRC New York City to people with intellectual and developmental disabilities, potential is recognized.

Contact AHRC NYC - www.ahrcnyc.org or 212.780.4491

AHRC
new york city

Marco R. Damiani, Chief Executive Officer
Sharyn van Reepingen, President, Board of Directors

Robot-Assisted Instruction for Children with Autism: How Can Robots Be Used in Special Education?

By Jean-Pierre Bolat
CEO
MOVIA Robotics, Inc.

In today's high-tech world, quality teaching in special education is an essential factor that many specialists need to fulfill. Special education teachers are well-trained and often receive the latest skills and resources to provide effective intervention for children with autism. However, high expectations and limited funds make it difficult for classrooms to provide the best enrichment that many children with special needs require. Being forced to use old, outdated equipment may compromise the goal of special education programs. Robotic technologies, however, allow educators to use the latest technological breakthroughs, helping students learn while also engaging them in exciting activities and social experiences that enrich their minds.

One way to utilize robots for special needs education is by personalizing techniques to fit each individual student's communication, social, and learning needs. As technology advances, it is only a matter of time before students can easily access the best and latest technological opportunities for improved education.

The Challenges Faced by Children with Autism Spectrum Disorder

Children diagnosed with Autism Spectrum Disorder (ASD) experience many difficulties in traditional school settings. These children need to learn how to interact with their peers, make friends, work with other children, and solve problems in a natural, uncontrolled environment that is accepting and enriching. This can be a difficult challenge for children with ASD. However, there is a useful tool that teachers can leverage. Using robotic technology, children with ASD will be able to practice these needed skills in a safe, non-judgmental, and fun way. By using robots for special needs education now, by the time the next generation arrives, many of the common challenges facing today's children with disabilities will be things of the past. The new paradigm of teaching will then involve robotic innovations that will profoundly affect education, technology, and society.

Educational Intervention of Robotic Assistive Technology

Robotics used to have a somewhat negative connotation when it came to the subject of autism by those who question the efficacy of robotics as assistive technology. The fear and stigma attached to robotics as being "non-human" are enough to discourage some parents from wanting their children to use robotic technology in any way. This stigma, however, is rapidly disappearing as more and more people discover the overwhelming benefits and opportunities robots provide. Since a child with ASD demonstrates various characteristics, ranging from finding difficulty communicating with others to lacking appropriate responses to



Jean-Pierre Bolat, CEO of MOVIA Robotics,
with robots Kebbi and Misty II

particular social cues, such a child needs a safe, anxiety-free, and calming atmosphere in which he or she can practice and make mistakes without judgment or fear. Robots, however, are now being programmed to help handle these and similar challenges.

We all know that robots cannot replace teachers and learning specialists, and this is definitely true; however, the digital age has certainly paved the way for incredible advancements in all sorts of industries, including education. Robotics in education can be used to support, assist, and augment the teaching professional, thus allowing more opportunity for the professional to assess, observe, and analyze a child's performance. Education is such a high priority because, unlike many other fields, it is tough to predict what the requirements of tomorrow might be. This makes teaching special needs students especially challenging, so using various assistive tools and techniques is often a great idea.

Roboticians and software engineers are continually working on the development of Robot-Assisted Instruction for special needs education. These robots will help children with learning disabilities and teach the essential skills that many take for granted. What's more, with Robot-Assisted Instruction, parents can look forward to a bright, new future of interactive learning.

Interactive Robots for Autism

Interactive robots are the next generation of treatment options available to children with ASD. To assist in working with patients, therapists and teaching specialists are now using the latest robotics technology.

While they are constantly developing and improving, these robotic systems already provide a much more robust interaction than is sometimes achieved by only conventional instruction in special education. As negative behaviors are often a barrier to educational access, robots can be key to eliminating children's frustrations by allowing them to express themselves more fully. With an enhanced technological system, parents will have an alterna-

tive to traditional methods for teaching and training their children. This program could change a child's life, providing better preparation for primary education and fundamental life skills learning.

Roboticians aim to create robotic systems that can work alongside a patient in a therapist-based program to improve so-

The Benefits of Robotics in Special Education

An education is about more than just being able to pass a test score, and the development of a child's mind and learning ability goes beyond just basic memorization. On the contrary, an education is about helping each student grow and develop in a healthy, nurturing environment. For any teacher who values the importance of encouraging creativity, inventiveness, and exploring new ideas, the benefits of robotics in special education will prove invaluable.

The benefits of robotics in special education are essential for parents, caregivers,

see Robots on page 37



MOVIA's Robot-Assisted Instruction is helping children with Autism unlock doors, especially during COVID shutdowns and remote learning

Proven Benefits of MOVIA's Robot-Assisted Instruction

Working with MOVIA's systems helps to give children focus, increase their attention span, and accelerate their learning trajectory. Children are motivated to work with the robots and enjoy going through lessons and activities, leading to greater and quicker learning, more time on task, and improved outcomes.

Please contact us for more information!

info@moviarobotics.com

860-256-4797



www.moviarobotics.com

© 2020 MOVIA Robotics, Inc.



Perspectives From Two Adults Living Independently in the Chapel Haven Community

Brave, Bold Kimber

By Kimber Marchesi

Kimber Marchesi came to Chapel Haven Schleifer Center from her hometown of Darien, CT in 2013. She learned how to live independently while enrolled residentially in Chapel Haven's REACH program, graduated and now lives in her own apartment in the community, accessing Chapel Haven's Supported Living services. She publishes her own blog and wrote this column in early February 2021.

You can view the blog here: <https://braveboldkimber.blogspot.com/2021/02/chapel-haven.html>

I came to Chapel Haven in 2013 right when I got out of high school. I was 18 and was scared to go to a new school where I had to meet new friends and learn life skills.

Before I came to Chapel Haven, I had no clue as to what life skills were. As I progressed in Chapel Haven, I learned many life skills including laundry, cooking, and cleaning.

I am very grateful for Chapel Haven and have continued to use the life skills in my apartment! After I graduated from the first program Chapel Haven offers, which is called REACH, I moved into the next program called BRIDGE, where the school introduces apartment living to folks that still need a little support from the support coordinators.

After a year of BRIDGE, I moved off campus to the next level which is called COMMUNITY. I've lived in the community now for four years, starting with a roommate in an apartment, and now I currently have my own apartment and love it!

I work at an art studio run by Chapel Haven Schleifer Center called UArts where the artisans are community members. I work Mondays and Wednesdays, and often pick up additional shifts. I so enjoy working there! I am very fortunate to be a part of an amazing community where I have friends. I live in a great city filled



Kimber Marchesi

with lots of things to do, and have an awesome job!

Mastering Independence at Chapel Haven

By John Nobiletti

In this article I will be writing about what Chapel Haven is, as well as how it helped me along the way with my diagnosis.

Chapel Haven is an independent living facility serving adults with various disabilities. At one point, I was diagnosed with Autism along with an anxiety condition. As soon as we got the news, my family and I began searching through programs that would best fit me and help me get on my way to thrive.

Chapel Haven is known as a state-of-the-art program throughout the world, as they accept clients and students from throughout the world. Chapel Haven teaches all the aspects of life, such as hygiene, cooking, cleaning, shopping, traveling, how to manage money, as well as managing living with a roommate.

When I first started my journey at Chapel Haven, I was a bit anxiety-filled about what my first time being away from home would be like. In my first few months, it took me awhile to adjust. From time to time I would be tempted to return home. But I continued to fight through it and



John Nobiletti

manage it day by day.

When I do go home for a visit, it usually takes 8 hours from where I live in Pennsylvania to travel to New Haven/Chapel Haven. I usually travel by car in which my parents drive me. I currently do not own a vehicle and I have not mastered the subway system. I will be traveling by train in the near future.

I've got to give major applause to Chapel Haven for helping me to overcome the difficulties I was trying to fix, in many different areas of my life. There is a new motto in my book: there is no such thing as you can't. It all comes down to motivation, willingness, as well as dedication.

I have been a part of the program since 2013. One thing I've got to say is, that the whole faculty of Chapel Haven does great work and cares about every student that they serve. When I first started, I was in a huge holding pattern on navigating my life in the right direction. Thankfully I was able to get the right support and stamina that got me through the barrier that I was navigating through and it was not easy. I can kind of compare it to steering a ship - you are steering the ship, so you need to have support and teamwork. Along the way, I came across some great friends and teachers.

Chapel Haven's location is in the Westville, New Haven area. The location is great. It has a city/suburban atmosphere, and it is conveniently located between New

York City and Boston. If you ever want a big city metropolitan vibe, New Haven is located between those two places and is just an hour drive.

As of 2021, aka the pandemic era, I am currently a community member working with the [Chapel Haven CareerAbility](#) vocational department to get me enrolled in a healthcare program that could get me a certification that would qualify me to work in a healthcare setting. Yale-New Haven Hospital is also a great aspect of New Haven seeing how it is rated as a top-notch healthcare facility throughout the nation.

Now, before I end this article. I would like to give some advice for students and parents seeking programs. Chapel Haven would be the one, it is top rated throughout the country and sadly there are not any comparable programs in most areas (I wish there were). It revolves around hard work, being positive and being motivated. Also, they have great recreational activities. It will be a great experience. Thank you all at Chapel Haven for helping me defeat my battle and making this possible for me.

About Chapel Haven: Founded in 1972, Chapel Haven Schleifer Center is an award-winning, nationally accredited transitional living program and approved private special education devoted to helping adults with cognitive disabilities and social disabilities live independent and self-determined lives. Chapel Haven Schleifer Center has grown to serve more than 250 adults (18 years of age and older) in the residence and the community with two distinct programs; REACH and Asperger's Syndrome Adult Transition (ASAT). Chapel Haven Schleifer Center recently completed a \$41.5 million campus expansion at its founding campus in Westville, CT that has delivered a new, four-story REACH residential and classroom campus; a new Welcome Center, and, in 2020, the Schleifer Adult Independent Living (SAIL) center, designed for adults to age in place in a vibrant and non-institutional setting. Contact us: admission@chapelhaven.org or go online to www.chapelhaven.org

Take your next step toward a thriving independent adult life!

For nearly 50 years, Chapel Haven Schleifer Center has empowered adults with social and developmental disabilities to live independent and self-determined lives. With our transformed campus, residential programs, virtual classes & recreation and careful adherence to safe practices, a happy adult life is within reach!



Find us on Facebook
[@chapelhaven](#)

For additional information, contact:
Christy Chandler, Director of Admissions
cchandler@chapelhaven.org or 203.397.1714, x185
www.chapelhaven.org



OPEN HOUSE

Saturday,
April 10th
11am-12:15pm

Register today!
admission@chapelhaven.org

Tools for Growth: Facilitating Community Living Skills Opportunities in Preparation for Independent Living

By Crystal Hayes, MEd and Misty Wagner
College Internship Program (CIP)

Graduating high school, going to college, finding an apartment, landing that first job, getting married - these are all exciting milestones associated with the transition from high school to independent living. For adolescents with autism, formal planning for this transition begins at age 14 with the IEP team, however, it is never too early to begin introducing and reinforcing important independent living skills such as problem solving, adaptability, and self-advocacy.

Many young adults on the autism spectrum have the strong desire to experience these common milestones, yet reality often presents stark differences in outcomes. According to the National Autism Indicators Report (2017), more than half of adults with ASD continued to live in the family home after high school, and 40% of those surveyed did not receive any in-home supports. Even more alarming, a similar report found that “nearly one in three young adults had no community participation...no volunteer or community service activities, no lessons or classes outside of school, or no other community activities outside of school” (Roux et al., 2015, p. 16).

A variety of factors contribute to what is commonly referred to as “the services cliff,” the time immediately following high school when mandated special education services cease and the individual is left to find support from other sources, often without formal assistance. This lack of organized support increases the weight of responsibility on families. Parents of individuals with ASD may wonder how to identify the appropriate level of support and the least restrictive environment for their child - ideally an environment where they will have the opportunity to build meaningful relationships, engage in enriching activities, and embrace independence to the greatest extent.

While independence doesn’t look the same for everyone, comprehensive programs such as College Internship Program



CIP Long Beach students head out for walking and running club

(CIP), focus on actively engaging young adults in the community and facilitating the acquisition of independent living skills in a supported living environment. CIP, which combines components of residential living, socialization, academic support, and vocational preparation, provides opportunities for young adults to learn independent living skills in the natural environment and with full range of access to local community resources and experiences. The goal is to provide the individual with increasing levels of independence while maintaining levels of support that promote continued growth.

The natural environment for learning independent living skills may be in the individual’s residence, in the community (i.e., the grocery store, the bank), or even through an online platform such as Zoom if, for example, role-playing for an online job interview is underway. Choosing the environment in which to practice these skills is an important aspect of self-awareness and self-advocacy, and can be decided upon during the development of the Person-centered Plan, as discussed below.

Tools for Growth

Community living skills range from caring for personal hygiene, self-medicating,

grocery shopping, and apartment safety, to navigating public transportation, scheduling personal appointments, and identifying health care providers. While the list of functional skills and competencies is extensive, three foundational skills that influence success in independent living emerge: 1) the ability to problem solve, 2) the ability to adapt to changes, and 3) the ability to self-advocate. The tools and processes outlined below are critical to empowering individuals with ASD to develop and apply these three foundational skills in their daily lives.

Continuum of Growth

The Continuum of Growth (McManmon, 2016) guides the individual through the process of better understanding and accepting their diagnosis in order to inform decisions and actions that lead to a productive and meaningful life.

Self-awareness, self-knowledge and self-understanding are crucial as the individual begins to acknowledge their own personal traits and those of the people around them. Gradually becoming aware of oneself and surroundings, they begin to discover unique strengths, recognize obstacles, and better understand how they fit within a community. In this stage, an individual is able to begin visualizing

and planning for the future. During the planning process, the team supports the individual with identifying the level they are currently involved in their community versus their desired level of involvement (Callicott, 2003). When an individual enters the **self-acceptance** stage, they are ready to confidently make changes, accept help and seek services within the community.

Self-advocacy is an essential component in nearly all aspects of life, as each individual identifies what they want in life, how to get it, and who will assist them. As confidence grows, individuals begin to **self-disclose** and accept accommodations leading to a healthier and more conducive school and work environment, as well as better access to direct support services. Finally, the last step on the continuum of growth, “**self-determination** allows the ASD or LD adolescent or young adult to start co-existing with comfort in the surrounding ‘neurotypical’ world” (McManmon, 2016, p. 31).

see Growth on page 25



CIP

College Internship Program

“The structure and support at CIP really helped me to thrive”

CIP is one of the most comprehensive transition programs in the world for empowering young adults with learning differences

1:2

1:2 STAFF-STUDENT RATIO

130

130 SOCIAL ACTIVITIES ANNUALLY

20-30 HOURS OF SERVICE WEEKLY

35

35 YEARS OF OPERATION

The College Internship Program (CIP) is a private program for young adults 18-26 with autism, ADHD, and other learning differences.

877-566-9247 | admissions@cipworldwide.org | www.cipworldwide.org


MENTAL HEALTH NEWS EDUCATION
PUBLISHER OF AUTISM SPECTRUM NEWS AND BEHAVIORAL HEALTH NEWS

2021 Virtual Leadership Awards Reception

Celebrating Leaders Making a Difference in People's Lives

Honoring

Marco Damiani

CEO

AHRC NYC

Excellence in Autism Award

Tony Hannigan, LMSW

President and CEO

Center for Urban Community Services

Lifetime Achievement Award

Hillary Kunins, MD, MPH, MS

Executive Deputy Commissioner of Mental Hygiene
NYC Department of Health and Mental Hygiene

Healthcare Hero Award

Allison Sesso, MPA

Executive Director
RIP Medical Debt

Behavioral Health Advocacy Award

Ian Shaffer, MD, MMM, CPE

Former VP and Executive Medical Director
Healthfirst - Behavioral Health (Retd.)

Corporate Leadership Award

WEDNESDAY, MAY 12, 2021

5:00 PM - 6:00 PM EST

REGISTER NOW



2021 Virtual Leadership Awards Reception

Pay online at BehavioralHealthNews.org/Awards or complete this form and mail this page to:
Mental Health News Education, 460 Cascade Drive, Effort, PA 18330

For more information contact Ira Minot, Founder, at (570) 629-5960 or iraminot@mhnews.org

Sponsorship Benefits	DIAMOND \$10,000	PLATINUM \$7,500	GOLD \$5,000	SILVER \$3,000	BRONZE \$2,000	PREMIER \$1,000	FRIEND \$750	1 TICKET \$150
Tickets - Registration Deadline: April 21, 2021	15	10	8	5	3	2	1	1
Sponsor listing on website, in event journal, all promotional materials and social media impression	✓	✓	✓	✓	✓	✓	✓	
Event journal advertisement	VIP Front or Back Page	Platinum Full Page	Gold Full Page	Silver Full Page	Full Page	Half Page	Quarter Page	
Print subscription to either publication	Large Group	Small Group	Individual	Individual	Individual	Individual	Individual	
Print/online advertisement in either publication	Full Page	Half Page	Quarter Pg					
Verbal acknowledgment during event live stream	✓	✓	✓					
Full screen digital advertisement during live stream	✓	✓						
60 minute webinar - Expand your reach with an educational presentation to our targeted readership	✓	✓						
Year-round listing as a sponsor on websites with logo and link to company website	✓							
Video messaging opportunity during live stream	✓							
“Presented By” on event journal cover and at the opening of event live stream	✓							

Event Journal Advertising	PLATINUM FULL PAGE	GOLD FULL PAGE	SILVER FULL PAGE	FULL PAGE	HALF PAGE	QUARTER PAGE	50/50 Raffle Tickets
Pricing - Submission Deadline: April 14, 2021	\$2,000	\$1,500	\$1,000	\$750	\$500	\$300	
Dimensions (in inches - width x height)	5 x 8	5 x 8	5 x 8	5 x 8	5 x 4	2.5 x 4	\$20 per Ticket

Sponsorship Level: _____

Total Individual Tickets: ____

Journal Ad Size: _____

Total Raffle Tickets: ____

Name: _____

Title: _____

Company: _____

Address: _____

City: _____

State: _____

Zip Code: _____

Email: _____

Phone: _____

Event Total: \$ _____

☐ Please find my enclosed check made out to: **Mental Health News Education, Inc.**

☐ Please charge my credit card number below

☐ I am unable to attend but would like to donate: \$ _____ (contributions of \$150 or more will be listed in Journal)

☐ My company has a Matching Gifts Program - Please call or email me

Card number: _____

Expiration date: _____

Security (CVV) Code: _____

Options from page 1

urban life is convenient and empowering, while for others it can be overwhelming. Think about the type of location, home size, shared living opportunity and property type that foster overall well-being for you or those you serve.

Choosing where to live is also tied to desirable life goals. When exploring housing options, consider whether the lifestyle, supportive amenities, physical amenities, access to the broader community, including jobs, education, healthcare and more align.

Choices are also contingent on whether or how a long-term services and supports (LTSS) provider and LTSS delivery model coincide with desired experiences and outcomes. LTSS is the term for assistance with day-to-day tasks such as meal preparation, personal hygiene, housekeeping chores, social outings and general assistance inside and outside the home.

2. The Housing/Service Provider Connection

The ability for people with disabilities to live in a home of their own is largely dictated by the LTSS they can access in that home. Two main categories exist for how LTSS and housing may be related: provider-controlled and consumer-controlled.

In provider-controlled settings, the resident and LTSS provider are exclusively linked. The provider takes care of all housing details and cannot be changed. Residents pay rent or an all-inclusive fee to the service provider. If for some reason this provider can no longer support the resident as agreed, the resident must relocate. Examples of provider-controlled housing include traditional group homes, host family homes or tuition-based residential programs.

In consumer-controlled settings, there is no link between the residence and the LTSS provider; each resident chooses their own provider and can change them if needed and stay in their home. The resident is in control of and responsible for their home



A resident of Marbridge in Manchaca, Texas enjoys a workout. Fitness centers are a key amenity for attracting prospective residents.

setting, including communication with the landlord and maintenance/repairs.

Although most consumer-controlled properties are rental units, there is growing demand for home-ownership options to avoid fluctuations in the rental market and bypass landlords. There is also a growing trend of consumer-controlled, planned communities with built-in amenities designed to serve individuals with autism or I/DD who choose their preferred LTSS provider. The property may also include unique supportive amenities, including various transportation options, a meal plan, organized life skill or social activities, or other cognitive-accessible features, to name a few.

3. Support Needs

Deciding how services are delivered and by whom is an important step in the process. An individual’s level of support needed for personal wellness and community integration is strongly influenced

by daily routines, frequency and nature of care, and those who support them. LTSS are covered out-of-pocket or through Medicaid. Support needs must be aligned with the LTSS delivery model and provider that best suit the individual’s needs. Some people may only need drop-in support, others may have moderate support needs and still others may require higher levels of support such as 1:1 support to help them navigate on a daily basis.

4. Physical and Supportive Amenities

Builders and housing providers are developing their properties in ever-diverse ways, with some offering abundant amenity packages attractive to the neurodiverse market. Consider the growing list of both physical and supportive amenities that extend beyond the property type and LTSS delivery model.

Physical amenities are built-in, residential features that can make life easier and

more enjoyable. Common physical amenities range widely from sensory-friendly design and security features to smart-home technology and transit access. When considering housing, individuals and their families can match their life goals, interests, lifestyles and LTSS needs with the available physical amenities.

Supportive amenities are supports or features that are part of the property and benefit any and all residents; they are not individualized LTSS. Common supportive amenities range from community life and life-skills training to meal service and health and fitness activities. The cost of supportive amenities may be covered in rent or through out-of-pocket fees.

For some people on the autism spectrum who do not have an intellectual disability or may not be eligible for Medicaid-funded LTSS, these physical and supportive amenities can be the difference between homelessness and successful independent living.

5. Funding Options

To live in a consumer-controlled setting, one must be able to afford rent. Affordable housing is very difficult to access. Families should begin planning for housing costs well in advance and, if needed and possible, apply to be put on the waitlist for housing assistance from the local Public Housing Authority.


Housing choices are largely determined by access to LTSS. Adequate Medicaid funding for someone with high support needs to live in a consumer-controlled setting is not available in most states. Advocacy efforts can change this! Individuals and their families must explore the different funding options (often called “waivers” that vary by state) and the reputation of the LTSS providers in their local area. Various funding sources are also listed in *A Place in the World*.

A new generation of supportive housing options are in demand and being delivered. The goal of *A Place in the World* is to fuel a robust marketplace while helping individuals and their families recognize that a diagnosis need not stand in the way of friends, jobs, supportive communities - and homes of their own.

Helpful YouTube Resources:

- A Place in the World: Fueling Housing and Community Options for Adults with Autism and Other Neurodiversities: www.firstplaceaz.org/a-place-in-the-world/
- A Place in the World: Fueling Housing and Community Development for Neurodiverse Populations: www.youtube.be/BKzaf_wnR7Y
- A Place in the World: Housing Market Guide Example, First Place AZ: www.youtube.be/CR3UaUYZy0Q

Desiree Kameka Galloway is the director of the Autism Housing Network, a project of the Madison House Autism Foundation, and a sought-after disability housing expert. Denise D. Resnik is the parent of an adult with autism; founder, CEO and president of First Place AZ; and co-founder of the Southwest Autism Research & Resource Center (SARRC).



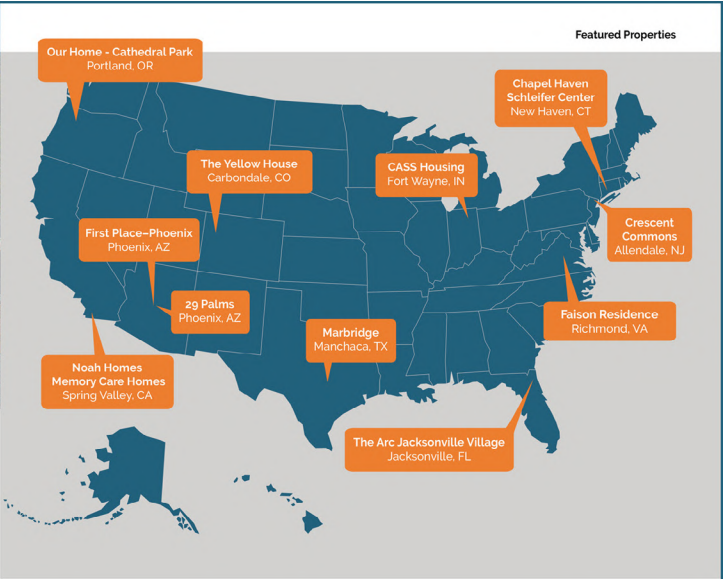
Housing Market Guide

For adults with autism, intellectual and developmental disabilities (I/DD) and other neurodiversities to make meaningful choices about housing and services, they need a range of options that reflect a diversity of preferences, goals, support needs and price points.

Property Selection

This Housing Market Guide is a collection of diverse properties serving a broad range of residents with neurodiversities across the U.S. Properties were selected to illustrate the application of *A Place in the World* nomenclature and represent a variety of:

- Individuals (residents) and their support needs
- Long-Term Services and Supports (LTSS) delivery
- Residential units and housing developments
- Physical and supportive amenities
- Lifestyles
- Affordability
- Funding options



The properties are listed alphabetically by state. The guide provides a snapshot of each property, recognizing that each has evolved over time and will continue to adapt to meet the needs of current and future residents. Contact each property for up-to-date information on availability, pricing and other details.

This guide not only highlights a range of residential options; it can also serve as a source of information and inspiration for individuals and families searching for the housing and service-delivery options best suited to their needs, as well as for developers, advocates and decision-makers who can broaden the number and range of options in communities across the country.

For a more comprehensive roster of innovative housing solutions across the U.S., visit autismhousingnetwork.org/housing.

A page out of the “A Place in the World’s Housing Market Guide,” a comprehensive resource featuring various properties around the country servicing a range of needs and preferences.

Your Child’s Right to an Appropriate Transition Plan

By **Oroma Mpi-Reynolds, Esq.**
Founder & Managing Attorney
MSR Legal & Consulting Services, PLLC

One of the main objectives of the Individuals with Disabilities Education Act (IDEA) is to ensure that children receive an appropriate education that prepares them for further education, employment, and independent living.¹ Accordingly, school districts must develop Transition Plans that are results-oriented. Transition Plans are designed to improve your child’s academic and functional achievement and to facilitate his or her movement from school to post-school activities.²

Post-school activities include:

- Post-secondary education,
- Vocational education,
- Integrated employment,
- Supported employment,
- Continuing and adult education,
- Adult services,
- Independent living, or
- Community participation.³



Oroma Mpi-Reynolds, Esq.

A Transition Plan should be a plan that:

- is based on your individual child’s needs;
- takes into account your child’s strengths, preferences, and interests;
- includes instruction and related services;
- includes community experiences;
- includes the development of employ-

ment and other post-school adult living objectives;

- includes the acquisition of daily living skills; and
- incorporates a functional vocational evaluation.⁴

In New York State, beginning at age 12, your school district should conduct an inventory of your child’s vocational and post-secondary interests.⁵ By age 14, districts in New York begin developing transition goals, aligned with your child’s academic goals, aimed at promoting a solid foundation for higher education or vocational interests.⁶ The IDEA requires that every individualized education program (IEP) created for a child aged 16 or older include appropriate, measurable post-secondary goals based upon age-appropriate transition assessments.⁷ Your child should work on Transition Skills based upon his or her needs in particular areas.

An appropriate Transition Plan will include a coordinated set of activities, known as Transition Services.⁸ Transition Services, including courses of study, are needed to assist your child in reaching the postsecondary goals identified on his or her IEP. Your child should have regular, structured opportunities throughout the school day to acquire specific skills within community settings and to generalize those

skills to a variety of home and community settings.⁹ Activities may include the development of customer service skills at the local grocery store; instruction on the safe use of public transportation; career and technical education; instruction towards career development and occupational standards; cooking; laundry; personal fitness; therapeutic recreation; leisure education; functional communication training; travel training; and social skills training.

With your or your adult child’s consent, the school should engage community resources and invite participating agencies to support a smooth transition to post-secondary life. For example, you may need:

- to petition the court for guardianship over your adult child;
- to apply for long-term care through your State’s home and community-based Medicaid waiver program; or
- a referral to your State’s Vocational Rehabilitation Services agency.

As your child approaches his or her pre-teenage years, try to learn as much as possible about your child’s post-secondary school interests. If possible, your child should attend all meetings where Transition Goals and Transition Services will

see Child’s Right on page 36



**Westchester Jewish
Community Services**

**Provides Comprehensive Behavioral Health Services
via Telehealth and In-Person**

- Dialectical Behavior Therapy
- Trauma Treatment for Child and Adult Survivors of Sexual Abuse and Domestic Violence
- Specialized Counseling for College Students
- Co-Occurring Substance Use and Mental Health Disorder Treatment
- Intensive Outpatient Services
- School-Based Mental Health Clinics
- Specialized Therapy for People with Intellectual and Developmental Disabilities
- Therapeutic Social Skills for Children, Adolescents, and Adults on the Autism Spectrum
- Bereavement Services
- Peer-led Wellness Groups

Contact: Leslie Hernandez, Director of Admitting
(914) 737-7338 x 3119

www.WJCS.com

845 North Broadway, White Plains NY 10603



Special Education Law and Children’s Advocacy

If your child has an IEP, give us a call!

Long Island: 503 Linden St., W. Hempstead, NY
Queens: 89-18 134th St., Suite 1, Richmond Hill, NY

www.MSRLegal.org

Call / Text: (516) 725-5514

Delray Beach, Florida
Addiction and Recovery Therapist
Individuals, Couples and Families

Mindy Appel, LCSW, ACSW, LMFT

Bank United Building
5300 W. Atlantic Avenue - Suite 408
Delray Beach, Florida 33484

appelmindy@gmail.com • www.mindyappel.com
(561) 926-7858

Housing and Supports: Parents are Vital to Positive Post-Secondary Outcomes

By Celeste Lenae Michaud, MA
Lecturer
University of Arkansas-Fayetteville

Keeley is a 23-year-old college graduate who was diagnosed with autism at age 8. To all those acquainted with her, Keeley appears to navigate the community and manage her life independently. Despite her independence, Keeley experiences much of her day with communication breakdowns between herself and others such as friends and co-workers. Keeley also struggles creating and maintaining organization such as planning her day, getting to work on time, and planning for enough food before the next trip to the grocery store. By the end of the day Keeley is exhausted. She finds that she needs time to be herself after a day of adapting to societal norms and finds relief flapping her arms and shaking her head. Keeley wants to live on her own, however she and her parents have been unsuccessful in orchestrating a plan for independent living that allows her to live on her own and receive needed supports.

Introduction

Living independent of your parents is a milestone many look forward to, but for some it becomes nearly impossible due to a complex set of barriers. Adults with



disabilities not only need to locate affordable housing, but also need to weigh out qualifications for support services and medical coverage. These complexities create a challenge for parents, educators, and self-advocates as they work to create the best individualized transition plan possible with the resources available. Parents can implement a systematic strategy to improve post-school outcomes for independent living.

Understanding Qualifications

Adults with autism without intellectual disability, sometimes referred to as “high functioning,” appear particularly vulnerable due to a gap in supports and the misconception that minimal help is needed (Alvares et al., 2020). Such classifications are not helpful when they do not accurately describe a person’s experiences and needs. An adult with autism may be con-

sidered “high functioning” because they do not have a diagnosed cognitive disability, but may experience significant needs for support to lead the independent lives they desire. Unfortunately, qualifications for support tend to be based on cognitive test results rather than a consideration of the whole person’s needs such as sensory, communicative, or self-advocacy discrepancies in the desired environment. Parents that plan ahead, explore available programs, and advocate work to overcome challenges and encouraging change with housing and support needs for adults with autism.

Planning Ahead

Parents can substantially increase positive outcomes for their child with a disability by actively engaging in the transition planning process during Individualized Education Plan meetings (Flowers et al., 2018). Discussing future career and independent living aspirations can guide the team on which assessments to give and determine which skills are needed to work towards these prioritized goals. Additionally, ensuring that the appropriate partners from future environments and services, such as vocational rehabilitation specialist, can promote positive post-secondary outcomes (Flowers et al., 2018).

see Outcomes on page 32

Neuro-Inclusive from page 12

voices of autistic adults and their families are heard and their stories shared.

You do not have to be a policy wonk or professional speaker to be a great advocate! As long as you are willing to schedule a meeting and share your story, you can make a big difference in your community. Here are three ways you can become a powerful advocate for more neuro-inclusive housing in your own community:

1. Ask your local elected or appointed officials to declare April 21 “Autism After 21 Day.”

Local officials are charged with addressing the needs of their immediate community and coordinating government efforts to help meet those needs. They also have to be reelected and should be aware of the voting power of the autism community.

- Schedule a meeting to share your concerns for the future of adults with autism or other I/DD in your community and the risk of displacement.
- Ask that they declare April 21 “Autism After 21 Day” to start raising acceptance of and opportunities for adults with autism. This [Autism After 21 Day Toolkit](#) with sample language can get you started.³

2. Make sure your local planning department and “comprehensive plan” include people with autism.

In every community, there is a planning department that provides design guidance,

reviews zoning and housing development applications, and shapes public policy related to growth, preservation and development. Ultimately, the planning department provides recommendations to an elected or appointed planning commission that either approves, denies or requests changes in community applications (including housing for people with autism or other I/DD). This team also leads a process every 10 years or so to create a comprehensive plan that determines community goals and aspirations. Such a plan ensures growth in the community is sustainable for a balance of future housing, schools, healthcare and first responder facilities, green spaces, retail and other infrastructure like roads and sidewalks. It is important that these two important players in community development understand the housing needs of adults on the autism spectrum so they can plan and ensure all public spaces, buildings and events are cognitively and physically accessible.

- Request a meeting with your local planning department to share housing needs and how spaces in your community can be more accessible; ask that they intentionally include people with autism and other I/DD in the next comprehensive planning process.
- Make sure to share with them the groundbreaking report, *A Place in the World: Fueling Housing and Community Options for Adults with Autism and Other Neurodiversities*, an indispensable guide for how future housing and community development can be more neuro-inclusive.⁴

3. Ask your local housing authority to prioritize housing assistance.

Housing assistance direct to individuals is managed by Public Housing Authorities (PHA) that oversee the local waitlists for affordable units or housing vouchers. They can create “preferences” in policy to prioritize critical needs in their community.⁵⁶ Adults with autism living with aging family caregivers are part of an invisible housing crisis of which they are likely unaware. Tell them people with autism are extremely low income and will be homeless or displaced when their family caregiver can no longer house or care for them. Although they cannot create a preference for a specific disability such as autism, they can create preferences that would prioritize this population to prevent displacement or homelessness.⁷

- Find [your local PHA here](#).⁸
- Plan a meeting and ask how the following preferences can be added to the PHA administrative plan: person with disability, residency preference, single persons with disability who are displaced or homeless, or for specific units designed for people with I/DD receiving services.

Including the interests of adults with autism as an integral part of the community means working together to ensure this often invisible and silent population is finally seen and heard. Your advocacy matters!

Helpful Links

- You Tube video about local communi-

ty action (Autism After 21 Day): www.youtube.com/watch?v=bz1TyKaLAhQ

- Autism After 21 Day Toolkit: www.autism-housingnetwork.org/tool-kit-to-create-autism-after-21-day-in-your-community/

Desiree Kameka Galloway is the director of the Autism Housing Network, a project of the Madison House Foundation, and a sought-after disability housing expert. Denise D. Resnik is the parent of an adult with autism; founder, CEO and president of First Place AZ; and co-founder of the Southwest Autism Research & Resource Center (SARRC).

Footnotes

1. www.firstplaceaz.org/wp-content/uploads/APITW-Report-01.05.21.pdf#page=72
2. www.cdc.gov/ncbddd/autism/features/adults-living-with-autism-spectrum-disorder.html
3. www.autismhousingnetwork.org/tool-kit-to-create-autism-after-21-day-in-your-community/
4. www.autismhousingnetwork.org/apitw-2/
5. www.law.cornell.edu/cfr/text/24/982.207
6. www.law.cornell.edu/cfr/text/24/960.206
7. www.usich.gov/resources/uploads/asset_library/PHA_WaitList.pdf
8. www.hud.gov/program_offices/public_indian_housing/pha/contacts

Practicing with Compassionate Care: A Missing Piece in Behavior Analytic Training

By Ashley Kemmerer, MS, BCBA
Clinical Supervisor
Graham Behavior Services

Becoming and practicing behavior analysis is often synonymous with a strong understanding of the technical components of behavior change procedures. Our training often emphasizes skills such as the memorization of terminology until it becomes second nature, evaluating and conducting research, and implementing evidence-based treatments. But while our technical skills and competence in these areas is important to our practice, there is an element of our training that is missing. That element is the ability to practice compassionate care. Our jobs as behavior analysts almost always involve working with people and, most frequently, the families of young children. Yet we receive little to no training in how to interact with families.

What is Compassionate Care?

There is no technical definition in behavior analysis to describe compassionate care, but the components involved have been identified. Taylor et al. (2018) describe that compassionate care involves interpersonal skills related to sympathy,



empathy, and compassion. They define sympathy as the ability to feel sorry for another but not necessarily with a shared experience. Empathy involves both perceiving the feelings of others and understanding or being able to experience that emotion. Lastly, compassion involves an action related to empathy that is meant to alleviate suffering. Generally, compassionate care refers to the ability to put yourself

in the shoes of those you are working with and provide meaningful support based on those feelings.

Why Is It Important?

Although we know behavior analysis can be useful in many different industries and populations, according to the most recent data provided by the Behavior An-

alyst Certification Board (BACB), most practitioners work with individuals with autism or other developmental delays. This means that many of us are working with families who are in varying stages of life with a child that has a diagnosis. Whether they just received the diagnosis or have had years of therapies and supports, it can be a major stressor. Ignoring the stresses that our clients and their families are going through can be a huge barrier to providing successful services.

Imagine for a moment, someone comes to your home to help you with your child or family member. As they ask you to describe your concerns you become visibly upset and begin to cry. As you're crying the professional says, "Ok great. Thanks for that information. Let's move on to the next question." How would that make you feel? Someone is in your home asking you about sensitive issues and they completely dismiss your feelings.

When a family feels disregarded by the person designated to work with their child it can lead to a negative rapport between the professional and family. There is evidence from other fields such as medicine and mental health that compassionate care can lead to increased patient satisfaction, adherence to treatment, enhanced quality

see *Compassionate Care* on page 28

Growth from page 19

Person-Centered Planning (PCP)

Person-centered planning is a process that brings focused attention to the voice of the individual, taking into account their unique strengths, obstacles, interests and personal goals, and outlining the support necessary to make their desired life a reality. Wehman (1998) commented, "All person-centered planning approaches begin with the belief that all individuals, regardless of the type or severity of their disabilities, not only benefit from services provided by their communities, but also offer their communities many gifts and capacities. It follows then that all people should live and be contributing members of their communities" (p. 25).

Self-advocacy is the cornerstone of person-centered planning. By exploring the following sample questions, support teams are able to facilitate self-advocacy opportunities and ensure the young adult is in the driver's seat when making decisions, adapting to changes in routine or expecta-

tions, and problem solving:

- What are your interests?
- What are the things you value in life?
- What are your strengths and what are the obstacles you face?
- What are your hopes and dreams?
- Who/what can help you make these dreams a reality?
- What are all of the possible outcomes?
- What can you do now to prepare for unexpected changes in your plans?

Conclusion

The PCP process, used in tandem with the Continuum of Growth, can be an empowering experience for individuals with ASD. Understanding that there is room for growth and taking charge of the process

engages young adults in their own learning and development, helps them build valuable self-assessment and planning skills, and prepares them for an independent living experience that best suits their specific needs.

Crystal Hayes, MEd, is the Interim Program Director at the College Internship Program (CIP) in Long Beach. Crystal holds a BA in Music Education and an MEd in Special Education, and has worked in the field of education for nearly two decades. Misty Wagner is the Head Student Advisor at the College Internship Program (CIP) in Long Beach. Misty holds a BA in Special Education and has worked in the field of education for 5+ years.

CIP is a national transition program for young adults with autism, ADHD and other learning differences. For information about their five year-round and summer programs across the US, visit www.cip-worldwide.org or call 877-566-9247.

References

Callicott, K. J. (2003). Culturally sensitive

collaboration within person-centered planning. *Focus on Autism and Other Developmental Disabilities*, 18(3), 60.

McManmon, M. P. (2016). *Autism and learning differences: an active learning teaching toolkit*. London: Jessica Kingsley Publishers.

Roux, Anne M., Shattuck, Paul T., Rast, Jessica E., Rava, Julianna A., and Anderson, Kristy, A. (2015). *National autism indicators report: Transition into young adulthood*. Life Course Outcomes Research Program, A.J. Drexel Autism Institute, Drexel University.

Roux, Anne M., Rast, Jessica E., Anderson, Kristy A., and Shattuck, Paul T. (2017). *National autism indicators report: Developmental disability services and outcomes in adulthood*. Life Course Outcomes Program, A.J. Drexel Autism Institute, Drexel University.

Wehman, P. (Ed.). (1998). *Developing transition plans*. Austin, TX: Pro-Ed.

**Berklee Institute for Arts Education
and Special Needs (BIAESN)**

Arts Education Programs/Graduate Programs
and Courses/Professional Development

berklee.edu/biaesn

 **Berklee**

Behavior Therapy
ASSOCIATES

ESTABLISHED 1979

www.BehaviorTherapyAssociates.com

Providing comprehensive clinical, consulting, and school-based service for children through adults, families, schools, and organizations.
Michael C. Selbst, PhD, BCBA-D
Executive Director

732.873.1212
info@BehaviorTherapyAssociates.com
35 Clyde Road, Suite 101
Somerset, NJ 08873

Tenants Celebrate Two Years of Independent Living in New Residential Model for AHRC New York City

By Lynn Uhlfelder Berman
and Dylan Watton
AHRC New York City

When AHRC New York City asked different departments to identify prospective tenants with intellectual and other developmental disabilities (I/DD) for 12 new Bronx apartments, it was uncertain about what to expect.

But what is abundantly clear after two years is that a partnership among AHRC NYC, the state of New York, and a developer to create affordable housing in the Bronx for people with I/DD has evolved into much more than a home.

"They all know each other, have each other's phone numbers and hang out...all without staff intervention," said Jennifer Teich, AHRC NYC's Associate Vice President, Individualized Supports. "I didn't expect them to gel organically the way they did."

Three ladies attend a yoga class most mornings at a studio around the corner. Three others go to church together. "The support they give each other has made them safer and happier," Teich said.

Then came COVID-19, coinciding with the one-year anniversary of living independently, a goal all the residents identified prior to moving in.

A Major Milestone Amid the Pandemic

The tenants marked their second anniversary at [Parkside Terrace](#) in March. Unlike the first year, there were new rituals to practice: Wash your hands as soon as you come in the house, morning temperature checks and masks, said Jennifer Jimenez, AHRC NYC Residential Habilitation Counselor.

Being home and watching the news also posed some problems. Anxiety increased and one tenant decided to self-quarantine because she didn't want to risk catching the virus. Jimenez took on the role of a mother - repeating herself constantly and reminding people to wear their mask anytime they left their apartment. "We had to be on top of them so they understood how serious it was," Jimenez said.

To support the tenant, who self-quarantined, Jimenez and Blanca Ortiz, Home Care Field Supervisor, explained to her that everyone needs to adjust.

"If you quarantine too long, it will be difficult for you to get used to the new normal," Jimenez said, recalling the conversation. "You need to dip your toe into it." The conversation helped.

The tenants, who already had formed strong friendships, would gather in the staff office off the building's main entrance. The office, which resembles a living room, became a gathering place to catch up with one another or seek assistance.



Walter Glasco enjoys the view from the communal outdoor space from Parkside Terrace in the Bronx

A Place to Call Home

For [Walter Glasco](#), moving into Parkside Terrace ended his bout with homelessness. Through AHRC NYC's employment program, Glasco secured a job at the Staten Island Ferry in 2007. At times, he was so cash strapped he could not afford mass transit. So, he walked nearly six miles to the West Side ferry terminal from a 33rd Street shelter on the far East Side. While sleeping in a train station, co-workers told him it wasn't safe to do that. "I didn't want to go back to the shelter, but I didn't have a choice," Glasco recalled. After my last stay in the shelter system, my Care Manager told me 'I'm going to get you in a good home, your own home.' I was overjoyed when I found out I got selected."

Glasco moved into his studio apartment at Parkside Terrace on March 24, 2019. "The neighbors are nice and I have a sense of privacy," he said. With AHRC NYC's support, Glasco is thriving in his home. "It means a lot to have my own space now," he said. "I'm learning something new every day."

Creative Thinking Reunites Tenant with Birds

Jimenez began working with Nora Katz two weeks after she had moved into the building. Katz, 65, had lived at AHRC NYC's Fordham Oval Plaza in the Bronx for more than 25 years and was ready to move to her own apartment.

Parkside, however, had a no pet rule, forcing Katz to part with her three beloved birds - Cuchi (a cockatiel) and Tom and Mary (parakeets.) "She was so heartbroken without her birds," Jimenez said. Her aunt began looking after them.

Jimenez started researching an idea. Within two weeks, she submitted documentation to certify Cuchi, Tom and Mary as support birds. Katz is thrilled to have

them living with her again.

"They make me happy and are good company," she said. "They give me support."

"This is what makes me happy. I love helping people," Jimenez said. "When someone is hurting, it hurts me too. She really, really missed them."

Mary, however, recently died. In her typical fashion, Jimenez suggested they consult a nearby pet shop about finding a new partner for Tom. "That made her feel a little better," Jimenez said.

Exceeding Expectations

Elizabeth Aguiar, Manager of AHRC NYC's Fordham Oval Plaza, is thrilled to see the three former tenants - Nora, Christie Cuttito, and Carmen Rodriguez - doing so well. "Nora is doing great," Elizabeth said. "She calls us on a daily basis to let us know how she's doing or to ask questions. We're



Nora Katz with one of her support birds enjoys living on her own

very proud of them and happy to know that they're able to do more than we expected."

"This is precisely why we as a field need to raise expectations of the people we support," said Marco Damiani, CEO, of AHRC NYC. "Only then will society erase the stigma surrounding people with disabilities and begin to see their abilities."

"I always imagined I'd live on my own," Katz said. "They said I wouldn't be ready, but I was. I can do what I want in my own apartment."

"Preparing Them for the World"

Catherine Nunez, Assistant Manager, recalled Rodriguez and Cuttito doing their own packing. "But Nora was living here for so long, I had to help her pick what she could take and pack her belongings," said Nunez, who took on additional responsibilities when Aguiar was out on medical leave. "I helped them pick their furniture and set it up. It was a lot of back-and-forth."

The women looked forward to being out in the community. "We were preparing them for the world," Nunez said. "They would have to be more responsible for money management. It was a challenge, but we did it and the outcome was great."

Beth Ann Silvestri, AHRC NYC Residential Coordinator, agreed. "I knew the women would not fail, but I didn't know their lives would be enriched so much with friendships, collaboration in community and general happiness," she said. "Shortly after moving in, I asked Carmen how she was doing. She just smiled and dangled her keys."

An Unfamiliar Process

The process was not easy. It challenged staff members across AHRC NYC to go outside of their comfort zones.

"A lot of times, unfortunately, we operate in our own little world and in our own little bubbles," Silvestri said, adding that other than Teich, no one understood the complexities of applying for affordable housing. The one thing they learned was they had to identify great applicants for housing. "Everybody brought their expertise to the table," Silvestri said.

"Never Doubt Yourself"

Chevonna Fabre is working on passing the written exam for her learner's permit with help from Jimenez. She also has learned how to pay her bills electronically from a check-cashing office. Fabre's advice to other individuals with I/DD: "Go forth; you won't be disappointed. Never doubt yourself. You can do all things."

Lynn Uhlfelder Berman does Public/Media Relations for [AHRC New York City](#). Dylan Watton is the Communications Coordinator for AHRC New York City.

Accessory Dwelling Units Offer More Housing Options and Keep Loved Ones with Disabilities Close to Home

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

Moving out of a family home is often one of the biggest decisions in a young person's life, representing a turn towards independence and a chance to create their own space in the world. While this is a big step for any individual, it can be especially challenging for individuals with disabilities. These individuals and their families are tasked with not only finding a home, but also securing caregivers or other forms of support in the process. Far too many people seeking supportive housing end up on a waiting list for months or even years due to limited availability. This issue was further highlighted during the peak of the COVID-19 pandemic, when many individuals with disabilities were forced to self-isolate but still required support and assistance from their families.

New York has one of the highest estimated adult populations with autism spectrum disorder (ASD) in the country at more than 340,000 individuals.¹ Currently, the primary housing option for these individuals is community-based housing in which



**New York State Assemblyman
Angelo Santabarbara**

they share a group home with other adults. Families of those living in community housing, however, have expressed concern with limited options for family caregivers to provide the individualized support necessary to address their specific needs.² As the father of a son who lives with ASD, this is deeply concerning, and I'm certain

that this concern is shared by other parents thinking about their child's future.

Accessory Dwelling Units (ADUs) are living spaces that share a single-family lot with a larger dwelling, mainly located within, attached to or detached from the main residence, generally containing a kitchen, bathroom and bedroom. ADUs were very common before the increase of suburban single-family homes.

In recent years the demand for ADUs has increased across the country among people of all ages and can be part of the solution here in New York State. ADUs could serve as independent housing for a family member with a developmental disability.³ This would allow disabled individuals to live on the same property as their family members or caregiver, providing them with an easy avenue for support and caregiving while still having their own independent spaces.

ADUs can also be an option for those who hope to remain in their homes as they age and want a different living arrangement that allows them to stay in their communities. Many older New Yorkers also often live in homes without accessibility needs. ADUs can be built with those needs in mind, allowing people to age in place with a family member or caregiver living nearby with the opportunity to downsize to a separate, more accessible home on their own property.

In the New York State Assembly I've proposed a bill that would allow homeowners to access an interest-free loan program for up to \$50,000 or 50% of construction costs to add an accessory unit of up to two bedrooms to their home (A.1410 of 2020).

According to a 2018 study conducted by AARP, 84% of families with a disabled relative would consider building an ADU to care for them.⁴ Unfortunately, cost is often a prohibiting factor, with average costs ranging from \$50,000 for an internal ADU to \$150,000 for a detached ADU. They are usually financed through a combination of savings, a second mortgage or a home equity line of credit.⁵ This challenge calls for proposals to help cut down on these costs by offering an interest-free, potentially deferred-payment loan for the construction of an ADU. This would ease the financial burden on families while also giving them an incentive to look into different methods of care and support other than group homes.

The ADUs covered by the proposal I have introduced could also be used as an alternative to assisted living or nursing home options. For elderly adults diagnosed with Alzheimer's disease or other forms of dementia, the physical and cognitive changes associated with the disease require the eventual need for 24-hour supervision

see Dwelling on page 34

A COVID-19-Inspired Housing Solution for Our Autistic Daughter

**By Marguerite Elisofon, BA
Author, Writer and Autism Consultant**

For many years I've been thinking about how and where our daughter Samantha (now 30) could live independently. She doesn't belong - nor does she want to be - in a group living situation and she is not yet ready to live on her own. After surviving 5 years of roommates at Landmark College and Pace University, it was clear that sharing a room with strangers would never be Samantha's cup of tea.

"I'd rather live with a boyfriend who will one day be my husband," she explained, as if her preference would magically yield Prince Charming and a cozy apartment for them to share. At the time, Samantha had successfully managed a 3-year relationship with an Aspie, living with him part-time in a small studio, so her hope was not totally unreasonable.

My daughter's dream is my dream. But how could we achieve it? Samantha receives SSDI and a small housing subsidy through her Self-Direction program. This stipend is not enough (and probably never will be) for living in Manhattan - the only community she has ever known, where all of her friends reside.

"Why can't you buy me an apartment like some of my friends' parents did?" Sa-



Howard, Samantha and Marguerite Elisofon in their living room

mantha asked many times.

"We can't afford it," was our oft-repeated refrain.

Still, we needed a solution. I signed up for housing lotteries, checked with Housing Ambassadors and even joined a group of parents whose goal was to find safe affordable apartments in Manhattan for our adult kids with or without support. None of these possibilities came to fruition. Clearly,

I could not rely on "the system" or anyone else. I knew I had to find an idea that would work for Samantha, who has yearned to be independent from the time she was a preemie infant in her crib struggling to turn her head. When she was stuck face down and I gently nudged her cheek, Samantha immediately turned in the opposite direction and screamed in fury. Our daughter has always been uber-determined to accomplish

as much as possible on her own.

In the meantime, Samantha continues to live with us in the rental where she grew up. But after her twin brother moved to Los Angeles in 2016, we started to think about buying an apartment. We no longer needed a third bedroom (though having a den was nice). Crunching the numbers, my husband figured that if we continued to rent our current Manhattan apartment, we'd probably spend a million dollars over 10 years, or until we could no longer afford it. Crazy right?

If we waited until rising rents and (my husband's eventual retirement) forced us to leave our current apartment, we'd have nothing to show for that million dollars of rent after 10 years. Worse still, our daughter would be left with no money and unable to live anywhere in Manhattan.

So, what is the solution for our family? Buying a co-op with all our names on the lease, so that when we are gone, Samantha can stay in the apartment and not have to pass the co-op board (which she could never do on her own).

After looking for nearly two years at two-bedroom co-ops and condos which allow co-purchasers, I became discouraged - until COVID-19 drove down prices. With so many Manhattan families fleeing the city for second homes or purchasing homes in areas where schools were open, real

see Solution on page 35

My Child with Autism Needs Anesthesia - What Should I Know?

By Sean P. Antosh, MD
Pediatric Anesthesiologist
Dayton Children's Hospital

Children with autism spectrum disorder (ASD) have an increased rate of hospital contact and are likely to require sedation and anesthesia for surgeries, procedures, and imaging tests. Lee et al. has demonstrated that children with autism were about two to three times more likely to experience an injury that needs medical attention. These hospital encounters create a stressful environment for patients with autism due to their need for a routine and inability to adapt to a quickly changing environment. Additionally, patients with autism are at an increased risk of adverse events occurring during hospitalizations. These adverse events, as described by Taghizadeh and colleagues, are more likely to occur if there is a failure to consider a child's routine, special interest, sensory sensitivities, and level of understanding. Preparation, understanding, and knowledge by the patient, parents, and care staff helps facilitate a smooth transition and ultimately a beneficial outcome.

Preparation for Anesthesia

Surgery is a stressful time for any patient, but especially those with ASD as they may



be overwhelmed due to the numerous new people they will meet, the new experiences of sights and sounds, and the inability to verbally communicate. Therefore, it is important to prepare early for the encounter. In his article entitled “[In the Doctor's Office: A Parent Perspective](#),” Mills discusses how social stories can help facilitate a successful experience by decreasing surprises through visual desensitization. The stories often include simple, reassuring descriptions and photos of different places the pa-

tient may visit while at the hospital, whom they might meet and what might happen. These social stories can be tailored with specifics by the facility that will be taking care of the child.

Another valuable preparation step is the development of an individualized coping plan. Swartz and colleagues have shown an individualized plan is helpful in the perioperative management of children with ASD and that knowledge of the severity level may be helpful in determining the

need for preoperative sedation. During the preoperative phone call, it is important to identify the patient's cognitive level, methods of communication, interests, stressors/triggers for maladaptive behavior, sensory challenges, as well as previous medical encounters and how they do with transitions. From this information, the team can modify the experience to best accommodate the child's needs and avoid potential triggers and warning signs of overload. As the child's advocate, parents can be proactive in requesting sensory friendly resources and a quieter environment. A sensory-adapted environment can help to reduce anxiety and improve compliance with medical situations. Many pediatric facilities have child life specialist who may help throughout the perioperative care. If the facility does not typically take care of ASD patients, it is important to bring coping and distraction objects. Additionally, it is helpful to discuss with staff how they can better provide care for the patient.

During the preoperative phone call, it is important to discuss if there is a flexible admission process. For example, is priority timing given to ASD patients, so they do not have to wait all day for their surgery or procedure? Is it possible to decrease the wait time prior to the start of surgery? Can other imaging studies, lab work, and/or tests be accomplished during the same anesthetic?

see *Anesthesia* on [page 37](#)

Compassionate Care from [page 25](#)

of information gathered, and improved clinical outcomes (Taylor et al., 2018). As most of us know, parent involvement is an important part of clinical treatment for children with developmental delays. Our ability to practice compassionate care could greatly improve parents' adherence to treatment plans and participation in parent training.

It is also important to remember that our ethics code speaks to the importance of client and caregiver relationships, clear communication, and client preference. A behavior analyst practicing with compassionate care will likely be more successful at adhering closely to those ethical codes.

Lastly, working to practice compassionate care can also potentially improve the overall job satisfaction and happiness of behavior analysts. Even though as behavior analysts we often don't like to talk about feelings, we cannot discount their relevance to everyday life. Decreasing our stress and improving happiness within the context of our jobs can make us more effective practitioners, as no one functions at their best when they are unhappy and stressed.

How Do We Put Compassionate Care Into Practice?

Currently, most behavior analytic training programs do not focus on teaching compassionate care skills. As long as that continues to be true, those of us in the field need to work on these skills on our own.

A possible first step is to generally work on improving our own perspective taking skills. It may be helpful to use elements of Acceptance and Commitment Therapy (ACT) and mindfulness to achieve this. These therapeutic strategies often focus on acceptance, values, and awareness in the moment. They can also help to work through being presented with aversive stimuli such as an emotional parent.

Another way to begin practicing these skills should be to focus heavily on the individuality of each of your clients. To look at behavior analysis as a set of principles rather than a manualized protocol. In a recent article, Callahan et al. (2019) drew a comparison between “traditional behavior techs or analysts” versus what Foxx originally coined as “behavioral artists.” Behavioral artists have a set of interpersonal skills that make them more effective at their job and they generally provide a behavior analytic treatment that looks more televisable. The treatment being televisable refers to a level of safety, respect, and rapport between the clinician and the client and their family. This type of treatment could be viewed by anyone and anytime with positive feedback, such as, “That looks like something I would want for my child.” The article lists seven characteristics that represent a behavioral artist:

1. Likes people and is good at establishing rapport
2. Has “perceptive sensitivity” and attends to very subtle changes in their client

3. Actively avoids failure and sees difficult clients as a manageable challenge (genuinely wants their clients to succeed)
4. Has a sense of humor
5. Is optimistic and sees behavior change in a “glass half-full” context
6. Is thick-skinned: doesn't take negative client actions towards themselves personally; maintains objectivity and positivity
7. Is “self-actualized”: does whatever is necessary (creativity) and appropriate to facilitate and produce positive behavior change

Although it would of course be best if all of these skills came “naturally” to each of us in the field, it does not mean that these skills cannot be acquired over time. We should all focus on changing our own behaviors in the target direction of these characteristics. Making our own behavior changes will benefit our clients as well as our own well-being and satisfaction as a behavior analytic practitioner. It will certainly take practice, but we all know that behavior change is possible with the right strategies put into place.

Ashley Kemmerer, MS, BCBA, Clinical Supervisor at Graham Behavioral Services, has been working in the field of ABA for more than 10 years and has been a board-certified behavior analyst (BCBA) for the last 8 years. She is currently pursuing a PhD in applied behavior analy-

sis and works as a clinical supervisor for [Graham Behavioral Services](#) in New Jersey. Ashley has worked primarily with children and adolescents with various diagnoses in the school, home, and residential settings throughout her career in ABA. She has always been passionate about working with individuals with special needs and is thankful to have made a career out of it.

References

Callahan, K., Foxx, R. M., Swierczynski, A., Aerts, X., Mehta, S., McComb, M., . . . Sharma, R. (2019). Behavioral artistry: Examining the relationship between the interpersonal skills and effective practice repertoires of applied behavior analysis practitioners. *Journal of Autism and Developmental Disorders*, 49(9), 3557-3570. <https://doi.org/10.1007/s10803-019-04082-1>

LeBlanc, L.A., Taylor, B.A. & Marchese, N.V. (2019). The Training Experiences of Behavior Analysts: Compassionate Care and Therapeutic Relationships with Caregivers. *Behavior Analysis in Practice*, 13(2), 387-393. <https://doi.org/10.1007/s40617-019-00368-z>

Taylor, B. A., LeBlanc, L. A., & Nosik, M. R. (2018). Compassionate care in behavior analytic treatment: Can outcomes be enhanced by attending to relationships with caregivers? *Behavior Analysis in Practice*, 12(3), 654-666. <https://doi.org/10.1007/s40617-018-00289-3>

A Parent Advocate's Hard-Fought Journey

By Dr. Renee Kasinsky
Parent Advocate

Throughout Daniel's life I have advocated for my intellectually challenged son on the autistic spectrum. My journey began early in Daniel's life, as the parent of an adopted infant from Peru. I have learned throughout Daniel's life that advocacy is an art that requires flexibility, networking and at times outright doggedness. During my journey I always understood the importance of passion, confidence, and a larger vision based on Daniel's special abilities. But I also had much to learn to become informed and effective. Advocacy requires learning how the system works and taking advantage of all the avenues within it to advance your child's well-being as well as to create system change. Successful advocacy requires a multi-pronged approach using strategies both inside and outside of the system. Daniel's school age years required using different strategies than as a young adult faced with less available resources. Step by step, evaluating my options and networking with others, I "kept on keeping on" until I reached successful outcomes for my son. Follow along with me on my long and twisted journey as a parent advocate.

My initiation into the world of special education advocacy began when Daniel



Dani and Renee marching for Peace in Cambridge, MA

was in the first grade. He was struggling learning to read. Daniel's IEP team was unwilling to provide him with additional reading help. I went to the state Bureau of Special Education Appeals, representing Daniel without a lawyer. I was told that the odds for parents winning were almost nonexistent. Undeterred, I used the Hearing Officer of this appeal as my resource to inform and assist me with the process. The officer made a favorable finding. Daniel re-

ceived reading practice before school with his classroom teacher as well as additional extended summertime services. This early success spurred me on to further advocacy.

In 1997, the Massachusetts state special education standard, "maximum feasible benefit" (Ch. 766) was under attack, substituting the more limited federal standard of "free and appropriate public education." Together with hundreds of other advocates, educators, and special needs parents, I tes-

tified at a hearing in the Massachusetts State House, citing my son's experience. In this lobbying experience, I witnessed how the power of advocating together with those with similar interests can reverse power dynamics. A decade later, parent lobbying helped pass the legislative Autism Omnibus law in August of 2014. It expanded the Department of Developmental Services (DDS) eligibility criteria for individuals with autism and those on the autistic spectrum. My participation in these hearings inspired me to seek change within my Cambridge SPED system.

In Daniel's second grade I became the local Parent Advisory Council (PAC) parent Co-Chair for Special Education. It gave me a network of parents experiencing similar problems with their children. I became acquainted with various parent advocacy groups, including the Massachusetts Federation for Special Needs. The Federation offered a parent training on state special education regulations. Armed with training, I began advocating for other students. I consulted a seasoned advocate, a founder of Ch. 766 and the Federation, who informed me how to evaluate the Cambridge SPED programs using the federal Department of Education. Her contact initiated a federal Review finding more than twenty major noncompliance issues throughout Cambridge schools. How special education

see *Parent Advocate* on [page 34](#)

Community Living in the Era of COVID-19

By Nicole LeBlanc
Disability Rights Activist
Human Services Research Institute (HSRI)

As we cope with the disruption of this pandemic, many of us are wondering what our new normal will look like on the other side. Before COVID-19, many people with disabilities went to day programs or had individualized 1:1 staff supporting them at work or in activities in the community. Now, because of COVID-19, we are all being forced to see and make connections to the community in a mostly virtual way.

In the face of COVID-19 our society was forced to make drastic changes in how we live our day-to-day lives. Some of these changes, like moving our work, schooling, doctor's appointments, and events to a 100% virtual format, busted long-held myths and made services and the work world more accessible to people with disabilities. But we still have a lot of work ahead to maintain and grow the progress made in the area of accessibility. Especially as we move from a pandemic to a post-pandemic world.

Going back to the old way of doing business is not acceptable to the disability community because the old normal did not work for many of us who were denied basic accommodations in our day-to-day lives. Many of us were denied access to the sup-



Nicole LeBlanc

port and accommodations we need to thrive and grow. We must embrace a new normal that accommodates and plans for life with a disability or chronic health issue.

Healthcare and Access

In a pandemic world, one thing that would greatly benefit people with disabilities, seniors, and others is a return of doctors and nurses doing house calls and a growth of hospital-at-home programs. Policy chang-

es like this are needed because it is now more important than ever that we get serious about addressing health disparities in people with developmental disabilities and moving away from one-size-fits-all models of medicine and service delivery. I say this because people with disabilities have some of the highest death rates and risk for poor outcomes if they catch COVID-19.

The future is flexibility; the days of a one-size-fits-all way of providing services are over. A one-size-fits-all service or living model is bad policy because it can have a negative impact on our health and quality-of-life outcomes. A one-size-fits-all system is also not very accommodating in meeting our unique needs. And COVID-19 has proven once again that living in segregated settings is hazardous to our health and survival.

Finally, we must use the lessons learned from this pandemic to transform our system to focus more on preventive care. As a society, we need to move away from the model of "wait for disease and then rush in to treat it." Shifting to home visits will allow people with disabilities and other vulnerable populations to receive preventive care and disease management without having to worry about the risk of catching COVID-19 when traveling to a doctor's office. House calls could also help independent doctors stay in business given that many private doctors have reduced services during this pandemic; according to a report

from the American Medical Association, [81% of Primary Care Doctors are providing fewer in-person visits during COVID](#). Delaying preventive care can backfire in the long term. We know that by putting off cancer screenings and immunizations against deadly diseases we risk long-term consequences to public health outcomes. Home visits will go a long way toward helping people with chronic health problems, sensory issues, and transportation challenges to access healthcare in a safe way. In [a recent survey](#), "92% of adults say care at home is equal to or better than facility-based care."

While this change is especially important during the pandemic, in a non-pandemic world these changes are also beneficial, given the many access barriers people with disabilities and other populations face in receiving needed services.

Online Services

During the COVID era, everyone has had to adjust what community means to them. People's community lives are happening online, including their shopping, banking, working, schooling, doctor visits, and social gatherings. Today's community living requires equal access to technology. But many of us face challenges with this.

Many of us live off of SSI or SSDI and

see *COVID-19* on [page 36](#)

Teaching from page 13

within school and in-home support programs where teaching is delivered in a systematic way. This type of instruction typically occurs in a controlled environment (e.g., classroom) and is most often used when a person is first learning a skill. An example of formal instruction may involve working with a person on the skills required to maintain a conversation. The prepared lesson will focus on specific social skills and may use a script or hypothetical examples.

While formal teaching is a crucial aspect of skill acquisition, instruction should not be limited to only formal opportunities. It is vital to use naturally occurring situations and events to reinforce skill acquisition in the person's everyday life. Naturalistic or incidental teaching takes place in the person's everyday environment by using naturally occurring teaching opportunities that occur throughout the day. An example of naturalistic teaching may include a money management lesson while a person is at the mall with a caregiver. If the person expresses interest in purchasing new shoes, naturalistic teaching would involve the caregiver using this opportunity to provide meaningful instruction towards enhancing the person's skills so they are better able to complete the transaction independently in the future.

When planning for formal or naturalistic instruction, the team must simultaneously plan for generalization across various settings, people, and situations over time (Cooper, Heron, and Heward, 2007). The goal of generalization is to ensure that the learner will be successful with performing these skills independently when faced with novel situations in the future. Because there are many variables in the community, planning for generalization is critical.

The last step in the instructional planning phase is to set mastery criterion and



Todd Merritt, PhD, BCBA-D

program for progress monitoring. Mastery criterion refers to the level of independence at which the team would consider the skill to be learned (Cooper, Heron and Heward, 2007). This criterion is established based on the individual needs of the learner and it is important to note that not every learner will define success or independence in the same way. The team should take a person-centered approach and base the mastery criterion on the person's goals and abilities. Progress monitoring involves periodically assessing a previously mastered skill and determining if the person demonstrates the same level of mastery over time. Consistently monitoring for success, even after skills have been mastered, ensures that lapses in acquisition or generalization can be identified and addressed.

Independent living may be considered the ultimate goal for people with I/DD and the team must continue to keep this goal in mind when designing supports and services. Through a person-centered planning approach, the team can identify how



Jessica Basir, MS, BCBA

to best help a person achieve this goal. It is important that the individual and the natural supports available to the person play an active role in both the development and implementation of supports. Although this independent living goal may not be realized by all, there are approximations of independent living that allow for the supports and services to be tailored to best meet the needs of the individual. Individuals with I/DD may live with their natural/biological families and receive supplemental supports to enhance their independence, supervised community programs with 24/7 staffing supports, supported living arrangements with various levels of staffing supports, or independently and receive minimal supports elsewhere. A person may demonstrate greater independence towards independent living when supports and services are focused on skill acquisition. As the needs of a person change throughout their lifetime, the paid and natural supports that are available to them should be customized through the person-centered planning process to pro-

vide the greatest level of independence possible.

Todd Merritt, PhD, BCBA-D, LBA-NY is Director of Behavioral Services and Jessica Basir, MS, BCBA, LBA-NY, CT is a Behavior Intervention Specialist at The Arc Westchester, the largest agency in Westchester County, NY, supporting individuals with developmental disabilities, including those on the autism spectrum, and their families. For more information, visit www.ArcWestchester.org.

References

Cooper, J. O., Heron, T. E., & Heward, W. L. (2007). *Applied behavior analysis*. Upper Saddle River, NJ: Pearson Merrill Prentice Hall.

Developmental Disabilities Assistance and Bill of Rights Act of 2000, 42 U.S.C. § 15001 et seq. (2000). www.congress.gov/106/plaws/publ402/PLAW-106publ402.pdf

DiGennaro Reed, F. D., Strouse, M. C., Jenkins, S. R., Price, J., Henley, A. J., & Hirst, J. M. (2014). <https://doi.org/10.1007/s40617-014-0011-6>

Home and Community Based Services, 42 C.F.R. Parts 430, 431, 435, 436, 440, 441, and 447 (2014). www.govinfo.gov/content/pkg/FR-2014-01-16/pdf/2014-00487.pdf

Individuals with Disabilities Education Act, 20 U.S.C. § 1400 (2004). <https://uscode.house.gov/view.xhtml?path=/prelim@title20/chapter33&edition=prelim>

Partington, J. W., & Mueller, M. M. (2012). *The Assessment of Functional Living Skills*. Marietta, GA: Stimulus Publications.

Rehabilitation Act, 29 U.S.C. § 701 et seq. (1973). <https://dhs.sd.gov/drs/Section%207%20Rehab%20Act%202014.pdf>

Inclusion from page 14

& Purcal, 2017). Organizations have tremendous influence over the attitudes and beliefs of their communities. For example, businesses have the power to influence inclusion on a massive scale through a variety of strategies. They include inclusive hiring practices, issuing public statements about inclusive hiring, partnering with disability service organizations for public service announcements, and including people with ASD as stakeholders in decision-making. These efforts increase the personal contact of employees and customers with individuals with ASD, further reducing stigma through the development of relationships between people with and without ASD. Organizations make decisions about who to include and empower every day.

Are businesses, faith and community organizations, social groups, educational institutions, and government agencies creating opportunities for people with ASD to contribute? These are essential questions not asked often enough. Leaders in these organizations can learn about the benefits of inclusion, through full representation from the community, including people with ASD. Listening to and empowering people with ASD is a choice (Risley, 1996).

The most important thing anyone can do to create inclusive communities is to have friendships and relationships with people



John Bryson, MS Ed, CESP

with disabilities. Choose to listen and learn from them. Embrace the feeling of discomfort that comes with change. Use the experience to advocate for inclusion. Inspire others to be the change you want to see in the world.

John Bryson, MS Ed, CESP, is Senior Manager, Corporate Consulting, and Brad Walker is Vice President, Community Living Supports at NEXT for AUTISM. Contact John Bryson by e-mail at jbryson@nextforautism.org. Contact Brad Walker



Brad Walker

by e-mail at bwalker@nextforautism.org. NEXT for AUTISM can be found on the web at www.nextforautism.org.

References

Botha, M., & Frost, D. M. (2018). Extending the Minority Stress Model to Understand Mental Health Problems Experienced by the Autistic Population. *Society and Mental Health*, 10(1), 20–34. <https://doi.org/10.1177/2156869318804297>

Fisher, K. R., & Purcal, C. (2017). Policies to change attitudes to people with disabilities. *Scandinavian Journal of Disability Research*, 19(2), 161–174. <https://doi.org/10.1080/15017419.2016.1222303>

Hassiotis, A. (2020). The Intersectionality of Ethnicity/race and Intellectual and Developmental Disabilities: Impact on Health Profiles, Service Access and Mortality. *Journal of Mental Health Research in Intellectual Disabilities*, 13(3), 171–173. <https://doi.org/10.1080/19315864.2020.1790702>

Merrells, J., Buchanan, A., & Waters, R. (2017). The experience of social inclusion for people with intellectual disability within community recreational programs: A systematic review. *Journal of Intellectual & Developmental Disability*, 43(4), 381–391. <https://doi.org/10.3109/13668250.2017.1283684>

Risley, T. R. (1996). Get a life! In L. K. Koegel Jr., R. L. Koegel, & G. Dunlap, *Positive behavioral support* (pp. 425–437). Baltimore: Paul H. Brookes.

Slater, P., McConkey, R., Smith, A., DuBois, L., & Shellard, A. (2020). Public attitudes to the rights and community inclusion of people with intellectual disabilities: A transnational study. *Research in Developmental Disabilities*, 105, 103754. <https://doi.org/10.1016/j.ridd.2020.103754>

“Infinite Solution Finders:” AHRC New York City’s Educational Advocacy Guides Parents of Students with Disabilities

By Dylan Watton
Communications Coordinator
AHRC New York City

Rosemeri Linares embraced the challenges and the need for knowledge when she found out her son Adrian was on the spectrum. “Adrian was diagnosed with autism a little before he turned two. I had to quickly learn all the things that come with having a child with a disability,” she recalled. “I had no idea prior to getting the diagnosis all the things that come with that - evaluations, doctors’ visits, IEP meetings. You must get familiar with them immediately.”

Navigating the breadth of disability services, especially in the school system, can be overwhelming for any parent or guardian. Katherine (Kate) Hoy, LMSW, AHRC New York City’s Director of [Advocacy Services](#), knows this fact well and has dedicated her career to helping families find the quality supports to which they are legally entitled.

Educational Advocacy

“We provide one-on-one support for parents and professionals to help them understand their rights in special education in NYC, and to help them participate meaningfully and effectively in their child’s IEP



**Katherine ‘Kate’ Hoy,
Director of AHRC New York
City’s Advocacy Services**

meetings,” Hoy explained.

“Parents are by law equal members but too often, on purpose or inadvertently, they are not fully informed participants. We see that when they are not able to participate fully, communication breaks down and ultimately it impacts the child. We’ve seen outcomes improve exponentially when parents know their rights and act on them.”

Adrian had found some success at the first schools he attended. Over time, however, his mother felt that he was beginning to stagnate and not receiving the instruction he needed to achieve his goals.

“I know how well Adrian can do if he has everything in place he needs to succeed. He is a visual learner and needs a lot of visual supports in place. The school just wasn’t meeting any of those needs. They weren’t tailoring to the needs of a child with autism - the kids have other disabilities and they are all grouped together.”

“From age 3-21, a child’s primary service location is school. It’s so critical to get their services right as soon as possible,” Hoy said.

Many Facets to Advocacy

Linares was introduced to AHRC NYC’s Educational Advocacy through the previous director, Paul Hutchinson, in 2016. She needed guidance on Adrian’s entry into the school system for students with disabilities.

“That was a key point, getting Adrian that non-public school placement,” she said. “Paul sent me places I can go to. He referred me to where they were doing a study for autism, and Adrian got a thorough, extensive evaluation, and got that for free. I thank Paul a lot for that.”

In summer 2020, Linares reached out to AHRC NYC again. “I filled Kate in on my concerns. She went over with me some of

the main points that we needed to discuss. We were going to have an IEP, and to request change of placement we needed to have new evaluations,” she recalled. Hoy guided her through the additional steps of drafting letters, scheduling meetings, and making the appropriate contacts in a timely fashion.

“We are infinite solution finders,” Hoy said. “I can’t guarantee I will find something, but I can promise I will not abandon you. We can prepare as much as possible and go from there. That is something that families really value.”

Adrian is now attending Learning Spring, a school specifically for children on spectrum. “He is doing amazing,” his mother beamed. “He will be starting hybrid sessions soon, but even with remote I hear him talking and all the teachers are all so wonderful. It’s a different feel. He loves the school.”

“I would recommend AHRC NYC’s advocacy, because you need someone that gets everything going on right now. I would not be able to know this information on my own. Get someone to help you navigate through this. You don’t want to do this alone.”

New Advocacy Cases – Please call our Advocacy Services Hotline: 212-780-2799 or email us at Educational.Advocacy@ahrcnyc.org. Dylan Watton is the Communications Coordinator at AHRC New York City.

Suitable Housing and Community Living: Autistics Face Many Unusual Challenges

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

Whether they can live independently or require assistance and support, autistics need resources to live in communities, of which they often want to be a meaningful part. First and foremost, adequate housing must be made available. Even for those who can live independently and find and maintain employment, or receive suitable benefits and subsidies, basic supports may nevertheless be indicated. Those who require assisted living will, at some point, need to be placed in appropriate facilities that can provide whatever supports are necessary. In either case, they will be living in larger communities that may consist of other autistics, individuals with various disabilities, or perhaps be neurodiverse. As such, they must be prepared and receive adequate support for the challenges most autistics face where interactions with others are concerned. Those providing assistive and support services need to understand these and other challenges, and generally be equipped to help autistics with their unusual needs. Autistics often have deficits and face difficulties that are far less common in other



Karl Wittig, PE

populations, and which affect their ability to live independently and become part of the surrounding community.

Housing Accommodations

Housing accommodations for autistics can vary widely and depend greatly on the level of self-sufficiency and independent

living skills of the individual. Those having adequate skills can certainly be placed in conventional housing and may require little assistance. If they are gainfully employed, they should be able to live in any residence that they can afford and have the skills to maintain. Otherwise, subsidized housing or other benefits need to be made available to provide adequate accommodations. For such individuals, any deficits in daily living skills need to be remedied using whatever instruction or therapy is indicated. It has always been my belief that many autistics are more capable of such than is generally recognized, and greater efforts are needed to improve these skills as much as possible. Also, assistance with finding housing, which can involve the search for rental apartments or dealing with real estate agents, may be appropriate.

For those who are unable to live independently, some form of assisted housing is needed. Once again, this can vary widely depending on the challenges and circumstances of the individual. Whether these accommodations are exclusively for autistics or serve a broader population, the atypical needs of autistic individuals must be fully understood by those providing assistive services and met to the greatest extent possible. For example, autistics often have significant difficulties that otherwise comparable individuals rarely if ever have, especially where

daily living, social skills, and other basic areas of life are concerned. These deficits need to be immediately recognized and accommodated or remedied when present.

Also, many autistics famously have regular routines that they insist on adhering to, strong preferences concerning personal items (such as clothing, in my case), a variety of sensory sensitivities (e.g., selective eating issues, as with me), along with very intense special interests and strongly preferred activities. All these considerations need to be respected and accommodated to whatever extent possible. This is in contrast with many assisted living facilities, such as those for senior citizens, which cater largely to more typical or common challenges and preferences, as well as more popular recreational activities. Many autistics, for whom these often vary widely from typical norms, are anything but well-served by such practices.

More significantly, waiting lists for such housing are typically quite long, with periods of ten years not being uncommon. Given the dramatic rise in autism rates among the general population over the past two decades, the number of residential units available for autistics needs to be greatly increased. Once again, assistance with finding the most appropriate and suitable

see Challenges on page 38

Outcomes from [page 24](#)

Keeley will benefit from an IEP that addresses independent living skills while considering programs she likely qualifies for in adulthood.

Explore Programs and Services

Housing Support - Many people with disabilities live with family, in group settings, foster families, institutional settings, and in their own dwelling (Westling & Kelley, 2020). However, factors such as affordability, perceived safety concerns, and available supports narrow options. The [Residential Information Systems Project \(RISP\)](#) reports that about 60% of respondents that receive Long-term Support Services (LTSS) live with family with an increasing trend of moving from segregated settings to community-based settings. The survey further supports a trend of increasing number of adults with disabilities living with family (Larson, 2020). With approximately 1.3 million individuals with Intellectual and/or Developmental disabilities (I/DD) residing with parents 60 years of age or older (Braddock et al., 2017), parents must plan for independent living for their child beyond their lifetime.

The Department of Housing and Urban Development (HUD) have multiple programs to support supply and demand of affordable, sustainable housing for those with low incomes. One such program is the [Housing Choice Voucher](#) which allows a choice of any dwelling that meets the voucher requirements. Local public housing agencies are responsible for paying a subsidy to the property manager on behalf of the qualified applicant (Westling & Kelley, 2020).

Keeley is a good candidate for the voucher program if she is within the financial qualifications. She will need supports from a different source as HUD programs are not specifically designed for people with autism or I/DD.



Celeste Lenae Michaud, MA

Individual Supports - Home and Community-Based Service (HCBS) waivers are designed to provide LTSS for those qualified in the community. Every state has its own criteria and number of individuals served at a time and many states have waitlists. It is suggested that parents begin the application process early as the wait can be 10 years or more. Applicants who have assessed cognitive disabilities tend to qualify for HCBS waivers (Westling & Kelley, 2020).

Supports without a waiver include natural and technology-based supports (Westling & Kelley, 2020). Natural supports utilize people within the typical network of interactions experienced in daily life such as neighbors and co-workers; Technology can be used to encourage independence without relying on a person (Westling & Kelley, 2020). Parents and self-advocates can collaborate with organizations to develop an individualized technological support plan.

Keeley does not qualify for an HCBS waiver but could reside in her own dwell-

ing if natural and technological supports are orchestrated.

Parents as Participatory Change Agents

Parents are a constant in a child's life and therefore better understand the capabilities and strengths their child has. Parental involvement is vital to their child's success and post-secondary out-comes despite a potential lack of educational expertise (Hsiao, 2018). Parents can also advocate in communities by serving as committee members, joining a local organization for advocacy, and participate in community meetings.

Keeley and her parents can advocate during IEP meetings and join local organizations that bring awareness on the barriers for adults with disabilities.

Conclusion

For many adults with disabilities, living independently is possible with the right resources. Despite the obstacles, families and self-advocates are encouraged to plan ahead and explore programing before it is needed. Skill building and being intentional on the plans about life beyond secondary school becomes vital, as support is no longer based on entitlement, but on qualification. A parent that plans ahead, explores available resources, and advocates is a parent that brings about the best opportunity for positive outcomes.

Additional Resource

[www.simply-home.com](#) - An organization focused on utilizing technology to support independence.

Celeste Lenae Michaud, MA, is currently a PhD student in the Leaders for Transition program at the [University of Arkansas-Fayetteville](#). To contact author, email Celeste at cmichaud@uark.edu.

References

Alvares, G.A., Bebbington, K., Cleary, D., Evans, K., Glasson, E.J. (2020). The misnomer of 'high functioning autism': Intelligence is an imprecise predictor of functional abilities at diagnosis. *Autism*, 24(1), 221-232. <http://journals.sagepub.com/doi/10.1177/1362361319852831>

Braddock, D.L., Hemp, R.E., Tanis, E.S., Wu, J. & Haffer, L. (2017). The State of the States in Intellectual and Developmental Disabilities: 2017. Boulder, CO: University of Colorado, Coleman Institute for Cognitive Disabilities.

Flowers, C., Test, D.W., Povenmire-Kirk, T.C., Diegelmann, K.M., Bunch-Crump, K.R., Kemp-Inman, A., Goodnight, C.I. A demonstration model of interagency collaboration for students with disabilities: A multi-level approach. *The Journal of Special Education*, 51(4), 211-221. <http://journals.sagepub.com/doi/10.1177/0022466917720764>

Hsiao, Y., Higgins, K. (2018). Parent Empowerment: Respecting their voices. *TEACHING Exceptional children*, 51(1), 43-53. <http://journals.sagepub.com/doi/10.1177/0040059918790240>

Larson, S.A., Eschenbacher, H.J., Taylor, B., Pettingell, S., Sowers, M., & Bourne, M.L. (2020). *In-home and residential long-term supports and services for persons with intellectual or developmental disabilities: Status and trends through 2017*. Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration.

Westling, D.L., Kelley, K.R. (2020). Opportunities for persons with IDD to live in their own homes. *Education and Training in Autism and Developmental disabilities*, 55(4), 367-381. <https://search.proquest.com/scholarly-journals/increasing-opportunities-persons-with-idd-live/docview/2463173613/se-2?accountid=8361>

Preparing from [page 10](#)

ensures that a child is getting the well-rounded preparation they need for years beyond childhood service availability. Targeting community living competence early throughout ABA intervention programming in the most natural setting possible could promote successful long-term outcomes for the individual into adulthood.

One component of early services that is sometimes overlooked, although essential, is parent and caregiver training. Parents and caregivers play a key role in the treatment of their child for their entire life, long after intensive childhood services. Therefore, practitioners need to effectively equip parents with the knowledge and fundamental skills necessary to successfully implement Applied Behavior Analysis (ABA) interventions. Given that the number of individuals diagnosed with ASD has risen since the 1990's, leading to more adults in need of services, it is now more critical than ever that parents are educated on the basics from the start (Anderson et al., 2014). Giving parents the skill set they need early on will provide individuals with

ASD more opportunities for learning, aiding in transitional and independent living further down the road.

The most effective way practitioners can assist parents and caregivers in acquiring these skills is by training using Behavior Skills Training (BST). A study conducted by Lavie and Sturmey (2002) noted the effectiveness of behavior skills training on rapidly teaching non-behavior specialists aspects of ABA. This approach provides opportunities for parents to demonstrate basic skills through rationale, modeling, rehearsal, and feedback. If parents are equipped with the fundamentals early on (e.g., reinforcement, antecedent management, extinction, function-based treatments) then the skills the learners acquire can be practiced with fidelity more consistently over time. More intensive teaching and practice will ultimately award them a greater chance that crucial skills will generalize to new environments and people. This generalization or carry over of skills needs to occur early for individuals living with ASD so that when they reach late adolescence and early adulthood, they can lead more meaningful and independent lives.

In essence, the key to a successful, quality life as an adult begins as a child. Many factors come into play when developing an ABA treatment program at a young age, however, the continuous strive for independence across all skills is imperative. Creating a well-rounded program that includes a variety of skills throughout the individual's treatment can increase proficiency and ensure that the fundamental skills are acquired early on.

Samantha Smith, MS Ed, BCBA, LBS-PA, is Clinical Supervisor; Rebecca Miller, MS, RBT, is a Registered Behavior Technician, and Julia Robertson, MS Ed, QASP-S, RBT, is a Registered Behavior Technician and Social Media Coordinator at Exceptional Learning, A First Children Company. For further information please contact Dr. Jeff Selman, VP Clinical Services of First Children Services at jselman@firstchildrenservices.com or visit www.firstchildrenservices.com.

References

Anderson, K. A., Shattuck, P. T., Cooper, B. P., Roux, A. M., & Wagner, M. (2014).

Prevalence and correlates of postsecondary residential status among young adults with an autism spectrum disorder. *Autism*, 18(5), 562-570.

Key findings: Cdc releases first estimates of the number of adults living with autism spectrum disorder in the United States. (2020, April 27). Retrieved February 17, 2021, from <https://www.cdc.gov/ncbddd/autism/features/adults-living-with-autism-spectrum-disorder.html>

Lavie, T. & Sturmey, P. (2002). Training staff to conduct a paired-stimulus preference assessment. *Journal of Applied Behavior Analysis*. 35(3), 209-211.

McGreevy, P., Fry, T., & Cornwall, C. (2014). *Essential for Living: A communication, behavior and functional skills assessment, curriculum and teaching manual for children and adults with moderate-to-severe disabilities*. Winter Park, FL: Patrick McGreevy, Ph. D., P.A.

Partington, J. W. (2012). *The assessment of functional living skills*. Marietta, GA: Stimulus Publications.

Smart Home Technology and Autism

By Holly Mero
Director
Vivint Gives Back

Good parents worry about their children's safety. For most, this centers on keeping toddlers away from medicine, sharp objects, electrical outlets and other physical dangers in the home. As children grow, parents can usually start worrying less about these things and focus on their children's social and economic welfare.

But not parents of children with autism. They also grow concerned about their child's social and economic welfare, but most likely don't have the luxury of worrying any less about the physical dangers their child faces at home.

Regardless of their child's age, these parents still sleep with one eye open for fear that they may slip out of bed and find a kitchen knife at 2 a.m. They still leap to their feet with every creek of the floor, worried that their child is wandering out the front door. They still can't leave their child alone to go upstairs for five minutes without worrying that they may hurt themselves.

It's parents like this that can benefit the most from the peace of mind that comes from reliable smart home technology.



Smart Home Technology and Autism

Here are several ways smart home technology can help:

Keep track of your child - You can always know where your child is with strategically placed interior smart door sensors that notify you on your mobile device when they open a door.

Get the rest you need and still keep an eye on your child - With an indoor camera

in a bedroom, you can keep an eye on your child even at night by watching live video on your mobile device. This is especially helpful for a child who also suffers from seizures or other medical conditions. Camera footage of a seizure can also be a great tool for medical professionals to determine treatment and medications.

Protect your child from potential household hazards - You can protect and monitor your child by placing smart sensors on anything that opens and closes, like

knife drawers, medicine cabinets or closets where you store cleaning supplies.

Monitor in-home therapy session and tutors - If your child receives in-home therapy, a camera is a great way to monitor activity during sessions. By observing sessions via camera, you can also learn from therapists without distracting your child or disrupting the session.

Learn how to better support your child - Viewing camera footage also provides a clear picture of how your child is progressing. While a child may be performing well during treatment, those behaviors don't always stick. Being able to see what your child is accomplishing in session is empowering and informs your own interactions with your child. You can make requests and reinforce what your child is learning in therapy knowing what they're capable of.

Manage the people coming and going - With in-home treatment therapists, tutors and caregivers coming in and out of your home throughout the day, a smart lock and doorbell camera make it easy for them to enter and leave, while still keeping your house safe and secure.

Preempt water disasters - If your child

see Smart Home on page 35

Police from page 11

2,700 CIT programs operating in the United States,³ which would represent 15 to 17 percent of police agencies. However, the number of people interacting with CIT-trained officers is believed to be higher than that proportion would indicate because the model is most easily adopted by large, urban police forces.

It's hard to say, though, how beneficial the training's been. A **2019 meta-analysis published in The Journal of the American Academy of Psychiatry and the Law** found evidence of an improvement in attitudes among CIT-trained officers and an increased perception among them that they were using less force. But it's been more difficult to establish whether CIT has helped reduce officer and citizen injuries. And there's debate as to whether it's had any impact on the overall arrest rates.

While it's been challenging for researchers to even pinpoint what constitutes a mental health crisis call, it's almost impossible to boil any such scenario down to a single trait. For instance, **Blacks are nearly three times more likely to be killed by police than whites**.⁴ Compound that with the **increased militarization of policing nationwide**⁵ and **the risk of gun violence among certain segments of the population**,⁶ and those larger trends may be obscuring or even counteracting the effects of CIT.

Fostering Trust

Many people of color talk to their children about how they should interact with police. And though their circumstances



Kristine Quinby, MEd, BCBA, LBS

may be different, the parents of children with special needs should also educate their children about how to behave if they're ever approached by the police.

Error on the side of caution and assume that the police in your community have not been specially trained in how to communicate with people with special needs.

Encourage your child to remain calm. Don't make any sudden movements or reach for anything, and don't try to run away. In most situations, it would be beneficial for your child to disclose their diagnosis. If they're not confident in their ability to do it verbally, consider using a replaceable card with some basic information that can be given to the officer at the scene. They'll still need to express, or at least signal, their intent before reaching

for the card to avoid prompting a reaction from the police officer.

If your autistic child is prone to eloping or public tantrums or is non-verbal, teach them a series of simple commands, including stop, come here, get down on the ground, hands up, turn around, and show your hands. Familiarizing your child with them will better enable your child to follow an officer's directions and, in turn, ensure their safety. You may need to enlist the help of a professional, but try on your own first.

Ultimately, familiarity is the best means of preventing any situation in the community that involves someone on the autism spectrum from escalating. Call your local police to let them know about your child's diagnosis. If they're open to it, visit the station, too. The more time your child spends around the officers who patrol your neighborhood, the more comfortable they'll become with them.

Gradually, the police will also come to know your child and their temperament. Which was the case with the man at the beginning of this story. Fortunately for him, he's known in his community, and the police are aware of his diagnosis. Because of that, the threat of the situation going sideways once they arrived was significantly reduced.

Kristine Quinby, MEd, BCBA, LBS, is Founder, President and CEO of Potential. She can be reached at [Potentialinc.org](mailto:kquinby@potentialinc.org), kquinby@potentialinc.org, or (215) 579-0670.

Footnotes

1. Rava, J., Shattuck, P., Rast, J. et al. (2017) The Prevalence and Correlates of

Involvement in the Criminal Justice System Among Youth on the Autism Spectrum. *J Autism Dev Disord* 47, 340–346; <https://doi.org/10.1007/s10803-016-2958-3>.

2. Rogers, Michael S., McNeil, Dale E., and Binder, Renée L. (2019) Effectiveness of Police Crisis Intervention Training Programs. *The Journal of the American Academy of Psychiatry and the Law Online*, JAAPL.003863-19; <https://doi.org/10.29158/JAAPL.003863-19>.

3. Rogers, Michael S., McNeil, Dale E., and Binder, Renée L. (2019) Effectiveness of Police Crisis Intervention Training Programs. *The Journal of the American Academy of Psychiatry and the Law Online*, JAAPL.003863-19; <https://doi.org/10.29158/JAAPL.003863-19>.

4. Bor J, Venkataramani AS, Williams DR, et al. (2018) Police killings and their spillover effects on the mental health of black Americans: a population-based, quasi-experimental study. *Lancet* 392:302–10; [https://doi.org/10.1016/S0140-6736\(18\)31130-9](https://doi.org/10.1016/S0140-6736(18)31130-9).

5. Bove, Vincenzo, and Evelina Gavrilova. (2017) Police Officer on the Frontline or a Soldier? The Effect of Police Militarization on Crime. *American Economic Journal: Economic Policy*, 9 (3): 1-18; DOI: 10.1257/pol.20150478.

6. Wintemute, Garen J. (2015) The Epidemiology of Firearm Violence in the Twenty-First Century United States. *Annual Review of Public Health*, 36 (1): 5-19; DOI: 10.1146/annurev-publhealth-031914-122535.

Parent Advocate from page 29

students were inappropriately referred, disciplined and not placed in the least restricted environment were discussed. Subsequently, the Massachusetts Department of Education threatened to withhold special education entitlement money until Cambridge satisfied federal and state SPED requirements. The PAC then requested a public hearing by the School Committee to address the findings of the review. Parent after parent testified, bringing noncompliance issues to life in a packed room. This hearing forced the early retirement of the SPED Director of thirty years who gave little support to parents. I represented the PAC for the hiring of a new director committed to addressing noncompliance issues. Major changes parents advocated for were initiated across the school system.

System reform is an exceedingly slow process. It didn't happen soon enough to address Daniel's specific needs. Daniel continued to fall behind his peers academically and socially by two years. I considered an out-of-district private school placement for Daniel's fourth grade year and initiated legal action. Mediation was offered as a first step by the system. I went alone to the mediation as my lawyer confided that no one had been successful against Cambridge's SPED director. Ironically, my advocacy was responsible for my success in obtaining an out-of-district private placement at Landmark School. Written into the mediation agreement, I was "to cease all advocacy for special education students in the Cambridge public schools." The director agreed to send Daniel to Landmark, in exchange for eliminating my effective advocacy for Cambridge students. I immediately violated this agreement continuing to advocate for students.

As Daniel aged, his difficulties communicating became more apparent. After a good year at Landmark, he developed behavior problems in response to unmet needs. Landmark was no longer a "good fit" and he was told to look elsewhere for middle school. Researching programs, I found an academically self-contained program within an inclusionary model in a Newton school that Daniel's team agreed to. Beginning in Daniel's 6th grade, this move coincided with the sudden tragic death of Daniel's dad, my partner, while playing

on the Cambridge Community basketball court. Daniel's initial honeymoon allowed him to learn new skills of sign language, gardening and basketball. His delayed response to his dad's death slowly surfaced difficult behavioral responses both at home and at school. Once again, I had to find another school placement. I became an overwhelmed single mother. Daniel required more overall support than I or the public school could provide. Multiple school placements had taken a toll on Daniel. His greatest need now was a school that would see him through high school graduation. Once again, I spent many months visiting various in-state and out-of-state residential schools with a Cambridge SPED administrator. Using the expertise and presence of Daniel's neuropsychologist, we argued a strong case for an out-of-district residential placement.

The team sent Daniel to a residential out-of-state school in Pennsylvania. Daniel spent four continuous high school years at The Pathway School. We both navigated many challenges throughout these years. Daniel benefited from Pathway's emphasis on his positive abilities. Despite the expected ups and downs, it was an overall successful experience that met Daniel's needs. In his final year Daniel graduated with his high school diploma. Daniel spent an additional couple of years honing his daily living skills at Chapel Hill, a post-graduate program in Connecticut.

As a young adult in his 22nd year, Daniel returned to his hometown to face a desert of resources. After six years of 24/7 supports in out-of-state residential schools, Daniel was unrealistically expected to transition into the community without any supports. I networked extensively everywhere, and I went seeking an appropriate young adult program. Eventually I found a newly formed residential group home operated by the Jewish Family and Children's Service in Waltham, primarily serving young adults on the autistic spectrum. After a year of meetings with staff and potential residents, I moved Daniel there using my retirement savings. Unfortunately, after a week at this placement Daniel was sent by staff for a psychological hospital evaluation. It landed him inappropriately in and out of hospitals for over a year. Daniel descended into chaos, totally unraveling, bouncing between different hospitals, home, a

stabilization unit, and eventually a DDS homeless shelter. I continued advocating for Daniel during this difficult time, writing and calling the state Department of Mental Health (DMH) eligibility officer daily. After many months, Daniel received eligibility from DMH and returned home with a DMH outreach worker providing two hours a week. Feeling alone one evening, Daniel called the police, which initiated an emergency room visit and again he was sent to the hospital. My advocacy became fiercer.

I reapplied to DDS for adult services; the more appropriate state service for Daniel. Again, he was denied eligibility. Using my citizen rights, I contacted my local state representative who made available her legislative liaison to DDS to cut through the red tape; but with no result. In the wake of a feverish nightmare, I stumbled forward. The time had come for an "out of the box" action: a "sit-in" demonstration with my women friends in the Mass Executive Office of Health and Human Services. Within an hour of that "sit-in" the Commissioner of DDS called my state representative saying, "I wasn't aware that Daniel had developmental disabilities." Disrupting business as usual, I had finally made enough trouble to be heard. Utilizing my new contacts with an executive office planner and the DDS Commissioner, my extraordinary action got Daniel out of the hospital and into a DDS group home without DDS eligibility. This Boston group home initially gave him a modicum of stability. The absence of appropriate services for two years however was consequential. Daniel lost many of his hard-gained living skills as well as confidence in his abilities. The group home kept him out of the hospital, but part-time non-professional staffers could not provide him with the necessary skills he would eventually need to become more independent. I decided to challenge Daniel's DDS non-eligibility.

In 2007, using a lawyer from Boston Legal Services, Daniel appealed the DDS decision and lost. At that time, I had no inkling that for multiple years I would mount a marathon struggle involving two appeals for fair hearings and two separate Superior Court appeals. Over six years I acted as Daniel's pro se lawyer, without formal legal experience. My hope was to create a lifelong support system for my son as well as for other persons who needed similar

supports but had been turned down for eligibility and were not in a position to spend years fighting the system.

In a fair hearing I became both his lawyer and a fact witness, calling witnesses, organizing exhibits and writing my final memorandum. The hearing officer's decision favored DDS. It provided an opportunity to appeal this decision to the Superior Court. A year passed, doing various motions. After I did my final oral argument, to my surprise, the Superior Court Justice ruled in favor of my motion but remanded the case back to DDS with questions. For me, it meant, another round of a so called "fair hearing" with the same hearing officer. Again, he reaffirmed his previous decision. Fueled by anger and reminded of the Superior Court ruling in my favor, I appealed Daniel's case back to the Superior Court. This time the Court reversed DDS's eligibility decision in Daniel's favor. Now as a young adult of 32 years, Daniel has another chance a decade later to begin where he left off at age 22.

During the course of these legal battles, Daniel was slowly developing more independent skills through a day program for successful artists at Gateway Arts and a travel training program offered by the MBTA. Daniel began to act and feel more confident. After a long search I found Step by Step, a private, integrated holistic program with individual apartments where residents hosted peer dinners with staff support. Daniel began regaining his daily living skills within the context of community living. He now has continuity of support services funded by DMH and DDS for his more independent life.

My advocacy journey on behalf of Daniel encompassed many different strategies. I operated on many levels and wove together different approaches at various stages of his development successfully obtaining services for him as well as for others. Throughout Daniel's life, my vision for him was always for full entitlement of his civil rights and the most independent level of appropriate services. Throughout this long journey I was continually learning new skills and benefiting from the knowledge and support of other parents, advocates, lawyers and friends. Now my Daniel can be all that he can be.

Dr. Renee Kasinsky, parent advocate, can be reached at reenekasinsky@gmail.com.

Dwelling from page 27

and an increasing need for assistance with daily living and activities.⁶

More communities are now allowing ADUs that adhere to local size and lot placement limits in residential areas, as long as they meet to local zoning requirements. Other states including New Hampshire, Vermont, Oregon and Washington have already passed laws requiring most or all cities and counties to allow ADUs, with some restrictions. Others have applied already existing regulations for the construction of ADUs. But some local governments

apply additional rules to ADUs.

It is important to ensure that the most vulnerable members of our community are not forgotten or left behind. People want to live in their own communities near family and friends. As we begin the COVID-19 recovery process, we need to rethink housing and find better options, like ADUs. Making ADUs more accessible to New York families will help provide our loved ones the ability to live independently, but with a built-in safety net.

As the chair of the New York State Assembly Subcommittee on Autism Spectrum

Disorders, I welcome any and all questions and concerns readers may have. Please feel free to contact my office at 518-382-2941 or send me an email at SantabarbaraA@nyassembly.gov. You can also find more information on my website at www.nyassembly.gov/Santabarbara.

Footnotes

1. www.cdc.gov/ncbddd/autism/features/adults-living-with-autism-spectrum-disorder.html
2. www.nyassembly.gov/leg/?default_fld=&

leg_video=&bn=A01410&term=2019&Summary=Y&Memo=Y

3. Ibid.

4. www.aarp.org/content/dam/aarp/livable-communities/livable-documents/documents-2019/ADU-guide-web-singles-071619.pdf

5. Ibid.

6. www.health.ny.gov/statistics/brfss/reports/docs/2021-02_brfss_cognitive_decline.pdf

Solution from page 27

estate prices started to fall. The supply of two-bedroom apartments during 2020 grew as demand plummeted.

Eventually, I started seeing possibly-affordable two-bedroom apartments with split bedroom layouts on high floors in the neighborhood of our choice. At the same time, my husband was working from home (thanks to COVID-19) and was able to dash out on weekdays to see promising apartments.

Despite lower prices due to the pandemic, apartment hunting was still a frustrating process. Sometimes the layout was wrong, or the second bedroom was too small. Sometimes the apartment faced a brick wall, or else the maintenance was crazy. Our goal was to take a small mortgage and pay it down, so Samantha could afford the maintenance someday. We figured that even if she couldn't afford the apartment or chose to live elsewhere, her assisted decision-making team could help her to sell it and buy something smaller, leaving her a nest egg.

One day I complained to a friend, Andy Cohen, whose father and uncles were residential builders on the Upper East Side in the 1960s.

"You should really look at the G line at 300 East 74th Street, Andy advised. "It has a REALLY big living room and the bedrooms are split, so Samantha can have more privacy and so can you."

No G line apartments were available over the summer when I looked on StreetEasy and



The view from our new apartment

called my broker. But in October, Howard and I finally saw apartment 31G and fell in love. Standing out on the balcony amid breathtaking views, I confessed, "I could definitely live here and be excited about it."

"It's got a lot going for it," Howard agreed. "I love that we can stay in our neighborhood, use the same dry cleaner and walk to our favorite restaurants."

Samantha would be happy too. We were moving diagonally across the street and staying on Second Avenue - a smooth and simple transition. Our daughter would have greater privacy, as our bedrooms would no longer share a wall, and she could navigate easily on her beloved Q train and familiar buses. Samantha would learn how to use

a new, easy set of appliances, including a washer dryer. We assured her that her room could be painted her favorite color of green, and all of her furniture would fit (just barely).

Still, I was a little concerned about Samantha and the co-op board. Although our broker assured us that we were financially qualified and our references were stellar, I've learned to take nothing for granted. Although we had disclosed Samantha's autism, she is sometimes a wild card. What if one of the board members addressed her as Sam instead Samantha (one of her triggers)? What if she rambled or didn't answer the questions she was asked? Or what if she interrupted to

complain that she wasn't being included in the conversation? Although unlikely, I prepared her for these scenarios. "Smile and listen. Only speak when someone addresses you. If they call you Sam, please let it go. Remember, 'less is more' and 'teamwork makes the dream work.'" These are catch phrases she enjoys and understands.

Nothing ever goes smoothly for my family. Samantha was perfectly charming and our Zoom interview went well - until we suddenly lost our internet connection! No kidding! Could there possibly be a worse time for our internet company to fail us? Fortunately, we reconnected by phone and successfully completed the interview. At the end, Howard remarked happily that the apartment "checked all of our boxes."

"You checked all of our boxes too!" One board member responded kindly.

So we're in! Or at least we will be - after the wall is restored to Samantha's room, after the kitchen and closets are redone, etc. Sooner or later....

One fine day, New York City will reopen, and Manhattan real estate will appreciate, and maybe, just maybe, Samantha can live happily and mostly independently ever after.

Marguerite Elisofon lives in New York City and blogs about disability issues for [The Never-Empty Nest](#) and [The Good Men Project](#). Her website is: www.MargueriteElisofon.com. Contact: mkelisofon@gmail.com Twitter: [MargueriteNEN](#)

Scaffolded from page 4

Transition program students. Ms. Di Gregorio has a B.S. from SUNY Buffalo and a M.S. in Rehabilitation Counseling from Northeastern University.

References

Bruyere, S., Sonnenfeld, J., Cunningham, T., & Giannantonio (2019). Autism in the Inclusive Organization: Implications for Research and Practice. Proceedings from a Symposium for the Academy of Management Annual Meeting Proceedings.(1):14216. DOI: [10.5465/](#)

AMBPP.2019.14216symposium

Migliore, A., Timmons, J., Butterworth, J., & Lugas, J. (2012). Predictors of employment and postsecondary education of youth with autism. *Rehabilitation Counseling Bulletin*, 55(3), 176-184. doi: 10.1177/0034355212438943

Moore, E.J. and Schelling, A (2015). Postsecondary inclusion for individuals with intellectual disabilities and its effects on employment. *Journal of Intellectual Disabilities*. DOI: 1744629514564448

Pillay, Y. and Brownlow, C. (2017). Pre-

dictors of Successful Employment Outcomes for Adolescents with Autism Spectrum Disorders: A Systematic Literature Review. *Journal of Autism and Developmental Disorders*. 4(1):1-11.

Roux, A.M., Shattuck, P.T., Cooper, B.P., Anderson, K.A., and Narendorf, S.C. (2013). Postsecondary Employment Experiences Among Young Adults with an Autism Spectrum Disorder *Journal of the American Academy of Child & Adolescent Psychiatry*, 52 (9): 931-939.

Shattuck, P.T., Narendorf, S.C., Cooper, B., Sterzing, P.R., Wagner, M. and Lounds Taylor, J. (2012). Postsecondary Education and

Employment Among Youth with an Autism Spectrum Disorder. *Pediatrics*, 129:1042-1049. doi:10.1542/peds.2011-2864

Standifer, S. (2012). *Fact Sheet on Autism Employment*. Autism Works. The National Conference on Autism Employment. Retrieved from <http://autismhandbook.org/images/5/5d/AutismFactSheet2011.pdf>. October 15, 2017.

Wehman P.H. et al. (2013). Competitive employment for youth with Autism Spectrum Disorders: Early results from a randomized clinical trial. *Journal of Autism and Developmental Disorders*, DOI 10.1007/s10803-013-1892-

Smart Home from page 33

loves water, smart flood sensors can come in handy. It's not uncommon for children with autism to turn on faucets and leave the water running. If they happen to plug the tub or sink, flood sensors in the bathroom or kitchen will notify you of the presence of water before damage occurs.

Prevent wandering - If your child wanders, smart window and exterior door sensors might be the most crucial smart home components you can install. It can take mere seconds for your child to disappear.

With smart sensors, your wanderer will trigger an alarm and mobile device notification when they try to exit your home. Paired with an outdoor camera on your home, you can even know which direction they headed should they make it out before you get to them.

Increasing Safety and Peace of Mind

Consider the King family. Breck King and her husband are the parents of four children, including their son Owen, who has autism and is prone to wander. On one occasion, Owen slipped away while Breck

was tending to another child. Frantic, she began a feverish search through the neighborhood and called the police for support when she couldn't find him.

Owen was eventually discovered wearing nothing but his diaper in the dirt in a neighbor's backyard. Without understanding Owen's condition nor seeing Breck's frantic and determined search for her beloved son, the concerned neighbors reported the Kings to protective services for child neglect. This added additional heartache and pain to an already stressful situation for the Kings. Unfortunately, their story isn't unique - it's shared by many parents

of children with autism.

Now listen to Breck's comments after living with smart home technology:

"It's been life-changing. For the first time since before Owen's diagnosis, I can have somewhat of a normal role as a mom. I mean, I'm able to cook dinner now. Life was really scary before our smart home system."

A smart home system isn't the answer to every challenge parents of children with autism face, but with cameras, door and window sensors and other smart devices, it certainly can help them find some ever-so-needed peace of mind.

COVID-19 from page 29

work only part time, which causes us to live in poverty. This makes it difficult for us to pay for the devices, and the internet and phone services, that let us connect to the community. In rural areas especially, access to high-speed internet or internet in general is poor. And many people with disabilities need support to learn how to use various forms of technology. And some of us face challenges with not having control over our lives and technology use, especially if we live in segregated settings or are under guardianship. It is common for staff and parents to restrict our access to technology. Without technology resources though, it is hard to survive and thrive in a fast-growing digital world.

While a virtual community life allows us to avoid catching COVID-19 and eliminates transit barriers we face day in and day out, it is not without other challenges. Moving services online caused issues at the start of the pandemic. For instance, at the beginning of the pandemic we were told that SNAP benefits (formerly food stamps) couldn't be used to pay for grocery delivery. This problem is now solved in some places but not all. We have also found in many cases that [web-based services are not accessible](#) to all people with disabilities.

Peer Mentoring

The COVID-19 pandemic disruption has led to higher rates of anxiety and depression in our society. As we confront this mental health pandemic, we must make peer mentoring and peer support the norm. Peer mentoring is when a person with a disability supports someone else with a disability, and peer mentors can be paid or unpaid. Peer mentors bring unique skills as a result of lived experience with a disability or mental health challenges. The services they provide are more empowering and less controlling, which is a big difference. I have found that peers with disabilities will often tell it like it is and tell the truth. People without disabilities will often give you biased information or impose their values. For instance, it is not uncommon for support staff to impose their values or be very opinionated when it comes to giving advice to people with disabilities (e.g., giving their opinion on topics like should I break-

up with boyfriend, stop taking meds, find a new job or cut hours, end a shared living arrangement, etc.).

Peer mentoring can allow folks to learn how to live in their own apartment in the community. You can match someone just moving into an apartment with another person with a disability who has experience living independently. This allows them to learn life skills like cooking, apartment upkeep, community navigation, budgeting, and promote better health by teaching them how to eat healthy and exercise, and it can even offer mental-health support during tough times. By getting support from someone with a disability who has more skills, a person can be supported to achieve the goal of living on their own. Lastly peer mentoring will go a long way toward reducing the social isolation, loneliness and boredom caused by this pandemic.

Housing Supports in the Community

It is my hope that we move away from group homes and institutions and shift toward providing all services in the community. The pandemic has shown us again of the many risks that life in segregated settings poses, and I think there will be a bigger push for people with disabilities to live in their own apartments or in shared living arrangements. For this to occur we must fight for massive funding in low-income accessible housing. The housing must be on public transit routes close to downtown areas. I say this because many people with disabilities do not or cannot drive and it is difficult to get to places. This is especially true for those of us who do not get any home and community-based waiver supports.

There will also be a need for funding for the technology and technology programs that can help people to live independently. An example of this the Howard Center in Vermont where they have a program called [Safety Connection](#). This allows the agency to support folks at night remotely with an alarm system. At night, Suzie Q will arm her system and staff speaks to her over a loudspeaker to check in. After that, if she has a crisis or someone breaks in, they will send a responder over to help.

Working in the Community

The best thing about this pandemic is

that it has exposed the fact that many jobs can be done from home. And new ways of doing things are more accepted, such as video resumes, remote job coaching, and remote tours of workplaces. To make a change to remote work, some people will need Vocational Rehabilitation (VR) services. Some people may be more open to talking about what services they truly need in a remote setting. For those of us with anxiety we may be more open to saying what barriers or challenges we have. And we may need to give VR counselors tips on how they can better address our needs.

For people transitioning from school to adulthood, remote planning sessions have made it easier for parents to attend. And many pre-employment skills trainings, job fairs, and workshops are now being done remotely.

Looking Ahead

As a society if we take advantage of the opportunities this crisis has given us, we can come out of this pandemic nightmare to a more disability-friendly world. Our so called "normal" world prior to COVID-19 was not great for a lot of us in the disability community.

The time for systems change is during the pandemic, not after it's over. I say this because right now the media and society are paying attention to the negative impact of COVID and how our current system and attitudes about people with disabilities puts vulnerable populations at high risk for COVID-19. Now is when we should be designing a system that makes us healthier and safer. The high rates of COVID cases in segregation gives advocates something to point to when unions and pro-segregation groups say we should keep segregated settings open. Prior to COVID, I often heard parents say, "My kid is too disabled to live in the community" and they should have a choice between community and segregated settings.

Systems change can be scary, but if done right it will lead to a healthier and more inclusive world. This crisis is the perfect time for us to evaluate how we make businesses more accessible, safer and flexible for customers and workers with disabilities. Flexibility is the "New Normal" in all aspects of community life. Gone are the days when everyone in the business world insists on being face to face 99-100% of

the time. Many people with disabilities have dreamed of the day when society would be more accommodating to us. By not having to be face-to-face all the time, it goes a long way in allowing us to be active in our community without always having to worry about transit issues, crowds and risking our health.

Having the capacity to make all functions virtual is one of the greatest equalizers of our time. The reason for this is a majority of us in the disability community do not drive, and reliable and accessible public transit is hard to come by - and para transit service is often unreliable or unacceptably slow. But, being able to do our day-to-day business online offers peace of mind to those of us with chronic health issues. The less we have to worry about our health the better.

In a post-pandemic world, it is my hope that we, as a society, can continue to offer both virtual and in-person services. Doing this will allow agencies and businesses to reach a broader audience for events and basic government services.

One area where going all-virtual could help is in agencies that administer public benefits like SSI, SSDI, Medicaid, SNAP and so forth. I personally would like to see Social Security move to all-virtual when it comes to asking for various forms of documentation and filling out paperwork like the work activity report or any other forms they need. Doing things like this online is much easier and less stress than having to run around printing out stuff. If we could allow for this to be done electronically it would save time, energy, stress and money.

Editing support provided by Connor Cleveland. Nicole LeBlanc is the coordinator of the Person-Centered Advisory and Leadership Group (PAL-Group) for the National Center on Advancing Person-Centered Practices and Systems (NCAPPS). For more information, Nicole LeBlanc can be reached at nleblanc677@gmail.com or (802) 505-0253.

NCAPPS is funded and led by the Administration for Community Living and the Centers for Medicare & Medicaid Services and is administered by Human Services Research Institute (HSRI).

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, Inc.

Child's Right from page 23

be discussed. Then, think critically about whether your child is on track to attain the practical skills necessary to live productively and independently. Which basic skills does your child lack? Does your child have a means of functional communication? Can your child get dressed in the morning? Send a text message? Travel on public transportation? Understand traffic signals? Complete a job application online? Count money? Operate an ATM machine or write a check?

Even if your child is already in high school, it is not too late to obtain appropriate Transition Services before he or she graduates or exits at age 21. An independent educational vocational assessment funded by your school district may shed light on the Transition Goals

and Transition Services that your child needs. Seek out advocacy support or legal representation when necessary to preserve your child's right to an appropriate Transition Plan.

For more information, email Oroma Mpi-Reynolds, Esq. at Oroma@MSRLegal.Org or visit www.MSRLegal.Org. Oroma is the founder and managing attorney of MSR Legal & Consulting Services PLLC, a New York-based special needs law practice with offices in Queens and Nassau County. Oroma primarily focuses on enforcing the rights of children (from birth to age 21) under the IDEA and Section 504 of the Rehabilitation Act. Since 2008, she has represented parents and school districts alike, including the New York City Department of Education and several Long Island boards

of education. Immediately prior to opening MSR Legal, Oroma served for two years as the Director of Legal Services for Gersh Academy, a private school for children with Autism Spectrum Disorder. She holds a Bachelor of Arts degree in Anthropology with a concentration in sociocultural anthropology from Yale University, and a Juris Doctor degree from the Benjamin N. Cardozo School of Law of Yeshiva University. Oroma frequently blogs about the impact of the coronavirus pandemic on special needs parenting. Her posts can be found here: <https://www.mslegal.org/special-needs-parenting-the-coronavirus>

Footnotes

1. 20 U.S.C. § 1400(d)(1)(A)

2. 34 C.F.R. § 300.43(a)(1)

3. 20 U.S.C. § 1401(34)(A); 34 C.F.R. § 300.43(a)(1)-(2)

4. 20 U.S.C. § 1401(34)(B)-(C)

5. 8 N.Y.C.R.R. § 200.4(b)(6)(viii)

6. 8 N.Y.C.R.R. § 200.4(d)(2)(ix) (a)

7. 20 U.S.C. § 1414(d)(1)(A)(i)(VIII); 34 C.F.R. § 300.320(b)(1)

8. 34 C.F.R. § 300.43(a)

9. *Ex Parte James*, 713 So. 2d 869, 925 (Ala. 1997)

Anesthesia from page 28

Day of Procedure

Elliott and colleagues have shown that children experience higher preoperative anxiety if they have a diagnosis of ASD. Additionally, they found more parents of children with autism said they would need a premedication as compared to parents of typically developing youth. During the preoperative discussion with the anesthesia team, they may suggest taking doses of home medications prior to arrival to the hospital to ease the transition to the perioperative setting.

There are several sedative type medications that may be given depending on the child and their behavioral needs. These may include midazolam (Versed), ketamine, or dexmedetomidine (Precedex); which may be given via oral, nasal, or intramuscular injection. It is important for the providers to know what medications the patient is on at home and if any adverse reactions happened in the past to determine the best medication, if needed, and route of administration. Arnold et al. found patients with ASD were less likely to receive a standard premedication; however, they were significantly more likely to receive a nonstandard premedication - most commonly intramuscular ketamine. Sometimes, a combination of medications may be necessary in rapidly escalating maladaptive behaviors for the safety of the patient and staff.

Depending on a facility's policies and procedures, a pediatric surgical patient will either undergo general anesthesia via an in-

halation mask prior to intravenous line placement or have an intravenous line placed prior to the operating room. Depending on many patient factors including patient age, weight, and comorbidities, a decision is made as to when the intravenous line will be placed. At pediatric-specific facilities, the intravenous line is typically inserted after inhalational induction, unless it would be deemed unsafe to do so. With proper preparation and the assistance of guardians, intravenous placement may be quick and benign.

Discussion with the anesthesia team regarding anti-emetics and effective analgesia depending on the procedure is necessary. With knowledge of many patients' oral aversions, effective control of risk of nausea and emesis is imperative. Typically, patients will receive prophylaxis medications as well as intraoperative hydration to decrease the risk of nausea postoperatively. Taghizadeh and colleagues found it's hard to distinguish between pain, nausea, anxiety, or emergence delirium in patients with ASD as they regain consciousness. Valuable information for recovery room staff is understanding a patient's typical response and expression to pain. Arnold et al. suggests that patients with ASD were 50% less likely to complain of pain, and likely to have similar postoperative pain experiences to patients without ASD. Vlassakova recommends the use of the FLACC (Face, Legs, Activity, Cry, Consolability) scale to assess pain. A multimodal approach for adequate analgesia may consist of acetaminophen, anti-inflammatories, opioid medications, and possibly regional anesthesia. Depending on the sur-

gery, regional anesthesia will help numb the operative location for several hours after the procedure. Additionally, the use of familial terms and simplistic language is beneficial in the recovery process. Typically, patients with ASD are best served by early removal of intravenous cannula and by allowing them to recover in a quiet room with parents and comfort items present.

The perioperative environment poses challenges for children with autism due to changes in their daily routines, sensitivities to sensory input, and communication difficulties. Parents of children with autism are the experts and best advocates for the care their child receives during the procedure. Patients with autism require more consideration in the perioperative process to include priority scheduling, decreased wait times, sensory accommodations, and early discharge.

Sean Antosh, MD, is a board-certified pediatric anesthesiologist at Dayton Children's Hospital in Dayton, Ohio. He has clinical interests in improving the perioperative experience and care of children with Autism Spectrum Disorders. Recently, he has developed dedicated sensory adaptive environments in the perioperative environment at Dayton Children's. He may be contacted at: antoshs@childrensdayton.org for further questions or information.

References

Arnold, B., Elliott, A., Laohamroonvorapongse, D., Hanna, J. Norvell, D. and Koh, J. (2015), Autistic children and anesthesia:

is their perioperative experience different?. *Paediatr Anaesth*, 25: 1103-1110.

Elliott, AB, Holley, AL, Ross, AC, Soleta, AO, Koh, JL. A prospective study comparing perioperative anxiety and posthospital behavior in children with autism spectrum disorder vs typically developing children undergoing outpatient surgery. *Pediatr Anesth*. 2018; 28: 142-148.

Li-Ching Lee, Rebecca A. Harrington, Jen Jen Chang, Susan L. Connors. Increased risk of injury in children with developmental disabilities. *Research in Developmental Disabilities*. 2008: Pages 247-255.

Mills B. In the doctor's office: a parent perspective. *Pediatric Clinics of North America*. 2012: 59: 13-18.

Rady Children's Hospital. My Surgery Social Story. Available: www.rchsd.org/documents/2020/06/adi-surgery-social-story.pdf/

Swartz, JS, Amos, KE, Brindas, M, Girling, LG, Ruth Graham, M. Benefits of an individualized perioperative plan for children with autism spectrum disorder. *Pediatr Anesth*. 2017; 27: 856-862.

Taghizadeh, N., Davidson, A. , Williams, K. and Story, D. (2015), Autism spectrum disorder (ASD) and its perioperative management. *Paediatr Anaesth*, 25: 1076-1084.

Vlassakova BG, Emmanouil DE. Perioperative considerations in children with autism spectrum disorder. *Curr Opin Anaesthesiol*. 2016 Jun;29(3):359-66.

Robots from page 17

and teachers who want to see their students learn, thrive, and have the best developmental experience possible. Using a wide range of technology, such as Robot-Assisted Instruction, to enhance the learning and socialization experience, educators can communicate the fun and imagination that all children need to learn.

There are countless benefits of robotics in special education. Teaching science and

math to struggling students with autism is a challenge that can be made much more manageable with technology. By providing a stimulating, hands-on environment, teachers can help their students discover the wonders of technology and embrace the opportunities it offers them.

One of the most notable benefits that robotic assistive technology could ever contribute to society would be to engage children with autism or other learning disorders in meaningful interactions, helping

them to overcome the challenges they face every day. In many cases, these challenges prevent children from learning the necessary skills they need to succeed in life.

If you have a child with autism who struggles to interact with you, Robot-Assisted Instruction can make a great deal of difference in your life. And, since many children with autism are in great need of extra support, especially in improving their communication abilities and helping them interact with others, this technology could

benefit the larger community. Interactive robots for autism may prove to be the answer that we were all hoping for.

Do you want to unlock your child's full potential? MOVIA's Robot-assisted Instruction (RAI) helps children with special needs and abilities learn and grow using the best collaborative robotic technology. Contact us today by visiting www.moviarobotics.com if you would like to learn more about MOVIA's robotic assistive technology systems!

Finding Home from page 15

care of their home by sharing chores and cooking for each other, which is especially helpful for Patrick on days he goes to his job at Ventures Business Services, a social enterprise of Vista.

Patrick is one of the many Vista members who continue to receive support from Life Skills Instructors to guide the completion of certain tasks. Life Skills Instruction is tailored to the individual. For example, Leslie, a highly independent woman with autism, is adept with the stove and loves making hamburgers, garlic lemon chicken, meatloaf, and other recipes with minimal direction from her LSI. Instead, Leslie and her LSI work as a team to get tasks done faster, like when they divide up the grocery list during shopping excursions. Outside of Life Skills Instruction, Leslie has built an active schedule for herself filled with walks around Clinton, playing yard games like cornhole with her roommates, and attending Vista activities like bowling.

Some individuals prefer to live alone and are still able to stay social and engage with the community. Carl, a Vista member with autism for over 20 years, enjoys be-

ing able to "do his own thing" while having many of his friends as neighbors. He and several of his friends decided to start a tradition of having weekly dinners together, often meeting at Chip's Pub prior to COVID. The friends have maintained their tradition during the pandemic by meeting virtually. On workdays, Carl takes the local 9 Town Transit bus route from Clinton to his job at Robert's Food Center in Madison, where he engages with customers and co-workers. With almost 90% of Vista members who desire to work in paid positions along the shoreline, members often utilize public transportation independently or take advantage of Vista's ride service to get around their communities.

Nathan, another Vista member with autism who has his own condominium, finds ways to stay social through the Vista Village activities. Because Vista members live across the shoreline, the "Vista Villages" allow members who live in nearby towns to come together for social gatherings. Typically, these gatherings would include parties and in-person activities, but events have turned virtual during the pandemic. Nathan is also someone who has embraced the concept of personalizing his own

home, particularly since he and his family were recently able to purchase his condominium. A passionate Marvel fan, Nathan made his home feel like "him" by decorating with movie posters and dioramas and setting up a space for his art supplies. To make his kitchen suit his needs, Nathan purchased an organizational shelving unit to hold many of the special devices he loves to use. Using an onion chopper, for instance, helps him feel more comfortable and excited in the kitchen. Another new item is his air fryer, which he independently cooks with to make healthy food options like falafel.

Nathan has had a unique journey at Vista; when he first moved into the dormitory after arriving from Florida, he was determined to move back to the sunshine state and be with his family as soon as he graduated. Yet, as Nathan began to make friends, join clubs to develop his writing and artistic talents, and ultimately find a job that he loves, he realized that the shoreline had truly become his home. "I love it here. I was so happy to come back to my friends and my job after I temporarily moved back to Florida during COVID. This is my new home, and this is my family."

In hearing the stories of these Vista students and members, it is evident that each person is thriving because they found a home and a life that is the right fit for them. Having and maintaining your own home, building a social circle, finding meaningful employment, and engaging with your community is possible if you are willing to be flexible in how you accomplish it. We encourage you to imagine the possibilities!

Please note: The names of the Vista students and members in this article have been changed for privacy reasons. Becky Lipnick is the Communications Lead at Vista Life Innovations. For over 30 years, Vista has supported individuals with disabilities achieve personal success. Learn more at www.VistaLifeInnovations.org or contact Becky at BLipnick@VistaLifeInnovations.org.

References

Dealing with Change - A Guide for All Audiences. (2020, August 14). National Autistic Society. <https://www.autism.org.uk/advice-and-guidance/topics/behaviour/dealing-with-change/all-audiences>

Executive Function from page 6

compilation of messes if one struggles to identify and address them as they come up. Knowing what one takes note of and will act on can help to determine what needs to be done to set up an individual for success. It is no secret that it can be much more gratifying to participate in a preferred activity than complete a chore that will not have immediate consequences. Any moments to bring awareness to those consequences helps to rationalize the importance of prioritized tasks.

Overall, it should be noted that such strategies to support individuals on the autism spectrum with living independent lives are not revolutionary nor wildly different from those who are seen as neurotypical use. However, it is the focused effort and intentionality that make all the difference. Rather than riding on the assumption that such tools will be uncovered and implemented on one's own, support should be given to help guide a productive life in the vision the individual themselves establishes. Being a source of support in operationally defining what each task looks like and where it will fit in a given day is helpful to



Alissa Cappelleri, MAT

create focused plans and cover a breadth of daily living skills. Coaching through modeling and being alongside them for repeated practice can be beneficial and instill confidence in one's own competence in the long run.

Alissa Cappelleri, MAT, Program Coordinator, *New Frontiers Executive Function Coaching*, can be reached at info@nfil.net or (646) 558-0085.

References

Dawson, P., & Guare, R. (2018). *Executive Skills in Children and Adolescents: A Practical Guide to Assessment and Intervention – Third Edition (The Guilford Practical Intervention in the Schools Series)*.

Dawson, P., & Guare, R. (2016). *The smart but scattered guide to success: How to use your brain's executive skills to keep up, stay calm, and get organized at work and at home*. Guilford Press.

Gray, K. M., Keating, C. M., Taffe, J. R., Brereton, A. V., Einfeld, S. L., Reardon, T. C., & Tonge, B. J. (2014). Adult outcomes in autism: Community inclusion and living skills. *Journal of autism and developmental disorders*, 44(12), 3006-3015.

Kleinhans, N., Akshoomoff, N., & Delis, D. C. (2005). Executive functions in autism and Asperger's disorder: flexibility,

fluency, and inhibition. *Developmental neuropsychology*, 27(3), 379-401.

Panerai, S., Tasca, D., Ferri, R., Genitori D'Arrigo, V., & Elia, M. (2014). Executive functions and adaptive behaviour in autism spectrum disorders with and without intellectual disability. *Psychiatry journal*, 2014.

Silberman, S. (2015). *Neurotribes: The legacy of autism and the future of neurodiversity*. Penguin.

Smith, L. E., Maenner, M. J., & Seltzer, M. M. (2012). Developmental trajectories in adolescents and adults with autism: The case of daily living skills. *Journal of the American Academy of Child & Adolescent Psychiatry*, 51(6), 622-631.

Wallace, G. L., Kenworthy, L., Pugliese, C. E., Popal, H. S., White, E. I., Brodsky, E., & Martin, A. (2016). Real-world executive functions in adults with autism spectrum disorder: Profiles of impairment and associations with adaptive functioning and co-morbid anxiety and depression. *Journal of autism and developmental disorders*, 46(3), 1071-1083.

Challenges from page 31

residences for specific individuals will also be of great value.

Travel and Transportation

Closely related to the availability of adequate housing is that of adequate transportation. Outside of a few major metropolitan areas and large cities (such as New York, where I live) with good public transit, this requires having access to a car or otherwise being dependent on someone else who can drive you everywhere. For many autistics, learning to drive has always presented a significant challenge, even when they can afford the cost and expenses of an automobile. As such, some form of transportation needs to be made available to autistics whatever their residential setting.

If they are fortunate enough to live in a location served by public transit, they need to know how to access and navigate through the system, or else be instructed in such (ironically, more than a few autistics are greatly fascinated by and have extensive knowledge of their local transit system – they will need little or no help with this). Otherwise, provisions must be made for adequate transportation to all essential activities, such as work and medical or social service appointments, as well as recreational and social ones. For those who can learn to drive a car, driving instruction appropriate for autistics needs to become a high priority, given the high percentage of autistics who do not drive.

Recreational Activities

Recreation constitutes a significant part of life for everyone, including autistics. Many autistics, however, have unusual preferences in their choices of recreational activities and interests. As such, traditional group activities that are organized by social service entities and assisted living facilities may not be suitable for many autistics. For example, these activities often involve

sports or games that may not be of interest or, more significantly, that they are not able to participate in (especially the many autistics who have poor motor skills and coordination). Other activities may simply be entirely outside their restricted range of interests. Although such activities can sometimes be successfully used to broaden an autistic person, there can also be strong aversion. In the latter case, the autistic is hardly well-served by such efforts despite their good intentions.

Activities that are more appropriate for autistics usually center around their specialized interests and, when present, areas of unusual abilities (i.e., splinter skills). Although these vary widely among individuals, it is often observed that significant numbers of autistics gravitate towards certain specific interests and, as such, group activities planned around these will attract at least a few (perhaps more) members of an autistic community. More generally, autistic interests largely tend to lie within a confined number of restricted categories. As such, many activities related to any of these categories, while not catering to the specific interests of some individual autistics, may nevertheless be acceptable to them, and thereby constitute suitable group activities for larger numbers of autistics. Finally, activities outside the range of an individual's specific interests but to which there is no significant aversion can be used to broaden their horizons. This in turn can help with improved socialization into wider and more diverse communities.

Finally, activities outside the autistic community that involve extensive socializing, particularly those requiring higher levels of social skills, are generally not appropriate recreation for autistics, and should generally be avoided. At the very least, such activities need to be accompanied by appropriate interventions such as social skills training or coaching, or other forms of instruction or therapy. The result should always lead to greater acceptance by and involvement with the respective communities, and never to discourage-

ment of the individual because such is not the result. In all the above cases, it is imperative that the individuals and organizations that organize recreational activities for autistics be completely aware of the needs of this population, and always take them into full consideration when planning activities.

Community Living

Regardless of their housing situation, autistics need an opportunity to become a part of the greater community in which they reside, or otherwise find an adequate community to which they can belong. The former situation is usually preferable and will often require appropriate assistance and support services to make it possible. In particular, the challenges faced by most autistics with social skills and socialization need to be addressed, perhaps extensively. Even something as basic as finding and being introduced into local communities can present challenges that require intervention; such services must be made readily available when needed. A more fundamental prerequisite, however, is that instruction and coaching and, where warranted, therapeutic interventions for social skills and socialization be provided at the earliest appropriate time. These skills are essential for an autistic to have any chance of being successfully integrated into any community, particularly a neurodiverse one.

As was the case for recreational activities, the specialized interests and unusual talents of many autistics can be a key to community involvement. If a substantial segment of the local community happens to share a particular interest, this can greatly help an autistic become part of that community. Otherwise, finding other communities of individuals dedicated to that interest can be of tremendous value. Also, an autistic who has splinter skills that can be used to either meet a practical need of the community (such as technical, information, or financial skills), or to help pro-

vide recreation (e.g., artistic talents) can use these to become an accepted and even valued member of that community.

Communities consisting entirely of autistics have been forming in recent years, particularly support and social groups. I have had the opportunity to attend, facilitate, and help to organize such groups with GRASP (www.grasp.org) and Aspies for Social Success (AFSS) (www.nyautismcommunity.org), both of which are peer-run organizations (for and by individuals on the autism spectrum). Such groups provide communities where autistic challenges are understood and appreciated. For those who belong to other communities, these can provide an additional refuge where they can address issues that may not be understood, let alone appreciated, by their more mainstream communities. For others who, sadly, have not found communities to be a part of, they constitute perhaps their only opportunity to belong to one. Traditionally, these groups have met in person at a variety of venues (e.g., meeting rooms, diners) but, with the advent of the COVID-19 pandemic, the number and frequency of online meetings among these groups has greatly proliferated (some are held every week) over the past year. The result has been a dramatic flourishing of these virtual communities, not to mention a considerable mitigation of the isolation experienced by so many during the pandemic.

In all the above instances, the presumption that the skills required are so basic and instinctive that they do not need to be taught must be completely discarded when dealing with autistics, regardless of their perceived intelligence or whatever unusual talents they might have, however exceptional. This needs to be done if the fundamental needs of the autistic community, including the need for community, are to be met.

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

Mental Health News Education

Board of Directors

Chair

Debbie Pantin, MSW, MS-HCM, President and CEO
Outreach

Vice-Chair

Rachel A. Fernbach, Esq, Deputy Director and Assistant
General Counsel, New York State Psychiatric Association

Secretary

Yvette Brissett-André, MPA, Executive Director and CEO
Unique People Services

Treasurer

Kimberly Williams, MSSW, President and CEO
Vibrant Emotional Health

Members of The Board

Anita Appel, LCSW, Senior Health Care Consultant
Sachs Policy Group

Peter D. Beitchman, DSW, LMSW, Principal
Behavioral Health Consultation

Constance Y. Brown-Bellamy, MPA, President and CEO
Brown Bell Consulting

Jonathan P. Edwards, PhD, LCSW, ACSW, Program Consultant
New York City Department of Health and Mental Hygiene

Roy Kears LCSW, CASAC, VP Recovery Services & Community Partnerships
Samaritan Village

Matthew Loper, CEO
Wellth

Barry B. Perlman, MD, Past President
New York State Psychiatric Association

Jorge R. Petit, MD, CEO
Coordinated Behavioral Care (CBC)

Keri Primack, CFP, Senior Financial Advisor, SVP
Gerstein Fisher

Joshua Rubin, MPP, Principal
Health Management Associates

Founding Chairman

Alan B. Siskind, PhD, LCSW

Executive Staff

Ira H. Minot, LMSW, Founder

David H. Minot, BA, Executive Director and Publisher

Autism Spectrum News

Editorial Board

Cindy Alterson, PhD, BCBA, Principal of Devereux NY CARES
Clinical Director, Devereux Advanced Behavioral Health-New York

Joel Bregman, MD, Psychiatrist
United Community & Family Services

Joseph D. Buxbaum, PhD, Director
Seaver Autism Center - Icahn School of Medicine at Mount Sinai

Susan Cortilet-Jones, MS, LMHC, Integrative Wellness Coach for Adults
Discovering Your World, Corp.

Lynda Geller, PhD, Founder, Spectrum Services
A Cooperative of Independent Practices & Organizations, New York, NY

Michael Gilberg, Esq.
Special Education Attorney, NY/CT

Ami Klin, PhD, Director
Marcus Autism Center

Becca Lory Hector, CAS, BCCS
Autism, Neurodiversity, & Inclusion Consultant/Speaker/Author/Advocate

Cecelia M. McCarton, MD, Founder and Executive Director
The McCarton Foundation, The McCarton School (for Autism)

Judith R. Omidvaran
Autism Parent Advocate, New York

Theresa Pirraglia, Co-Founder and Board Member
FECA, The Foundation for Empowering Citizens with Autism

Howard Savin, PhD, Chief Clinical Officer
First Children Services

Pat Schissel, LMSW, New York Director
Asperger/Autism Network (AANE)

Alison Singer, President
Autism Science Foundation

Fred Volkmar, MD, Professor
Yale Child Study Center

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

Dianne Zager, PhD, Head of School Emerita, Shrub Oak International School
Professor Emeritus, C.W. Post, Long Island University

Autism Spectrum News is a Quarterly Print and Online Publication of Mental Health News Education, Inc., a 501(c)(3) Nonprofit Organization

All inquiries regarding advertising, subscriptions, sponsorships, and submitting an article should be directed to:

David H. Minot, BA, Executive Director and Publisher

(978) 733-4481 • dminot@mhnews.org • 460 Cascade Drive, Effort, PA 18330 • www.AutismSpectrumNews.org

Mental Health News Education, Inc. does not endorse the views, products, or services contained herein. We are not responsible for omissions or errors. Mental Health News Education, Inc. is not responsible for articles submitted to us without the final approval of the organization’s Executive Director, CEO, or Public Relations Department. All articles and Advertisements are subject to final approval by our Editorial Board. We reserve the right to edit any article sent to us.

Disclaimer of Endorsement and Liability: The information, opinions and views presented in Autism Spectrum News (ASN) reflect the views of the authors and contributors of the articles and not of ASN, the Editorial Board or its publishers. Publication of articles, advertisements or product information does not constitute endorsement or approval by ASN and/or its publisher. ASN and/or its publisher cannot be held responsible for any errors or for any consequences arising from the use of the information contained in this publication. Although every effort is made by the Editorial Board and the publishers to see that no inaccurate or misleading data, opinion or statement appear in this journal, the data and opinions appearing in the articles including editorials and advertisements herein are the responsibility of the contributors concerned. The publishers and the Editorial Board accept no liability whatsoever for the consequences of any such inaccurate or misleading data, information, opinion or statement.

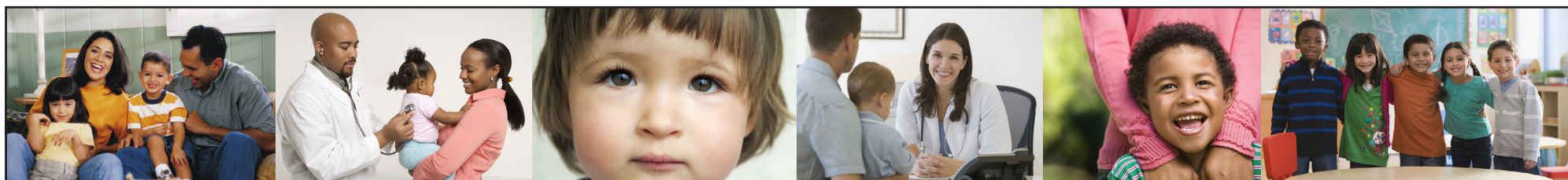
Copyright © 2021 Mental Health News Education, Inc. All rights reserved. Content contained in this publication may be reproduced for one-time personal use. However, anyone wishing to reproduce and distribute any content from within this publication for purposes other than personal use must request this intention in writing directly to the publisher. Failure to do so will be in violation of the copyright held by this publication.

AUTISM SPECTRUM NEWS

*Your Trusted Source of Science-Based Autism Education,
Information, Advocacy, and Community Resources*

www.AutismSpectrumNews.org

Your Trusted Source Since 2008



Autism Spectrum News (ASN) was developed to provide the autism community with a trusted source of evidence-based information and education, the latest in scientific research, clinical treatment best practices, family issues, advocacy and vital community resources.

In keeping with the publication's evidence-based mission, ASN has an esteemed Editorial Board that will only accept articles and advertising offering science-based information and/or treatments that have been proven safe and effective for individuals with autism spectrum disorder.

ASN By the Numbers

- A targeted autism readership of over **200,000** annually in print and online
- Over **25,000** social media followers on Facebook, Twitter, LinkedIn, and Instagram
- A searchable online database of over **1,000** articles available for free
- An online archive of over **50** quarterly issues going back to 2008
- The print edition of ASN is delivered to all **50** states in the country

Advertising Information: www.AutismSpectrumNews.org/Advertise

Subscription Information: www.AutismSpectrumNews.org/Subscribe



#YourTrustedSource

Autism Spectrum News is a quarterly print and online publication of Mental Health News Education, Inc., a 501(c)(3) Nonprofit Organization

For information about advertising, subscriptions, or how to submit an article, contact David Minot, Publisher, at (978) 733-4481 or dminot@mhnews.org