Autism and Community Engagement

The Importance of Community-Based Instruction for Individuals with Autism Across the Lifespan

By Kara Constantine, PhD, Todd Harris, PhD, Cathleen Albertson Deutsch, MA, BCBA, Amanda Duffy, MEd, BCBA, LBS and Lucas Cepeda, MS, BCBA

Devereux Advanced Behavioral Health

A Small Village Becomes an Autism Supportive Community

By Kathleen Marshall, MA Ed, SAS
Director of Program Services
Anderson Center for Autism

When looking toward the future, most parents hope their children will be happy, healthy, and enjoy a satisfying quality of life. For families with a child with autism, this desire is no different. The Autism Society of America identified nine key indicators to consider for assessing and improving the quality of life for individuals with autism: school inclusion, friendships and social connections, health and well-being, academic success, autonomy, independent living, independent employment, subjective well-being, and recreation and leisure (Repella, 2012). When considering many of these indicators, success is dependent upon being successful in community settings.

To be successful in the community, individuals with autism often require more than simple exposure or skill modeling. Simulated learning experiences often have equally limited results in achieving skill generalization in community environments (McDonnell, 2009). To maximize successful community outcomes, it is vital that instruction be delivered in naturally occurring settings. The following outlines the essential components of community-based instruction (CBI) and provides a case study that demonstrates the value of CBI in improving the quality of life for individuals with autism.

CBI Essential Elements

CBI describes skills training in natural settings that enhances learning and facilitates generalization (e.g., Walker, Uphold, Richter, & Test, 2010). More than classroom trips, CBI is systematic instruction on specific skills in community environments where the skills are naturally used (Florida Department of Education Bureau of Exceptional Education and Student Services, 2018). CBI can be used to teach skills such as dressing, eating, grooming, and personal care.

A Small Village of Rhinebeck, New York, is pursuing designation as an Autism Certified Travel Destination. So, Anderson Consultants searched for a way to make it happen locally. It was one of those things where so many forces come together to make something possible. A small grant was secured with targeted dollars and efforts focused on benefiting people in the little Village of Rhinebeck, New York, about 100 miles north of NYC and just a few miles north of Anderson Center’s main campus. Dutchess County Executive, Marc Molinaro, had already occasioned the public’s attention to “Think Differently” in support of all people with disabilities. The immediate welcoming and enthusiasm of such an initiative by Village of Rhinebeck Mayor, Gary Bassett, paved the way toward this community becoming “autism supportive.”

The Village of Rhinebeck Board approved the project and the establishment of the Autism Supportive Community Committee, tasked with planning, identifying goals and facilitating efforts toward establishing the Village as a supportive community. The Committee was comprised of key “stakeholders,” including: Mayor Bassett, School Superintendent, Chamber of Commerce Director, a representative from the local hospital and a physician’s office, a representative from Rhinebeck Masons, a representative of a local business/parent of a child with Autism, “advisors” from ACA and a local communication/ marketing business. The Advisors assisted with the development of communication, print material and social media postings. In addition, an Anderson Consulting representative served as facilitator; providing training and advising the Committee on...
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Deadline: December 3, 2019

#### Spring 2020 Issue
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Promoting Community Engagement and Social Connections Through Employment and Volunteering

By Ernst VanBergeijk, PhD, MSW and Charlotte Ochs, MSW

The Threshold Program at Lesley University

M ost parents, at some point, grapple with worry over how their child will fare. Will they be happy? Will they find meaningful connections? Will they find their passion? This is true for parents of children with autism. Added to typical concerns, like “is my adult child eating their vegetables and wearing a coat in the winter,” is the worry that your child will not find a place to belong. Individuals on the autism spectrum are found to be significantly more likely to not be invited to social activities or called on by friends than individuals with other categories of disabilities (Orsmond, Shattuck, Cooper, 2013). Twenty-eight percent of young adults with autism interviewed by Orsmond et al., (2013) reported having no social interaction at all. Another study found that limited quality of social relations contributes to higher anxiety levels in those on the spectrum (Eussen, Gool, Verheij, 2012). Some ways to combat social isolation and grow a community is through education, work and volunteering. Many neurotypical adults will socialize with those they meet at work and school.

Employment

The employment statistics for individuals on the autism spectrum are pretty grim. Without some sort of intervention, the unemployment rate varies widely with rates ranging from 65% - 90% (Chiang, Cheung, Li, & Tsai, 2012; Oll et al., 2017; Roux et al., 2013; Standifer, 2012; Holwerda, 2012 as cited in Walsh, 2014). The federal government does not track employment statistics for individuals on the spectrum. It only closely reviews the unemployment rates of people with all disabilities. However, the individual must engage in job seeking behaviors within the last 30 days to be considered unemployed.

Persons who are neither employed nor unemployed are not in the labor force. A larger proportion of persons with a disability—about 8 in 10—were not in the labor force in 2016, compared with about 3 in 10 of those with no disability (U.S. Department of Labor Bureau of Labor Statistics, 2017b).

Eighty percent of people with disabilities in general are not in the labor force and are not counted as a part of the unemployment statistics. They have given up looking for work which means they have lost an important avenue for community and social engagement.

A few key predictors of employment for this population are whether or not the student on the autism spectrum has had paid employment during high school (Carter, Austin, and Trainor, 2012); had their state office of vocational rehabilitative services present for IEP meetings during the student’s transition-aged years (Roux, Rast & Shattuck, 2018); and completion of some sort of post-secondary education like a college-based transition program or employment program (Moore, & Schelling, 2015; Wehman, 2013). In fact, according to Miliguore, Timmons, Butterworth, and Lucygs (2012), post-secondary college-based services was the best predictor of earning potential and, however, only 10% of the Vocational Rehabilitative Services database received such services. This group also found that the odds of youth on the autism spectrum finding employment were greater if Vocational Rehabilitative Services were involved in the job placement of the youth, but only 48% of youth on the autism spectrum ever received those services (as cited in VanBergeijk, 2020).

Volunteering

While gainful and fulfilling, long term employment is the ideal and volunteering is a mutually beneficial avenue to gaining job skills, social connections, and giving back to the community. Volunteering can lead to an agency creating a specific job for an individual on the autism spectrum who has contributed to the organization. Or at the very least, can result in letters of recommendation from supervisors and leads or referrals to jobs (Grandin & Duffy, 2004). As part of the college-based transition programs, students and alumni are encouraged to volunteer at a variety of local organizations such as local theaters, food recovery programs and river clean ups. Houses of worship, civic centers, and municipal youth programs are also great places to volunteer and develop social connections. As a group with big hearts and bigger personalities, this group of volunteers leaves a mark wherever they go. The opportunities presented by college-based transition programs as well as a staff dedicated to the holistic success of the students facilitates close, life-long friendships and the opportunity to create and maintain a social circle. From this social circle we have seen relationships bloom into marriages, peers help peers secure jobs, and alumni start and maintain traditions for decades.

Finding a College-Based Transition Program

There are approximately 250 college-based transition programs across the country. This number may sound like a large number; however, this is out of over 7,600 institutions of higher education. Unlike colleges and universities where there are dozens of choices per state, some states do not even have a college-based transition program. How do parents, other caregivers, and individuals on the autism spectrum find this proverbial needle in a haystack?

The search starts on the internet.

The Institute for Community Inclusion (ICI) at University of Massachusetts provides technical assistance to colleges and universities that have transition programs for students with intellectual and/or developmental disabilities. They also maintain a website known as THINK COLLEGE! (https://thinkcollege.net/), which is a repository of information on college-based transition programs. George Washington University is the home to the Heath Center, which is The National Youth Transitions Center clearing house (https://www.heath.gwu.edu/) and is an excellent resource for families searching for programs and seeking guidance in their quest for programs.

The Free Application for Federal Student Aid (FAFSA) website actually lists the over 75 U.S. Department of Education approved Comprehensive Transition and Post-secondary (CTP) programs by name and location. The CTP status enables those approved programs to provide Federal Student Financial Aid to eligible students with an intellectual or developmental disability. HOWEVER, the aid is in the form of grants and federal student work study monies only. The good news is that those forms of aid do not have to be re-paid.

The bad news is that students enrolled in a CTP are not eligible for subsidized and unsubsidized federal loans which make up the bulk of federal student aid. Finding the list of eligible programs is extremely tricky and requires at least 6 clicks from the home page to the actual list. The search engine on this web site is not helpful. Use the following URL to reach the list directly: https://studentaid.gov/sa/eligibility/intellectual-disabilities . Lesley University Threshold Program developed an e-Book titled Comprehensive Guide to Transition Programs (https://www.lesley.edu/six-qualities, which is available for free.

When searching for a college-based transition program, check to see: What areas of employment do they prepare their students for, and does this match your student's interests? Next, find out what independent living skills do they teach students in. Being able to successfully execute activities of daily living such as getting up on time, having appropriate hygiene and dress for work, as well as navigating mass transit to work are better predictors of employment than I.Q. and academic ability. Ask what kinds of support will your student receive if they were to enroll in a particular program. Another key question to ask these programs is, “Will you help with job searches and job placement?” Next ask the program about the program’s outcome data. What are their employment rates of their graduates? How long have they been tracking their alumni? What percentage of their graduates live independently? How satisfied are their graduates with their social lives and their sense of connectedness to friends and their community? What kinds of long-term support do these programs offer their graduates? By asking these questions, parents alongside their young adult can select the best program to meet the individual’s needs.

Through employment and volunteering, adults on the autism spectrum can have a high quality of life that leads to social connections and community engagement. Many colleges and universities have programs that help students with a wide range of disabilities prepare for the world of work and independent living teaching them not only employment and independent living skills, but also social skills with an eye on community integration. Finding the right program for an individual is going to require a little bit of research-on-line and in person with phone calls, with college visits to see how each fits that process. The right program will have a variety of supports for the individual that may spread across their life span as they grow and age.

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. He also oversees the Lesley University Threshold Alumni Center which provides life-long support for graduates of the Threshold Program. Beginning in the Summer of 2020, the Threshold Program will be offering a 6-week summer program for students ages 16-years-old and up.

Charlotte Ochs, MSW, is a Community Support Specialist at The Threshold Program at Lesley University. The Threshold at Lesley University is a non-degree post-secondary program for young adults with diverse learning, developmental, and intellectual disabilities. A graduate of both Syracuse University and Boston University’s School of Social Work, Charlotte collaborates with students and supports alumni of The Threshold program find and maintain employment, connect alumni to resources, and plan social activities. For more information, please visit https://lesley.edu/threshold-program.
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Community Engagement Through Integrated Community Living Options for Adults with Autism

By Patricia Wright, PhD, MPH
Vice President, Program Services
NEXT for AUTISM

With the increasing prevalence of autism documented in children over the past two decades, there is growing alarm about what will be needed for these children as they grow into adulthood (Anderson & Butt, 2018). Indeed, there are adults living with autism right now with unmet needs due to service waiting lists and the lack of appropriate funding and supports for the social service system. One of the greatest needs, particularly for individuals with autism who require significant support, is housing (IACC, 2019).

There is an ongoing debate about what is appropriate housing for people with autism who need significant levels of care (Mandell, 2017). Many adults with autism continue to live with their family members in adulthood (Anderson, Shattuck, Cooper, & Roux, 2013). As parents age, it can become increasingly difficult for them to provide appropriate supports. Eventually, adult children with autism will outlive their parents. Other adults with autism whose needs require close supervision and assistance, live outside of the home in supervised, residential settings (Lulinski, Jorwic, Tanis, & Braddock, 2018). These settings are typically organized with multiple adults with autism living in one residence with rotating shifts of staff. This shift work model results in the adults with autism often receiving support from more than a dozen different, direct-care professionals.

The challenges of developing and implementing 24-7 supervision to ensure a safe environment while simultaneously promoting a high-quality life are significant. Top among those challenges is securing and retaining qualified, direct support professionals (The Arc, 2014). The current turnover rate for direct service professionals is 45% annually (President’s Committee for People with Intellectual Disabilities, 2017). People with autism benefit from routine and consistency (Rydzewska, 2016). The lack of consistent staffing support is of concern. High staff turnover and shift changes decreases the consistency in programming.

One model that has improved staff consistency utilizes shared living (Strouse, Carroll-hernandez, Sherman & Sheldon, 2003). This model employs couples, individuals or families with children, to live in a shared environment with one or more adults with autism. The homes are located in integrated community environments (e.g. apartment buildings, homes in suburban neighborhoods) where people with and without disabilities reside together, building a quality life, together. Shared Living results in a staffing schedule with fewer professionals interacting with the adult with autism and increased programmatic consistency. It is often referred to as a Family Teaching Model.

In the Family Teaching Model one or more members of the Teaching Family are trained to take responsibility for providing direct programmatic support for their housemates with disabilities. Additional professionals may come in for work shifts, but the Teaching Family is in the same environment where those shift workers deliver programmatic support. The Family Teachers are a constant presence within the staffing structure and have a greater investment in the quality of supports in the home as it is where that family lives. The consistency of the Family Teachers is essential to programmatic success. Many adults with autism present with significant challenges in residential settings (Matson & Rivet, 2008). The Family Teaching Model can address behavioral challenges and has even resulted in decreasing aggression (De Wein & Miller, 2009).

Core to the Family Teaching Model is the belief that members of the household are equals. Although the Family Teachers may provide support and instruct, every adult in the household is of equal status. Decisions are made collectively, with the adults with autism participating to the greatest extent possible. Visual supports are provided to the adults with autism, and accommodations are made when necessary. This programmatic model can only be achieved with effective, consistent and invested supervision.

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Strategies for Increasing Social Networking and Job Readiness for Individuals with ASD Through Community Engagement

By Jocelyn Howard
Lead Career Coordinator
The College Internship Program (CIP)

In the past, opportunities for higher education and exciting career paths within a supportive and safe environment were few and far between for individuals with ASD. These challenges to independence and barriers to employment are now shrinking. We are now able to better equip and support individuals with ASD in overcoming these challenges through impactful initiatives such as community engagement.

Community Engagement can be a journey or social process that calls for organizations and communities (local, regional/state, national or global) to collaborate in dynamic ways that strengthen higher education, employment, and community partnerships. The primary elements of community engagement, volunteering, and community service include the enrichment of scholarship, research, and creative activity. It enhances classroom curriculum, strengthening our methods of instruction and learning environments for young adults with ASD. When individuals with ASD become more involved in community, civic and social service, they are taking a proactive measure (real-world application) in their education and employment preparedness.

Case Study

Jodie is a first-year college student who wanted to build her social skills, declare a major and get a job. Jodie had no work experience or resume, she could not decide on what to study in college and had some communication challenges. Specifically, she wanted to improve. She was advised to obtain an internship, participate in at least 10-20 hours of community service and to think about becoming involved in student government. The goal was to assist her in exploring her interests, to learn more about professionalism and workplace concepts. Jodie went on to participate in various community service events and local fundraisers. She obtained an internship as an Admissions Intern at CIP and volunteered at locations like her local animal shelter. Jodie also ran for Vice President of the Student Senate.

During her years of service as Vice President of the CIP Student Senate, Jodie participated in City Hall events and City Council meetings, helped organize a summer day trip to Catalina Island and helped support the recycling drive efforts. At the end of the year, Jodie shared how she and her fellow student senate members learned more about the importance of volunteering, how their efforts contribute to a larger goal or community milestone. The goal was to support student body events, clubs & activities throughout the year. She shared that her fellow peers learned more about professional attire, organization skills, critical thinking and how it felt “really good” to help someone, a special cause or project. Jodie also explained how she learned more about how to initiate conversations, be an active listener and build public speaking skills.

CIP students receive a certificate of accomplishment for participating at the annual Disability Mentoring Month in Long Beach, California City Hall Council Chambers

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Despite the advancement in autism research, one of the challenges that researchers still face today is engaging low-income, racial/ethnic minority, and non-English speaking families. Underresourced families who work multiple jobs have less time to participate in research; some families do not have access to transportation. Besides the financial reasons, it is also important to understand the cultural factors that can act as barriers to research participation for different groups.

For example, African Americans, who have experienced history of research abuse, are more likely than Caucasians to distrust the academic community (Corbie-Smith et al., 2002); Korean Americans, the majority of whom are first-generation immigrants, are excluded from most autism studies due to a lack of research offered in Korean; Latino families may hesitate to enroll in studies due to stigma associated with autism (Zuckerman et al., 2014).

To bridge the gap between research and community, autism researchers across the nation have partnered with their local communities. This team, called the AIR-B Network (Autism Intervention Research Network on Behavioral Health; Principal Investigator: Connie Kasari, PhD), consists of UCLA, UC Davis, University of Pennsylvania, University of Rochester, Drexel University, and each site’s community partners. With funding support from the Health Resources and Services Administration (HRSA), the AIR-B Network has developed interventions to help underresourced families of children with autism and has hosted free local conferences at each site to share research findings with community members for five consecutive years.

The conference is an integral part of community-partnered participatory research (CPPR), the model utilized by the AIR-B Network. In CPPR, community and academic members are equal partners that collaborate in all stages of research (Jones & Wells, 2007). CPPR-style conferences have shown success in engaging minorities in other disciplines, such as depression (Mendel et al., 2011), cancer (Jones et al., 2013), public health (Iyer et al., 2015), and stroke (Bharmal et al., 2016). UCLA, the coordinating site of the AIR-B Network, jointly hosts the annual autism conference in Los Angeles with its community partner and developer of CPPR, Healthy African American Families (HAAF).

UCLA and HAAF have formed a workgroup that meets monthly to discuss study design, recruitment, planning of the annual conference, data analysis and dissemination. The workgroup has grown over the years and its regular members include community-based organization staff, self-advocates, and parents from diverse cultural backgrounds. These partners have played a vital role in expanding the workgroup’s outreach to Latino and Korean American communities in Los Angeles.

The purpose of the annual autism conference is to report back the findings of AIR-B research projects to the community, to disseminate evidence-based autism information and to strengthen the partnership.
Community engagement is a broad term that is informed by an ecological perspective that one’s behavior is impacted by larger social, cultural and physical environments. Community engagement has been defined as “the process of working collaboratively with and through groups of people affiliated by geographic proximity, special interest, or similar situations to address issues affecting the well-being of those people” (Centers for Disease Control and Prevention [CDC], 1997, p 9). Community engagement has the goal of bringing various stakeholders together to work to change policy, increase resources, and inform programs and practices to improve health and behavior outcomes. As the incidence of Autism Spectrum Disorder (ASD) has continued to increase (Baio et al., 2018), community engagement has also increased. Large scale community engagement may include public awareness efforts such as the Autism Speaks 100 Day Kit for Young Children (www.autismspeaks.org/tool-kit/100-day-kit-young-children) and increases in research funding (Singh et al., 2009). However, it may also include smaller scale efforts such as home-based intervention geared towards improving outcomes for one individual with ASD. This article will focus on the role of home-based intervention services as a means of increasing community engagement in individuals with ASD.

Home and Community Services

Home-based services for individuals with ASD have been implemented for several decades. Early studies on the efficacy of treatment approaches such as applied behavioral analysis (ABA) found that services provided within home settings were effective in improving functioning in children with ASD (Lovass, 1987, McEachin, Smith & Lovass, 1993). ABA is now recognized as the primary evidence-based treatment for ASD (National Research Council, 2001) and may be effectively provided within educational, home, and various community settings. Home based services allow for a collaborative effort between schools, parents and community professionals. With services provided directly in the home and community, families have increased access to support while forging relationships in the community and teaching their children relevant skills.

The benefit of home-based intervention carries across many areas. First is that intervention within home and community settings facilitates targeting of skills primarily to the features of ASD. One of the primary deficits in the diagnostic presentation of ASD is lack of social reciprocity and perspective taking. Within various community settings, individuals with ASD often struggle to understand social norms and accepted standards of behavior. Moreover, many present with challenging behavior that interferes with their ability to demonstrate skills within the often-unpredictable community environment. Targeting intervention within a home or community setting encourages identification of skills that are socially valid and relevant to that setting. It also allows for skill generalization and the opportunity to take advantage of naturalistic learning opportunities.

Another benefit to intervention within home and community settings is increasing...
Living a Good Life: How to Build a Satisfying Recreation Program for Adults with Disabilities

By Catherine Sullivan-DeCarlo
VP of Admissions and Marketing
Chapel Haven Schleifer Center

Andrew Auerbach, 63, has been going on weekend recreation trips with Chapel Haven Schleifer Center in New Haven, CT, since he arrived at the program in 1977. Andy, who grew up on the Upper West Side of NYC, holds two part-time jobs during the week, so the weekend is prime time for relaxing and having fun. Some of his favorite weekend trips include Mystic Seaport, the Bronx Zoo, the Essex Steam Train and the Big E.

“I get a lot of benefits out of these trips,” he said. “I get mostly pleasure and social connectivity too.”

Like many agencies that serve persons with disabilities, Chapel Haven puts great emphasis on offering its adults, whose ages range from 18 to 66, lots of opportunities to socialize. From in-house activities like Karaoke Night and Bingo, to the mall, sports and activity trips across the tri-state area, the weekend calendar offers everybody the chance to get together, blow off steam, have fun and learn to manage leisure time.

They can also compete in sports through Special Olympics, sign up for classes that will bring them off campus and even get together to cook or work out.

Having a robust social calendar is important for all people, including those with disabilities. But there is an art to offering a meaningful experience.

“Recreation and leisure activities are a critical dimension of the quality of life for all people, including those with developmental disabilities,” according to Syracuse University’s National Resource Center on Supported Living and Choice Center on Human Policy. “They are a vehicle through which people have fun, meet new friends, and develop skills and competencies. So, what are the elements that make a program successful? One consideration is not just sending adults in one big group to a public place but offering them the chance to mingle and build relationships with the people in the communities they visit.

“Our clients benefit greatly when they go into the community. Not only do recreation trips in the community promote inclusion but they also help our clients build their confidence through social interactions and new experiences. Recreation is an important component of maintaining a healthy lifestyle,” says Emily Westman, director of recreation at Chapel Haven Schleifer Center.

Another important component of a good leisure program is lessening the intimidation factor of entering places such as museums. That is one of the goals that Chapel Haven’s Art Director, Tina Menchetti, had in mind when she worked with the Yale Center for British Art on a program called “Out to Art.” Menchetti chaperones students to the museum for a wide range of activities.

“I sometimes wonder who gets more out of the program – our special visitors or the museum staff,” said Linda Friedlaender, Senior Curator of Education at the Yale Center for British Art. “Weekly visits have strengthened social, emotional, and cognitive growth by providing spaces filled with new friends who work at the Center and art objects which are used in many ways. Students have fun exploring the galleries using costumes, mirrors, masks, instruments, etc.”

see Recreation on page 30
AHRC New York City Prepares People with Disabilities for Jobs
Partners with Salesforce to Provide Meaningful Work

By Lynn Uhlfelder Berman
AHRC of New York City

Salesforce employees know they can count on Kristian Goris to go above and beyond. “Working makes me feel very good,” he says. “Whenever I go to work, I’m not only doing this for myself, but I’m also doing it for my family and those I care about. It’s really a great feeling.”

Kristian wasn’t always this way. It has taken the 23-year-old, Bronx, N.Y., resident time to become who he is today. Once an introvert, who preferred not to speak with people, Kristian has worked hard, with the support of AHRC New York City’s Employment and Business Services’ (EBS) staff. Salesforce has opened its doors to Kristian and 22 other people with intellectual and other developmental disabilities (I/DD).

“Dedicated and Loyal Employees”

“Salesforce recognizes that Kristian and other people with I/DD are hard working, dedicated and loyal employees,” says Marco Damiani, CEO of AHRC NYC. “Working increases their confidence and self-esteem, impacting other parts of their lives in a positive way.”

Twenty-nine years after the signing of the Americans with Disabilities Act, employment remains an elusive goal for many people with disabilities. The labor force participation rate for working-age people with disabilities increased in August 2019 from the previous August, according to the Bureau of Labor Statistics Job Report released on September 6. It rose 5.2% to 34.7%. The labor force participation rate is the percentage of the population that is working or actively looking for work.

Fear of Traveling Independently

Michele Shapiro, Assistant Director of AHRC NYC’s EBS, recalls Kristian gaining some basic computer skills at a pilot program AHRC NYC had with Specialisterne, a work readiness program to assess soft IT skills. “But his biggest issue was fear; fear of employment and fear of traveling independently,” she says. Kristian’s father would drive him from the Bronx to the program’s SoHo office in Manhattan.

That fear of traveling may have stemmed from Kristian’s mother. “I was very nervous about him taking the bus or subway,” Maria Goris says. “He’s a good boy, very honest and I worried about people take advantage of him.”

At an internship at AHRC NYC’s Bronx office, Kristian took it upon himself to alphabetize files, while maintaining the file room and assisting staff with other tasks. The site was closer to home, but his father still drove him to the office and picked him up each day.

Kristian Goris, who receives support from AHRC New York City’s Employment Business Services, has found a home at Salesforce.

Commuting on His Own

EBS staff repeatedly discussed the importance for Kristian to learn to travel independently. It was a requirement for working at Salesforce. Having never traveled on a bus or a subway on his own, it took some courage, but Kristian finally asked his father to teach him how to travel on the subway. They would practice on Saturdays, taking a train to one stop and then reversing the route. Kristian caught on and today travels independently on his 40 minute commute to Salesforce’s midtown Manhattan office.

“Coming to Salesforce was a weird transition,” Kristian recalls. “I liked the Bronx office and enjoyed the people there. As time went on, I realized I had to move on and let go of the (Bronx job). Working here is a very welcoming environment. I don’t regret it.”

He performs light janitorial work, cleans dishes and makes sure conference rooms are in order. He’s eager to create a comfortable and tidy work environment for his Salesforce colleagues.

“Salesforce employees respect Kristian’s attitude to work hard and are very supportive,” says Natalia Dedyulya, Account Coordinator at AHRC NYC’s Manhattan EBS.

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Kristian Goris, who receives support from AHRC New York City’s Employment Business Services, has found a home at Salesforce.
Building Community Engagement with Vocational Training and Employment for Young Adults with Autism

By Julie Weiss, MSEd, BCBA, LABA and Julie LeBlanc, MS, BCBA, LABA
The New England Center for Children

We want our students with autism to be able to answer the question, “What are you going to be when you grow up?” Employment provides a sense of belonging, improved quality of life, community inclusion, and a paycheck. Historically, however, employment rates for adults with autism are low. As the number of individuals with autism has risen over the past decade, a greater number of employers have expanded their hiring practices to include those with autism, recognizing that this segment of the population has both the willingness and ability to work.

“I think if you’re patient in the training, and you work with these employees, that you’re going to find you’re going to get an employee that’s going to do a great job for you, show up for work every single day, and be excited about doing their job,” said Damian Smith, District Manager, Walgreens; the second largest pharmacy job,” said Damian Smith, District Manager, Walgreens; the second largest pharmacy

According to Wehman, et al., at three months post-graduation from high school, 90% of the group that received vocational training acquired competitive, part-time employment. Furthermore, 87% of those individuals maintained employment at 12 months post-graduation. Only 6% of the control group (those who did not receive vocational training) acquired employment by 3 months post-graduation and 12% acquired employment by 12 months post-graduation.

Using ABA in Vocational Training

Applied Behavior Analysis (ABA) is often used to teach children and adults with autism. ABA may help to improve skill acquisition and increase independence, leading to successful employment outcomes.

Vocational skill training can help those with autism learn how to follow directions, improve motor coordination, and increase consistency, reliability, and concentration. The focus should be on teaching social and functional skills that can transfer from one environment to another. Employment requires a repertoire of soft (social) and hard (job-related) skills.

Soft skills include initiating and responding to greetings, conversation skills, responding to social situations, following directions, practicing good hygiene, time management, and dressing appropriately.

Other skills important for the workplace may include money skills, social etiquette skills, communication skills, and job-specific skills. Safety skills, such as fire safety and riding an elevator or escalator, should also be considered.

Establishing Vocational Training Programs

Vocational skill development can begin as soon as State Labor Laws and the Department of Secondary Education Policies permit. In Massachusetts, at the age of 14, students may engage in up to 4 hours per week of vocational exploration within a school or organization. This often starts within on-site career development programs. These programs allow students to explore preferences for work, learn new skills, and gain confidence.

As students age, the amount of time spent on vocational training increases, as does paid and volunteer work. The goal is to develop a strong set of skills and increase work endurance to prepare them for transitioning out of a school program and into the workforce. Students may work in the community or within their school or organization.

Potential work options in these environments may include serving or preparing food, using a cash register, answering phones, and operating a copier.

Michael J. received vocational training in retail apparel sorting, folding, and organization

autism service providers to provide training and job opportunities for young men and women with autism.

Research has shown that vocational training can make a dramatic impact on an individual with autism’s ability to secure and maintain a job (Wehman et al., 2017).

Small Village from page 1

process planning, goal development and data capturing. The Committee identified reasonable goals that included opportunities for village members to learn about the initiative and Autism Spectrum Disorder. Open “education” forums were held during a six-month period at various locations to reach as many Village members as possible. A second goal focused on encouraging businesses and organizations to complete a pledge of doing one thing supportive for people with autism which quickly grew into the tag line, “#1Thing.”

Trained “Stakeholder Representatives” went business to business to speak with owners and managers about the project, answer questions and suggest “#1Thing” options. Simultaneously, the local Chamber of Commerce and ACA posted the pledges made, highlighting each business and organization. Social media was also used to communicate the Village’s efforts. For example, a “kick-off” event promoted in November drew interested community members to an open “education” forum at a local bookstore. Within six months, a total of 265 people attended the open forums and 58% of businesses and organizations implemented their #1Thing. As a result, people with autism and their families can receive reduced wait times and/or advanced ordering options at many Village of Rhinebeck restaurants. Village Police and Fire vehicles have been equipped with sensory kits to offer when they’ve responded to a scene and an individual needs a little extra support. Individuals and families can expect to access Sensory Safe Spaces at Village events such as parades and the community favorite, “Porchfest.” People using the Village Hall can expect to find clear signage and trained personnel. Village business owners are more aware of the benefits of hiring people with autism and other disabilities.

An integral part of the Autism Supportive Community endeavor was education about ASD. Business and community members were certainly motivated to be supportive but were unsure about how to interact with people on the spectrum; not wanting to “do something wrong.” Carter, Harvey, Lounds-Taylor and Gotham (2013) emphasized the importance of “equipping others” to interact socially with a person on the spectrum. The open forums proved to be a successful venue to impart information and general training about ASD as well as an opportunity for questions and problem solving.

The Autism Supportive Community Committee has already embarked on planning for Phase II of this project! The commitment

see Small Village on page 33
Navigating the road to adulthood is rocky for many people. But for young adults on the autism spectrum, the challenge is particularly tough. Social isolation can pose a significant challenge for these adults in their post-secondary school years, even when compared to young adults who had received special education services in school for intellectual disabilities, learning disabilities, and emotional disturbances. Research published in 2013 (Ormond, G.I., Shattuck, P.T., Cooper, B.P. et al, 2013) showed that 47.2% of young adults with ASD never received phone calls from friends and 48.1% never got invited to activities, percentages that were significantly higher than for young adults in the other groups. According to a study published in 2018 (Rai D, Heuvelman H, Dalman C, et al.), by age 27, 19.8% of individuals diagnosed with ASD had a diagnosis of depression compared to 6% of the general population.

The challenges faced by individuals on the autism spectrum don’t end after they come of age. They continue to need support to help them socialize, gain vocational skills, find and keep jobs, and do everyday tasks like housekeeping, food shopping, cooking, and handling money.

In 2008, fifteen families approached Westchester Jewish Community Services (WJCS), a large non-profit human services organization in Westchester County, New York, seeking an agency who could provide support to their young adult children who were not appropriate candidates for living in community residences, but still needed support to be able to live independently. That was the start of POINT (Pursuing Our Independence Together), a unique community that WJCS offers in partnership with JCCA, a non-profit organization in Manhattan. The goal of the community is to increase the members’ skills so they can live independently, provide vocational training and support for competitive employment, and create social opportunities. Today there are 57 members of POINT, ages 21 to 50, who have come from all over the United States, including California, Virginia, Florida, and New Hampshire, to participate in our community.

Participants in the POINT community find and live in their own apartments in downtown White Plains, NY, or with a roommate if they choose. They live within walking distance of each other and POINT’s community center. There is no staff on premises and people come and go as they please. Our experience indicates that there are no other communities like POINT in the country. Members participate in life skills, pre-vocational training and enjoy activities that fill an extensive social calendar, led by staff. With guidance from the POINT staff, our participants are helped to make good decisions, able to date, explore who they are, and, most importantly, reach their potential in independent living and competitive employment.

Research shows that post-secondary level employment opportunities for individuals with ASD are typically limited (Hendricks and Wehman, 2009), and among...
Partnering with the Community to Provide Information and Resources Related to OPWDD’s New I/DD ID Cards

By Jason K. Watson, BCABA, CBBA  
Director of Community Engagement  
Nassau Suffolk Services for Autism

By now, some of you may have heard about OPWDD’s (Office for People with Developmental Disabilities) new I/DD ID cards for individuals with intellectual developmental disabilities in New York State. These standardized cards are available upon request and can be a very useful tool in bridging the gap of communication and reducing possible risks that may present themselves when individuals with autism and other developmental disabilities are in situations involving law enforcement or other first responders. Interactions with law enforcement and emergency personnel is an especially concerning topic as children with autism grow up and become adults with autism.

I wanted to take a moment to follow up and provide some additional information as well as to let people know of some exciting new initiatives NASSA has been involved with related to these cards. Finally, I would like to provide a link to OPWDD’s website in order for individuals or families of individuals with autism or other developmental disabilities to obtain the ID card: www.opwdd.ny.gov/iddidcards.

Regardless of where an individual profile falls on the autism spectrum, I highly encourage families of individuals with autism or other intellectual disabilities in New York State to take the opportunity to get one of these cards.

First, I will provide some background information. According to OPWDD, the goal of this I/DD ID card initiative is to help first responders such as law enforcement, firefighters and other emergency personnel better understand and interact with people with developmental disabilities who may not be able to communicate their situation effectively. This new legislation was signed into law by New York State Governor Cuomo in 2018 and grew out of legislation sponsored by NY State Sen. Pamela Helming, R-Canandaigua, and Assemblyman Angelo Santabarbara, D-Schenectady. The legislation was inspired by Assemblymen Santabarbara who has a son with autism.

So far, there has been a positive response to the cards and there have been many requests for them. According to OPWDD, more than 7,000 cards were requested in the two months since they became available. Although this has resulted in a delay, it shows the potential value that these cards have for individuals and their families. Of course, there will always be critics and no system or plan will necessarily be perfect but for many reasons, these cards have the potential to ease tension in emergency situations, bridge the gap of communication, and possibly avoid truly tragic outcomes during difficult scenarios.

Some of the ways these new I/DD ID cards may be beneficial include:

- They can possibly reduce the risks associated with law enforcement interactions given the communication and potential to ease tension in emergency situations or plan will necessarily be perfect but for many reasons, these cards have the potential to ease tension in emergency situations, bridge the gap of communication, and possibly avoid truly tragic outcomes during difficult scenarios.

When Anxiety and Depression Coexist with Autism

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

Today, one in fifty-nine children are diagnosed with Autism. The characteristics of Autism often present in poor communicative and social skills, restricted or inappropriate affect and poor emotional regulation. Most of these individuals have significant functional impairments in one or more areas of their lives.Treating individuals with ASD can be challenging enough, but when you add depression and anxiety to the mix, the challenges become exponentially more difficult. Often times, this can lead to misdiagnosis or sub-optimal treatment (Chandrasekar, Sikich, 2015). Part of the problem is that, while there are many studies related to Autism and many on depression and anxiety, there is minimal research on the comorbidity factor.

Since expressive language is often deficient or impaired to a degree, commonly used screening tools can be unreliable. Individuals may not be able to appropriately identify or label their symptoms, and those around them often attribute the symptoms to the ASD diagnosis. Moreover, individuals with ASD may be less likely to engage in clinical studies, or if they do, their ASD status is not factored into the study. Further complicating diagnosis is the overlap in symptomology of ASD and those of anxiety and depression. Key features of ASD include social anxiety, withdrawal and perseverative, anxiety-based thoughts, making it difficult to tease out clinical anxiety and depression from Autism-related symptoms (Leyfer et al., 2006). As a result of these variables, specific prevalence rates are hard to identify.

A meta-analysis of over 7,000 studies (of which 66 met inclusion criteria) in The Journal of Abnormal Child Psychology revealed an estimated 4x risk of depression among individuals with ASD, compared to their neurotypical peers (Hudson, Hall, Harkness, 2017). In yet another study that examined 93 children and adolescents for the presence of clinically significant depression, the research found that, while only approximately 30% of individuals with ASD self-identified with depressive symptoms that rose to the criteria of clinical significance, the parent report of the same individuals placed that number at a much higher level - more than 75% (Wijnhoven et al., 2019). The discrepancies in these results points to several important factors and areas for future research. First, it is possible that individuals with ASD do not have the necessary self-awareness to distinguish their feelings from the normal spectrum of feelings. Second, parental involvement appears to be key in appropriately identifying these at-risk individuals. Routine screening of not only the individual, but also of the parent, should be incorporated into ongoing treatment. If we were only to look at the self-report of individuals with ASD, we risk losing a large percentage of the population. This can lead to the previously discussed undiagnosed comorbidity and resulting sub-optimal treatment.

What does clinical depression and anxiety look like in an individual with Autism? How does the presentation differ from neuropsychological individuals or individuals with ASD without clinically significant comorbidities? First, we go back to basics. When we evaluate a neurotypical individual for anxiety and depression that rises to the level of functional impairment requiring intervention and treatment, we look at their symptoms on a spectrum. Previous versions of the DSM included a Global Assessment of Functioning scale (GAF), which gave a numerical score from 0-100 in order to quantify the degree of impairment the individual was experiencing. Though eliminated from the DSM-V, the GAF can still be a valuable guidance tool in assessing where on the spectrum of functioning an individual exists. For any mental health issue to meet the criteria for a diagnosable psychiatric illness, there must be some level of functional impairment relative to the individual’s baseline. If we take this theory and apply it to individuals with ASD, even if their baseline functioning is very different from the norm, we can still make an assessment of how functionally impairing the depression or anxiety is, relative to previous levels of functioning. The benefit to this methodology is that it can reduce the confusion of distinguishing between what is a characteristic of ASD vs. a comorbid disorder. Anxiety and depression can present in many different ways in all individuals, regardless of their neurobiological status. By identifying and individualizing each person’s spectrum of functioning, we can create a person-centered diagnostic approach.
A Community of Caring Agencies Unites to Support Families in Camden County, NJ

By Jennifer Arey, BS, Rowan Integrated Special Needs Center, Sonia Cohen, MSc, First Children Services, April Young-DiPietro, LSW, Camden County Partnership for Children and Howard Savin, PhD, First Children Services

First Children Services and the Rowan Integrated Special Needs (RISN) Center are organizations that specialize in providing clinical services to individuals with intellectual and developmental disabilities in New Jersey. Many of the youth who these agencies serve are eligible for or already receiving services from the New Jersey Department of Children and Families (DCF) Children’s System of Care (CSOC). First Children provides these services which include in-home evaluations and therapeutic services to youth through several CSOC system partners including the Camden County Partnership for Children (CCPFC) Care Management Organization (CMO). This article was inspired by the collaboration between First Children Services, the RISN Center, and CCPFC in coordinating Camden County’s largest community resource fair in partnership with Camden County Freeholders and a host of similarly involved human services agencies.

Sometimes, it really does “take a village to raise a child,” and in Camden County, the Children’s Inter Agency Coordinating Council (CIACC) is creating a village for the youth in the community. The CIACC is a local advisory agent for CSOC comprised of local CSOC partners, stakeholders, educators, families, and private agencies. It serves as a mechanism to develop and maintain a responsive, accessible, and integrated system of care for children with social, emotional, and behavioral needs, substance use challenges, and/or intellectual and developmental disabilities. The CIACC has two subcommittees that are charged with bringing together resources for children in our community, the Developmental Disability (DD) Subcommittee and the Educational Partnership (EP) Subcommittee.

The DD Subcommittee is chaired by Jen Arey, patient navigator for the RISN Center. RISN provides South Jersey with its first special needs primary care facility that is focused on coordination of such integral services as preventative healthcare, reproductive health, and personal care. The DD Subcommittee is responsible for identifying and bringing together resources for local youth, especially those involved with the DCF’s Division of Child Protection and Permanency (DCP&P). The subcommittee also looks to identify the needs and challenges of youth with intellectual and developmental disabilities and report back to the state on the county’s needs. This mission aligns with Jen’s role at RISN, where she assists families in applying for state services and connecting them to programs in their area, making her a natural fit as the subcommittee chair.

The educational Partnership (EP) Subcommittee is chaired by Sonia Cohen, marketing director of First Children Services. Sonia initially joined the Camden County CIACCs to understand the framework of CSOC as a pre-requisite to providing quality services to the system partners with whom they hold contracts. Sonia felt strongly that it was important to give back to the community and found the CIACC to be a perfect forum to do that. Sonia’s experience working with the many school districts that First Children serves gave her the know-how to serve as the EP Subcommittee chairperson. The EP is an alliance between local school districts, CSOC partners, and agencies who serve youth. The EP organizes cross-systems trainings and forums and helps direct resources and services from DCF and other sources to families in need.

In Spring 2019, the Camden County DD and EP Subcommittees joined forces with the CCPFC, Camden County Freeholders, Jewish Federation of Southern New Jersey, and Camden County Educational Services Commission to plan the Camden County Resource Fair as a way to create community engagement on a large scale.

The Spring 2019 Camden County Resource Fair showcased over 250 vendors, all put together by April Young-DiPietro, CCPFC Community Resource Director, beginning in 2016 as a means for the CMO’s care managers to familiarize themselves with the various resources in the community. The CMO primarily serves youth who have social, emotional, and behavioral challenges and/or intellectual and developmental disabilities, so many resources were specific to youth with those challenges. The resource fair quickly grew to include other local DCF partners such as the Family Support Organization, Mobile Response and Stabilization Services, and DCP&P. By Spring 2018, the resource fair outgrew the CCPFC offices and was moved to the Voorhees Town Center, a mall which donated its space for the event. With the expanded space and parking, CCPFC was able to open the event to the public for the first time. This expansion paved the way for the Spring 2019 resource fair.

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The Spring 2019 Camden County Resource Fair served as a platform for the Children’s System of Care (CSOC) to demonstrate its commitment to supporting families and youth in need. The fair showcased a wide array of resources, services, and opportunities available to help families navigate the complexities of living with developmental disabilities. The event featured nearly 250 vendors, including service providers, community organizations, and educational institutions, all dedicated to enhancing the quality of life for individuals with special needs.

Moreover, the resource fair was an opportunity for families to connect with the Children’s System of Care (CSOC), which is a local collaborative network of community partners responsible for coordinating the delivery of services to children and youth with special needs. The CSOC aims to ensure that children and families receive the appropriate support and resources to thrive.

Jennifer Arey, BS, Rowan Integrated Special Needs Center
Sonia Cohen, MSc, First Children Services
April Young-DiPietro, LSW, Camden County Partnership for Children
Howard Savin, PhD, First Children Services

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Dental Care and Autism: What You Should Know

By Dr. Greg Grillo
Director of Dentistry
Dentally.com

Going to the dentist can be nerve-wracking for anyone. However, for a child with autism going to the dentist can be a much more difficult experience. An overload of sensory elements can make going to the dentist overwhelming and scary. Luckily, choosing the right dentist, knowing what to expect, and preparing for your child’s visit can all help make the experience easier. As a dentist who has worked with families for nearly 20 years, I know how important it is for your child to have a positive experience at the dentist’s office. That’s why I have put together information and helpful tips on what you can expect when taking your child to the dentist, and how to prepare to make it a positive experience.

Choosing A Dentist

Choosing the right dentist is the first thing you should do when it comes to your child’s dental care. While you may feel overwhelmed with choosing the right one, your child will have a more positive experience if you can find one that is perfect for them. There are many dentists that specialize in special needs care, plus, most dental offices will accommodate for any child with autism or special needs.

To help you begin your search here are some helpful tips:

Use Referral Services - Visiting the American Dental Association website (www.ada.org) is a great place to start searching for a dentist. Their search engine allows you to search for dentists by location and specialty. Another way to search is by doing some

William Killion, PhD, BCBA

Springbrook Autism Behavioral Health

Enlisting the help of a residential treatment facility can often be the most difficult decision parents of children with autism face, particularly if that treatment center is far from home. Parents who have likely had little to no separation from their child throughout the daily caregiving process feel innate anxiety leaving their children behind, and there are obvious challenges and stressors for children with autism leaving the comforts of home and family for immersive therapy at a residential treatment facility. But what may be surprising is the anxiety that children with autism sometimes face when returning home after adapting to life at a residential treatment facility. By understanding life at a residential treatment facility and planning ahead to have similar structure in place at home, parents can help make that transition easier for their children.

Children with autism crave structure (Applied Behavior Analysis Education, 2019). They need to be occupied and busy in order to avoid distressing behaviors that can cause stress for themselves and their caregivers. This is why, when children are admitted into a residential treatment facility, they have a very clear schedule and routine that keeps them engaged with positive activities from morning until evening.

Transitioning Back Home from a Residential Treatment Facility

By William Killion, PhD, BCBA

Days are filled with school work, therapy and plenty of physical exercise. Sports are a great way to keep students active and engaged. Therapists and other staff also work with the children to help improve any physical symptoms and behavior issues, and to provide support for children to develop coping mechanisms (American Psychological Association, 2019).

Children quickly adapt to this busy life at a residential treatment facility. Often times they can become anxious about returning to a home life, particularly one that is unstructured or historically associated with stressful family situations.

Upon completion of the residential treatment - which can be anywhere from about three months to a year - a discharge plan is created for each child, with the goal of maintaining stability so they are able to leave without the need for future re-admittance. In some cases, children may not need to be fully immersed in a residential program or they may need to transition from a residential program to a group home. While group homes are also residential-based programs, they are less restrictive and give children with special needs the opportunity for more flexibility in the form of day programs and activities outside of the residential home.

The goal upon discharge is to provide the least restrictive placement possible for the individual’s unique needs. Some individuals in a group home may require permanent residence, while most leave after between three months and a year. Once residents are released and ready to head back home, caregivers should follow the discharge plans in place to help the individual maintain stability at home.

Specifically, to ease the transition, caregivers should:

1. Talk to the therapists about what works. Therapists have been working with the child to develop evidence-based, proven strategies for success at home and school, including coping skills to stay calm when agitated.

2. Maintain a routine and schedule. While your schedule does not need to mirror that of the residential treatment facility exactly, maintaining a schedule helps children with autism reduce stress by being able to anticipate and prepare for the day’s activities. Keeping them active in an engaging way also helps to reduce anxiety and opportunities for bad behaviors to arise.

The goal of residential treatment is to provide long-term wellbeing and success outside of the program. For families struggling with behaviors associated with autism, residential treatment is often a necessary strategy for care. By understanding the goals and methods of treatment, parents can increase their child’s success beyond a residential treatment facility.

About William Killion

Dr. Killion is a Board-Certified Behavior Analyst at Springbrook Autism Behavioral Health in Travelers Rest, South Carolina, and author of the Functional Independence Skills Handbook or F.I.S.H. Developmental Program which is a curriculum for ABA used in 83 countries and translated into
When striving for independence with individuals with Autism Spectrum Disorder (ASD), families, Board Certified Behavior Analysts (BCBAs), and other professionals may immediately think of decreasing problem behavior such as screaming or off-task behaviors or increasing specific skills such as homework completion or washing their hands. However, a social skills repertoire and building social competence may be among the most important and valuable set of skills to teach an individual with ASD. Social competence, as presented by Romanczyk, White, and Gillis (2005), is the ability to effectively interact with other people, which can open so many doors beyond just being able to complete daily activities. As social skills develop, an individual has the opportunity to meet a variety of new contingencies and engage in contact with novel types of reinforcement, possibly peaking new interests!

Rosales-Ruíz and Baer (1997) initially presented the concept of behavioral cusps as behavior that “brings the organism’s behavior into contact with new contingencies of various social skills can decrease challenging behavior as well. For instance, the reduction of stereotypic behavior such as hand flapping may be observed when an individual becomes socially aware of others engaging in different behavior during down time, or the individual may simply be more involved in the social activity, therefore reducing the amount of time he has to engage in stereotypic behavior. Involvement in social activities allows for an increase in verbal and nonverbal communication skills as well. Requesting can be incorporated into a variety of activities, from more practice of newer targets to elaboration on basic skills (e.g., using a full sentence, asking for the bigger cup or the blue marker). Often, targeting requesting within social activities is more successful because it capitalizes on the child’s naturally occurring motivation and maintains the behavior by incorporating natural sources of reinforcement. Social activities can also be used to prompt mastered requests with peers, or to contrive opportunities for requests by providing some parts of a toy or game, but not all, or pausing an ongoing action to wait for a request. Other communicative or basic learning behaviors that can be targeted during social activities include tacting, listener behavior, and imitation. Tacts can often start as echoic behavior when modeling language about an activity (e.g., labeling farm animals while using an echoic prompt could promote spontaneous tacts when playing with safari animals). This can also be a time to work on generalization of tacts by asking the individual to name recently mastered items. For listener behavior, the child may point to named items by the speaker or match items, such as with a puzzle or a game like Perfection©. Social activities also provide an opportunity to continue to grow the individual’s generalized imitative repertoire, especially during pretend play for younger learners.

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When Residential Schooling Is an Option

By Susan Polesinelli Paraprofessional

As a single mom of a nine-year-old autistic son, I would never have imagined my son being placed in a residential school setting. All of the autism characteristics were there at the tender age of two. Through early intervention services and then my son being placed in a New York City District 75 program, they tried their best to help my son with ADL skills and control his behavior that was aggressive at times. As my son got older, his behavior began to become more aggressive towards me, his siblings, and school staff. Since he is non-verbal, it’s difficult for him to get his wants and needs met, therefore he could not control his frustration. When you receive more than one phone call during a school week to pick up your child because staff cannot control him, it’s absolutely inconceivable. My thoughts were, they should have skilled staff who know how to work with special needs children. In discussion at the time with the principal of his school, they were short staffed and could not accommodate his needs and thought a residential setting would be more appropriate. Not only did his behavior in school become more aggressive, but at home as well.

Having two other children, it was extremely difficult to manage my son with his meltdowns that sometimes consisted of scratching, biting, and pulling hair. In times of despair, residential schooling seemed to be the only beneficial solution for my son as well as for my family.

Fast forward seven months since my son’s new school placement: his behavior has improved, and he is under 24-hour care by skilled staff. Sometimes the most difficult, heart-wrenching decision you make in life, turns out to be the best one under your circumstances. For my son to grow up to be an integral part of society, where he is accepted in the community despite his disability, is wonderful. Parents, guardians, and caregivers, who are raising a child with autism have an inner strength that keeps them going. If residential schooling crosses their mind, it doesn’t mean they become less of a parent or have given up. Everyone’s situation is different, which is why a decision like this one should be made with thoughtful consideration.

I love my son dearly, and he and my two other children are the most important people in my life. My goal for my son is to see him flourish from a boy into young adulthood, acquire independent living skills, and be accepted as part of a society that, itself, needs to learn the meaning of acceptance and the incomparable joy of learning from individuals who are differently-abled, yet so amazingly gifted. As a parent, you learn a lot from your children. As a special needs parent, you take a step back, and try to see the world through their eyes.

I am his voice, he is my heart

Incorporating Social Skills Beyond the Teaching Environment

By Samantha Smith, MSED, BCBA, Jennifer Croner, MSED, BCBA, Kristen Dunek, MS, BCBA, and Shannon Vitelli, MEd, BCBA

that have even more far-reaching consequences.” The individual skills that combine to form a social skills repertoire can be considered some of the most fundamental behavioral cusps an individual can acquire. For example, an increase in social awareness of others in the environment may lead to acquiring new skills through observational learning or even the development of new friendships. Not only can social skills increase appropriate behavior leading to better outcomes but acquiring a repertoire of various social skills can decrease challenging behavior as well. For instance, the reduction of stereotypic behavior such as hand flapping may be observed when an individual becomes socially aware of others engaging in different behavior during down time, or the individual may simply be more involved in the social activity, therefore reducing the amount of time he has to engage in stereotypic behavior. Involvement in social activities allows for an increase in verbal and nonverbal communication skills as well. Requesting can be incorporated into a variety of activities, from more practice of newer targets to elaboration on basic skills (e.g., using a full sentence, asking for the bigger cup or the blue marker). Often, targeting requesting within social activities is more successful because it capitalizes on the child’s naturally occurring motivation and maintains the behavior by incorporating natural sources of reinforcement. Social activities can also be used to prompt mastered requests with peers, or to contrive opportunities for requests by providing some parts of a toy or game, but not all, or pausing an ongoing action to wait for a request. Other communicative or basic learning behaviors that can be targeted during social activities include tacting, listener behavior, and imitation. Tacts can often start as echoic behavior when modeling language about an activity (e.g., labeling farm animals while using an echoic prompt could promote spontaneous tacts when playing with safari animals). This can also be a time to work on generalization of tacts by asking the individual to name recently mastered items. For listener behavior, the child may point to named items by the speaker or match items, such as with a puzzle or a game like Perfection©. Social activities also provide an opportunity to continue to grow the individual’s generalized imitative repertoire, especially during pretend play for younger learners.

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Social activities, as engagement with a community to which one belongs, are an essential part of life for most people. Unfortunately, for autistics, there are often barriers that prevent them from participating in such. Before I address these issues, however, I need to emphasize that the commonly held belief that autistics are not interested in social engagement is totally false (as is the equally egregious idea that autistics are not interested in romantic or sexual relationships). Although some autistics do prefer to be by themselves and avoid social interactions, and others simply need more time alone than is usual, the fact is that most autistics, like everyone else, have a strong desire for some social life and community involvement. Sadly, because of deficits in social skills and socialization, they often have more difficulty attaining it.

In contrast with the typical population, which is largely capable of finding communities and social outlets through their own initiative, autistics often face significant challenges in doing so. Consequently, they may require assistance, and even active interventions, in order to succeed here. This can continue throughout the lifespan. As is often the case for autistics, they are ill-served by the notion that, because they have no serious intellectual disability, and often have unusual talents or “splitter” skills that are seen as remarkable, they should be able to accomplish this entirely on their own; once again, the belief that such an individual will eventually “pick up” these skills needs to be reconsidered. Consequently, it is essential that communities having autistic members, not to mention society as a whole, become more aware of the deficits of autism and the challenges faced by autistic individuals, and provide avenues for them to engage in social activities that are appropriate and that they wish to participate in.

There are two basic types of social and community activities: those created specifically for people on the spectrum, and those which serve the general population. Although the former can make inclusion of otherwise marginalized individuals somewhat easier, we must consider that the latter encompass most of the population and as such cannot be ignored. In either case, we must also examine activities appropriate for different stages of life, with the additional consideration that autistics often relate better to people in age groups different from their own.

As with many other aspects of autism, early intervention can yield great benefits later in life. In the case of socialization, deficits in social skills need to be identified and addressed as soon as they can be. These include difficulties in getting along with others, being part of a group, meeting people, and making and keeping friends. Depending on the individual and their circumstances, this can be done in the school environment, through qualified professionals, or by concerned family and community members who understand the issues and are able to help. Helping young autistics to engage in social activities at an earlier age can result in successful later outcomes, and hopefully avoid painful social experiences and the misery that they can bring.

Activities for Individuals on the Spectrum

Activities and communities for those on the autism spectrum, though still few and far between, are nevertheless slowly but surely proliferating. These may be organized by concerned members of the community (parents, family members, or others with an autistic person in their lives), by professionals who work with autistics and understand their deficits and challenges (psychologists, therapists, social workers, teachers, etc.), or by peer-run organizations of autistics (who best understand their own needs) that have emerged and grown in recent years. In any case, the persons in charge of organizing activities must understand the needs, deficits, and challenges of the participants and thereby address any issues that might arise (or preferably prevent them from happening in the first place).

Social activities should be chosen for or by an individual based on what they are interested in and what they are capable of handling (if necessary, with appropriate assistance or interventions). Activities and environments which largely involve things of no interest to an autistic individual and of which they have no knowledge, require

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Taking a Multi-Cultural Approach to Promoting Autism Awareness

By Solandy Forte, PhD, LCSW, BCBA-D
Milestones Behavioral Services

For decades caregivers, practitioners, educators, advocates, and researchers, to name a few, have exhausted resources in an effort to promote autism awareness in their communities (locally, nationally, and globally). According to the Center for Disease Control (CDC) (2019), the number of individuals diagnosed with autism spectrum disorder continues to rise regardless of race, ethnicity, or socio-economic status and currently the prevalence of autism is 1 in 59 children. Further, research has suggested that autism occurs approximately equally across ethnicities and cultures. A trend reported by the CDC indicated that more non-white children are being diagnosed with an intellectual disability and in fact receiving a diagnosis of autism later in life.

Many have strived to provide education to communities related to the signs and symptoms of autism and the importance of early intervention. In addition, various other topics related to autism are often provided to communities on topics such as education, evidence-based practices, legal rights (e.g., special education law, state insurance mandates, etc.), transitioning into adulthood, guardianship, and more. It is not an easy feat when community members come from different cultural backgrounds. In these cases, promoters of autism awareness are faced with barriers when attempting to deliver information that can be reasonably understood and translated into practice or advocacy. Some of these barriers include differences in social practices or nuances, language barriers (including differences in dialect), difficulties with forming healthy working relationships with community providers, limited resources, and non-adherence to treatment.

Taking a multi-cultural approach allows for communities to engage with individuals/groups in the community while drawing upon their community-based values, traditions, and customs. When a community member is heard they will be more apt to take an active interest, share, and participate in learning about the information that is being shared.

Discover - Showing a bit of humility will lead to discovery. Showing interest and asking questions about cultural practices, beliefs, and preferences will assist not only the leader of the group but also its group members in understanding the barriers faced when making decisions related to the treatment of autism. Through this process, community members are partnering and joining in the quest to finding solutions and navigating through these barriers. As you can imagine there are many decisions that a family needs to make with regard to assessment and treatment of a loved one who has been diagnosed with autism.

Examine your own cultural beliefs - In order to fully gain an understanding of other cultures you must examine your own cultural beliefs, values, and biases. Your own cultural beliefs will drive the formulation of your opinions related to autism treatment and the motivation to instill your beliefs in others. Examining and acknowledging any differences between your own cultural identity and others will help to avoid unintentionally dismissing other’s cultural practices, prevent biased perceptions and focus on finding solutions for educating a diverse group of individuals who share a common goal (in this case raising autism awareness). While it takes a skilled person to meet the needs of a multi-cultural blended group of individuals, it is well worth it in the end. Often times, groups are formed to serve a particular ethnic or cultural group and in most cases this is successful. However, with the limited resources (e.g., time, space, funds) individuals have to educate community members on autism it is probably worthwhile to consider a different approach. So, how do promoters of autism awareness use a multi-cultural approach to effectively engage their community?

Listen and Observe - Engaging in active listening and observation will lead to discovering what exactly a member is seeking to learn about autism and how they will best acquire, retain, and apply the knowledge that they have gained from educational sessions. Each culture and its subcultures will have differences in beliefs, attitudes, and preferences related to assessment and treatment of autism. An individual leading a multi-cultural group will need to pay careful attention to the communities needs as they vary among cultures. Understanding and responding to the unique circumstances of a culture can lead to effective interactions with individuals/groups in the community while drawing upon their community-based values, traditions, and customs. When a community member is heard they will be more apt to take an active interest, share, and participate in learning about the information that is being shared.

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Providing comprehensive clinical and school-based services for children through adults, families, schools and organizations. Steven B. Gordon, PhD, ABPP & Michael C. Selbst, PhD, BCBA-D

Visit Our Brand New Website! AutismSpectrumNews.org
Supportive and Community Housing - Find Your Forever Home

By Taveesha Guyton, BSW
Founder and CEO
We R Famile

It’s that time of the year when parents are shipping their kids off to school. From toddlers who have finally reached school age to young adults taking that next step into adulthood, this season is filled with many new adventures. Many young adults will be leaving home this fall for college and other vocational endeavors. For most young adults, this will be their first time leaving home. This transition may include the full college experience of a dorm room or off-campus housing. Some young adults are also moving to gain more independence which may include moving to the next town over, another county, or just down the street. Young adults with autism are no different. As individuals with autism embrace the transition from adolescence to young adulthood, it is important to be educated on the transition from adolescence to young adulthood, it is important to be educated on the transition. Supportive housing is a combination of housing and in-home services, such as education on activities of daily living which is intended as a cost-effective way to help people live a more stable, productive life. Supportive housing is intended to help these individuals acquire the skills necessary to transition to independence. As early as the age of 14, but not less than the age of 16, individuals on an Individualized Education Plan (IEP) should have transitional plans. This is a plan which identifies what services will be needed for the individual to transfer from adolescence to young adult. There are significant changes that happen when an individual with autism transitions from services provided by their school through the Individual with Disabilities Education Act (IDEA) to adult services. Parents and caregivers are often shocked at the long wait-list for some of the services available.

As with any transition, it is important to include the individual. Person-Centered planning is crucial. This meeting includes the individual and their support system to discuss how the transition will be handled and by whom. This meeting also discusses the individual’s strengths, challenges, needs, and preferences including housing options. Can this individual live on their own? Can this individual maintain their own personal hygiene? How about meal prep and finances? Who will be responsible for medication management, health, and safety?

Housing Options

Home and community-based services (HCBS) provide opportunities for Medicaid beneficiaries to receive services in their own home or community rather than institutions or other isolated settings. These programs serve a wide range of targeted populations such as people with intellectual or developmental disabilities, physical disabilities, and/or mental illnesses. Parents and caregivers can access this application through the agency for Persons with Disabilities. When planning for residential services, it is crucial to identify whether it is better to own or rent, what utilities would be needed, and if a roommate is financially required. Another important item to consider is how much will support and services be needed for this individual? Will this individual need around the clock care or low-level supervision?

Supported Living - Supported Living is where an individual lives on their own or with another roommate in a home or apartment but is supported by paid staff. This home or apartment is owned by a family member. Staff are available 24 hours a day, but they do not live in the house with the individual. The individual with autism may go to a day training center or sheltered workshop, work a part-time job, or be in the community with staff assistance. The staff’s primary job is to coach and train the individual in life skills such as banking, paying bills on time, food shopping, etc. Other job duties include assisting with making doctors’ appointments for optimal care, medication management, and ensuring the home is monitored for health and safety. Staff drive the individuals in their own personal cars or company cars/ vans.

The Supported Living staff sees these individuals on a weekly basis and make see Housing on page 32

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A more structured social activity may be a card game like Uno™. This provides great opportunities to work on requesting for a wild card color, or for information, such as asking who has the next turn. Individuals can also tact colors or numbers, or work on match-to-sample skills. Uno™ has an outlined set of rules, allowing individuals to work on following instructions, like skipping a turn or reversing the order of play. This activity can be adjusted depending on the age of the participants – one may wish to target good sportsmanship by modeling the appropriate verbal behavior of a winner or loser. A less structured example which can include the same types of social skills is a group painting activity. Here, one can work on mands for missing items, such as a paintbrush or a preferred paint color. It’s also a fantastic way to target sharing or turn taking among peers. Painting could be used to target imitation of a peer model, or to promote conversational volleys about each individual’s picture. Note how in all these examples, a variety of social skills are targeted; the specific skills targeted should always be individualized to each learner.

As discussed, social activities provide an opportunity for individuals to generalize skills from a more structured teaching format to the natural environment, as well as maintain previously acquired skills. A key component of teaching social skills though, is to target developmentally appropriate skills (e.g., fourteen-year-old boys would likely prefer to play video games or go biking than play Candy Land™ or blow bubbles outside). Examples provided thus far have targeted leisure times for children or adolescents, although social skills for older individuals in the workplace are just as critical to ensure a successful adulthood and possible employment. A recently published article evaluated the effects of behavioral skills training to teach job-related social skills to adults with ASD (Grob, Lerman, Langliniais, & Villante, 2019). The social skills targeted included responding appropriately to feedback and asking a supervisor for a task model; the treatment package included verbal explanations, modeling, and role-play with feedback. The study found that generalized responding across social skills rarely emerged, and that stimulus prompts were necessary for generalization of these skills to the job setting. These authors noted the importance of identifying prompt formats that would be easily transferrable to the actual job site. This study exemplifies two important notions related to teaching within social activities. The first is the importance of programming for generalization from the outset, rather than a “train and hope” approach (Stokes & Baer, 1977). The second is to recognize that individuals are acquiring a social skills repertoire, and research suggests that generalization of these skills is limited. Therefore, clinicians and parents must continue to teach new skills to add to this repertoire. Promoting social skills during all daily activities is a productive way to plan for generalization from the onset of teaching. This may also assist in tapping into natural sources of reinforcement as the individual may contact a variety of social reinforcers from many different people across various activities. Lastly, as the individual receives reinforcement during or following interactions with their family and caregivers, reinforcement is also provided for those family members and caregivers. This cycle of reinforcement can lead to more positive interactions across the family unit as well as encourage more community involvement as more skills are acquired. Some social outlets to look for within the community that could assist in promoting the generalization and maintenance of skills initially targeted at home, in school, or at a job may be specific social skills groups with peers of similar age and functioning level, sensory friendly activities, or groups at the local YMCA. These social outlets may directly teach new skills, and also provide a way to reach new peers and novel activities that may create new interests for those that may have restricted or limited interests!

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If you would like more information about Exceptional Learning, LLC, please contact our office via the phone at (610) 287-4000 or visit our website at www.exceptional-learning.com.

References


Five Tips for Traveling by Airplane with Kids with Autism

By Braden Josephson, PhD, BCBA-D
Clinical Advisor
Autism Care Partners/City Pro Group

As September begins and we settle into our lives, it’s clear that the summer has come to an end. We are getting our kids back to school and starting to plan holiday travel based on school schedules while our summer vacations fade into distant memory. This past summer, I traveled to Spain for a family vacation. For many of you, this may not have been, I highly recommend taking taps tours with locals and touring the Prado Museum! When we got back home, I was thinking about our vacation and how stressful it is to travel when your family is in tow. There are many logistical considerations to ensure a smooth ride (e.g., did you bring the right chargers, do you have enough snacks for potential flight delays, did you allow enough time to clear security, etc.). Airports can be chaotic and overwhelming even for neurotypical adults and kids. Additionally, the changes in routine, unpredictability, crowds, noises (e.g., overhead announcements) and visual stimulation from all sides can all make the experience difficult for people on the spectrum. As a result, many families who have children with autism choose to give the experience difficult for people on the spectrum. For those who have not did you bring the right chargers, do you have enough snacks for potential flight delays, did you allow enough time to clear security, etc.). Airports can be chaotic and overwhelming even for neurotypical adults and kids. Additionally, the changes in routine, unpredictability, crowds, noises (e.g., overhead announcements) and visual stimulation from all sides can all make the experience difficult for people on the spectrum. As a result, many families who have children with autism choose to give the experience difficult for people on the spectrum. For those who have not

Braden Josephson, PhD, BCBA-D

ners that families with kids on the spectrum have found very helpful when vacationing. In the end, with the right planning and consideration, travel can enable families to come together and create memorable experiences and can serve as a source of sensory experience expansion for children on the spectrum.

1) Use Social Stories

We worked with a family a year ago that was going to visit their relatives in South America. The family was unsure if they could make the trip because their 12-year-old son was refusing to go. They had previously planned to fly from NY to Florida when he was 8 and their son’s refusal behaviors were so intense that they rented a car and drove instead of attempting to fly. For the trip to South America, one of our BCBA supervisors constructed a social story for him that she personalized for this trip. Social stories teach appropriate behaviors to children with special needs using written and visual cues in a story-based format that help children anticipate and prepare for unfamiliar and stressful situations. This particular child loved to draw, so she helped him illustrate all of the steps that would occur throughout their trip (e.g., packing bags, the car ride to the airport, going through security and taking off his shoes, boarding the airplane at the gate, and getting on the airplane, etc.). His parents and therapists read the story to him multiple times before they left, and he carried the book with him on the plane. His parents referenced various pictures as they happened, for example: “The wheels are coming down, we are landing.” This story was very comforting to him and helped to lower his anxiety throughout the trip.

2) Take Your Time to Pack Smart and Keep Items Within Reach

You want to make sure that you have plenty of reinforcing items and activities to use to comfort, distract and entertain your child. These will be helpful to use as antecedent strategies to prevent disruptive behaviors along the way. Bring the items that make your child most comfortable at home and at school. Consider packing a favorite blanket or stuffed animal and favorite games. Noise cancelling headphones are a great item to include when packing for your trip and are particularly helpful for noisy airports and during take-off and landing. Additionally, many of the families with whom we work will take several highly reinforcing items “out of circulation” for a few weeks before the trip (e.g., a favorite board game or toy), to prevent satiation and to have them ready to motivate their child to successfully navigate the trip. Familiar snacks are another way to ensure comfort for your child in the event that he or she gets hungry. Make sure to download reinforcing videos to your iPad and cellphones ahead of your trip. And make sure your devices are fully charged. Ensure that key items you will need during the flight, like snacks, water, video screens are in your backpack or carry-on bag that you can fit under the seat in front of you for easy access. Do not put your essential flight items in your overhead bin because you may not be able to get to them quickly. I recently flew and saw a frantic parentarguing with a flight attendant because she needed something from the overhead bin and the fasten seat belt light was on due to turbulence.

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Family who come out to these conferences often find out about community resources and ongoing research that they would not have encountered in their everyday life. Also, as it is a less invasive and more natural way to learn about research, families are motivated to sign up for studies of their interest. Although it can take years and hard work to build strong partnerships between research and community, it may be worth striving for, especially in the long run.

For more information about the AIR-B Network, please contact Hyon Soo Lee at hyonsoolee@g.ucla.edu or visit http://www.airbnetworked.org.

References


Scaffolding Communications Skills for Elementary Students with Autism

By Joan Ramirez
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JLR Enterprises

When I decided to teach elementary Autistic children, my first task was to query many teachers as to their students’ learning styles. One size doesn’t fit all. Some children learn visually, others need to listen intently, some draw, and others need to write things out. In most cases, I will need to help them develop their own style of learning.

I would like to preface this article by stating it will be concise. Why? For the practitioners, teachers, and parents reading this piece, just the facts that can be applied in a user-friendly fashion will bring quicker results.

Teachers don’t have the “luxury” of time to wade through a ton of content to find a solution to a student’s learning difficulty. After pouring over lesson plans that have been refined to a fine-tooth comb, in many instances, to conform to curriculum demands, teachers must go back to the drawing board to accommodate the needs of a few students who have been mainstreamed but require individual time and attention. I pause to insert an overlooked but critical teaching element: Students can only learn in an environment where the teacher’s main objective is to see that the entire class is on point. What worked in the past might need to be massaged for a student who needs one aspect of a lesson introduced in a new way. Often the only method that works is the teacher’s willingness to work one on one with said student(s) until he/she/they are up to speed. Whatever it takes, that is what must be done.

When I first started teaching autistic students in mainstreamed and special classes, I would often create individual plans for each child. In theory this is a great idea. In practice, taking time constraints, behavior issues, and daily changes in schedules into consideration, this isn’t always feasible. The best thing any new, inexperienced or veteran teacher can do for his or her class is to have a solid set of lesson plans that have built-in options for all learning exigencies.

So, here we go, straight from my heart and my compendium of acquired knowledge.

Visual Scaffolding

Problem: A second-grade student is sitting in the last row of the class. She is frustrated and angry, and about to throw a fit because she wasn’t given a set of counters. She’s having trouble adding five plus six. To exacerbate her anxiety, the student has to write the answer in words on a timed test. She’s still not finished when her other classmates have handed in their papers.

Solution: Remember pick-up sticks? What I’ve done to scaffold this student is bring in a box of pencils, erasers, or any easy-to-manipulate counters. The student will use these “visual” tools to count out five pencils and six erasers, add them together, and then, with a review of the words needed to write a sentence, compose a sentence. Obviously, this solution has to be done in adequate time to take the test with a passing grade. REMEMBER: For the student who is visual and worried about failing, emphasis should be placed on the quality and not quantity of answers. The student must build up his/her written communications skills. To facilitate the child’s writing ability, a newly verbal presentation, depending on the level of comfort in talking to his/her peers, might be beneficial. As the child becomes more comfortable with basic addition and subtraction operations and presenting the problem in words, he/she should be encouraged to “teach” the class. For a very shy child, this can be accomplished through board work that doesn’t involve direct eye contact with peers. He/she can also call on a partner to help explain the problem. For those who like/enjoy eye contact, a dialogue with classmates should be encouraged. Both of these methods should be used at the beginning of the semester to give all students time to find their written and verbal communications comfort zones.

Auditory Scaffolding for English Language Learners

Problem: An English as a Second Language student is afraid the class will make fun of him because of his accent. He wants to read the first chapter of the new book club selection. He is too shy to stand up in front of the class.

Solution: The student can sit in the teacher’s chair surrounded by classmates in

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abilities that they do not have, or (especially) require too high a level of social functioning, need to be avoided, at least until that situation changes.

Traditionally, what has been considered the best activities for people on the autism spectrum are those that relate to specialized interests or talents. These provide a basis for social interaction which in turn helps to develop social skills and enables further socialization. Since this is not always possible, due to the broad range of different interests found in the autism community, activities which are at least related or similar should be encouraged as much as possible. Even though their specific interests vary widely, many autistics gravitate towards a smaller number of more restricted classes of interests, which can help to mitigate this problem. Activities which broaden the interests and abilities of an autistic person should, within reason, also be encouraged, or at least made enjoyable, to all or most members of an autistic community.

Social activities in wider (i.e., non-autistic) communities should be encouraged as much as possible. Unfortunately, this often necessitates providing supports and interventions for the autistic person, as well as increased awareness and accommodations on the part of the communities. Nevertheless, if the goal is to meet the social needs of those on the spectrum as best as possible, it becomes necessary to do this to as great an extent as is realistic.

Once again, early intervention needs to be provided as soon as is practical in order to avoid difficulties, not to mention painful experiences, further down the road. For many autistics, a good time to do this is early adolescence (if not pre-adolescence) and middle school, which is regarded by most autistics as the most difficult and painful time in their lives – it is at this stage that interpersonal and social skills, which autistics are typically deficient in, become more important for socialization than they had been up to that point. One of the rudest awakenings that I ever experienced was right around this time, when I realized that, not only were my contemporaries not interested in the things that constituted my as-then unidentified autistic perseverations (electricity and electronics, astronomy and space, atomic physics, public transportation, coin and other collecting), but often regarded them with ridicule and disdain. It was not until years later that I recognized interests expanded to other things such as history, politics and current affairs, and the social sciences to any extent; this certainly helped me with socialization.

Consequently, activities that involve special interests and talents should receive prime consideration for such individuals, even though they might take place in a non-autistic environment. Nevertheless, some measures need to be taken in such circumstances. First, the persons in charge of organizing these activities need to be made aware that autistics will be participating who face various challenges and have specific deficits, despite their great interest and often considerable talent. Where appropriate, this should also be done for at least some other members of that community. Second, someone who has a connection to the autistic individual should provide whatever supports are necessary. This requires, at the very least, monitoring progress in socialization, providing guidance and counseling where needed, and intervening on their behalf when necessary. This person can be a concerned family member or friend, or a professional who understands the skills and is equipped to deal with any eventualities.

In addition to special interests, unusual talents and abilities can also help with socialization. These can include practical skills (technical, financial, information-based, etc.) that are needed or otherwise valued by the community, as well as artistic talents (especially musical or visual arts) that are enjoyed by other members. Any of these can lead to greater acceptance by and socialization into the community. Still, the considerations stated above once again apply.

A word of caution, however: the fact that an activity involves an intense interest on the part of an autistic individual does not guarantee that they will be socialized into that community. I know this from personal experience of my own youth. In early adolescence, I joined an amateur ("ham") radio club – an activity which, given my interests and talents, could not possibly have been more appropriate for me. Nevertheless, I soon became marginalized, ostracized, and even reviled in this community for reasons that I never quite understood. This was made doubly painful by my not being able to understand why I was treated in this manner by people with whom I clearly had much in common. For some reason, adult supervision in this activity was lacking, and I did not receive any support in dealing with a situation that I was presumably expected to be able to handle at that point in my life. Clearly, some form of supervision or intervention was indicated here, and would certainly have made a significant difference for me.

Looking to the Future

Those of us on the autism spectrum have a great need for socialization and community, perhaps even more so than the typical population, because we have so often and for so long been deprived of such. We need to ensure that this does not continue to happen, and that as many avenues as possible are made available for autistics to socialize.

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Preparing for a Successful Holiday Season

By Nicole Alicino, PhD
Licensed Psychologist
Spectrum Psychological Services

Parties! Gift giving! Twinkling lights! The holiday season can be a source of joy and excitement for some but for individuals with ASD the holidays present unique challenges. With communication, planning, and patience, individuals with ASD and their families can successfully navigate and enjoy the most wonderful time of the year.

ASD manifests with difficulties in social communication, social interactions, restricted interests, repetitive behaviors, and sensory differences; many individuals with ASD cope with these difficulties by following well-established routines and behaviors. The holiday season often calls for changes to routines and struggles with flexibility are commonly observed in individuals with ASD, especially around the holidays. Whether its travel, houseguests, holiday attire or the increased sensory stimulations of crowds, smells, sounds, and lighting, the holiday season requires cognitive flexibility that can be practiced and developed.

The key to routines and prioritizing communication, planning and patience. Discussions on what to expect at holiday events, reviewing guest lists that may include unfamiliar family and friends, and validating the challenges individuals on the spectrum experience during the holidays will help create a foundation that will lead to positive outcomes for all.

3. Travel: During the holidays, travel can be particularly stressful for everyone, especially individuals on the spectrum.

B) Gifting should be encouraged to participate in self-advocacy and self-care. The increased social demands coupled with intensified sensory input and disrupted routines can be a recipe for overload, so individuals on the spectrum should practice establishing boundaries and communicating needs before the holidays arrive. Parents should also build self-care, sleep and alone time into the holiday schedule, giving individuals with ASD time to recharge and recover is critical.

Beyond the broad challenges inherent to the holidays, below are some guidelines to discuss, plan and prepare for holiday-related scenarios:

1. Gifts: Prior to the holidays, communicate with family members expectations around gift giving and budgets. Plan in advance all gift purchases and keep in mind that not all gifts cost money; kind gestures can be more meaningful than store bought items. When receiving gifts, it is polite to express gratitude, even if one does not like the gift. Lessen the anxiety around gifts by practicing gift giving and receiving in the weeks before the holidays arrive.

2. Holiday Attire: From formal dress to itchy sweaters, holiday attire can cause sensory sensitivities to certain fabrics and fits. Anticipate the dress codes for different events, communicate with hosts about exceptions or accommodations and try things on in advance.

3. Social Interactions: Visits from family and friends can be challenging for individuals on the spectrum.

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Nicole Alicino, PhD

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or disregard other’s beliefs, values, preferences, and practices, as well as promote a healthy relationship between you and community members, which is an important component. Sometimes this means being willing to step outside of your own comfort zone in order to learn the differences in cultural nuances. Again, the ultimate goal is to have the greatest impact on the community you serve as a whole while raising autism awareness.

Celebrate - Arriving at understanding differences in cultures and how culture impacts the treatment of autism is the first step. Take each and every moment to celebrate with your community and acknowledge the victories members have had in raising autism awareness.

It is evident that cultural and linguistic diversity influences the identification of children with autism. By taking a multi-cultural approach to educating diverse communities about the early signs and symptoms of autism as well as evidence-based practices, we are reaching to close the gap. Strive to make a difference in a community by providing them with information about autism that they may not have otherwise accessed. All efforts make a difference in identifying a child with autism and connecting them with the resources they need to access the most appropriate treatment.

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skills. She has gained social confidence, increasing her friendship circle and overall social skills. Jodie has held several on-call paid jobs this year and was recently presented with a Certificate of Accomplishment in Academic Excellence.

“I would recommend doing community service, volunteering or getting involved in student council ... it's good for practicing communication and learning how to give eye contact. I've learned skills that helped me get a paid job this summer like motor skills when doing tasks, attention to detail and teamwork.”

-Jodie

Two Strategies to increase community engagement among adults with ASD include an emphasis on social networking and transferable skill development, increasing positive outcomes for effective job readiness.

1) Social networking can be better understood by uncovering four vital elements: knowing your community, establishing strategies, building networks, and strategically mobilizing communities. When individuals with ASD learn effective tips and are coached to navigate through this process, they often benefit from new opportunities for growth and relationship development.

According to the community engagement continuum (Fig 1.1) of the International Association of Public Participation, methods in increasing levels of community engagement includes community involvement, impact, trust, and communication flow. When these concepts have a secure foundation and are then broken down and explored, we can creatively create opportunities for individuals with ASD to grow personally and professionally.

Other benefits of community engagement include the development of self-awareness, advocacy, confidence and that it can be really fun. As defined by Wasserman et al. (1994), social networks are necessarily rooted in traditional relationships such as kinship or friendship, but can develop out of geographic proximity, work relationships, or recreational activities.

2) Transferable skills, known as “portable skills,” are qualities that can be transferred from one job to another. Individuals with ASD likely already possess many transferable skills employers want, like organization, interpersonal communication, critical thinking, initiative, and self-management, to name a few. Assessing an inventory of transferable skills obtained using a checklist can help an individual with ASD strategically plan how to acquire the skills needed for a career or job of interest.

The CIP career department enthusiastically spearheads these efforts to educate, motivate and mobilize our student body to become active members of their communities. We assist young adults with ASD to develop pathways toward employment and self-sufficiency by building a portfolio of quality employment experiences. We strive in assisting students in assessing an inventory of employment skills and related interests, developing pre-employment skills, supporting on-the-job experiences and managing the growth of employer relationships. We aim to help increase opportunities for our students with ASD to participate in their communities and learn the importance of networking as a starting point in uncovering possible job opportunities.

As individuals with ASD work to build the pre-employment skills necessary for the workplace, they can start by focusing on community engagement. As noted in the career continuum (McManmon et al. 2018), community service is the foundation of leveraging passion into pay, individuals with ASD can learn more about their interests and personalities through volunteering and community service-learning opportunities. When young adults on the spectrum actively participate, they are building invaluable transferable skills; acquiring knowledge that is applicable to developing a quality resume and work ethic.

To learn more about community engagement opportunities visit the websites below:

- https://www.nationalservice.gov/programs/ Americorps
- https://www.aapd.com/disability-mentoring-day/
- https://www.volunteermatch.org/search

Jocelyn Howard, BA is the Lead Career Coordinator for The College Internship Program (CIP), a national transition program for young adults with autism and other learning differences. For information about their five-year-round and summer programs, visit www.cipworldwide.org or call 877-566-9247.

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Rogue Community College ©2019 http://www.roguecc.edu/emp/Resources/transferable_skills_checklist.htm


Promoting from page 4

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across a wide range of domains: community (e.g., travel, safety, shopping, accessing services), recreation/leisure (e.g., participating in organized sports, going to the movies), social (e.g., initiating conversations, using manners), communication (e.g., asking for help, ordering food), and employment (e.g., volunteer and work experiences) (Florida Department of Education Bureau of Exceptional Education and Student Services, 2018; Walker et al., 2010). In order to optimize the outcomes of CBI, teams should:

**Start early** - Some individuals with autism may need several years to master the skills needed to successfully navigate specific settings and generalize the skills to similar but different settings (e.g., Subway versus McDonald’s). Starting during the preschool years is ideal for many students with autism.

**Partner with families** - Staff should meet with the student and the family to gain information about present skills, behavioral challenges, and goals. It is important to identify community settings where the family frequents, as well as environments where the family may want to visit but is currently unable.

**Assess and target specific skills** - Identify pivotal skills that the individual needs to achieve greater independence at home and in the community using a structured assessment like the Syracuse Community-Referenced Curriculum Guide (Ford, Schnorr, Meyer, Davern, Black, & Demsey, 2010). Once a skill is identified, the team can create a task analysis which breaks the activity into smaller, observable steps (McDonnell, 2009).

**Collect data** - Conduct a baseline probe of the individual’s performance on the task analysis noting the types of prompts needed for each step. Gather data during each CBI session in order to determine progress and make data-based decisions (e.g., determination of skill mastery and when it is time to teach more advanced skills) (McDonnell, 2009).

**Use applied behavior analysis (ABA) to teach skills** - Develop instructional procedures based on ABA to teach the skills (e.g., chaining strategy, prompting and fading strategies, contingent reinforcement, error correction strategies) (McDonnell, 2009). The use of visual supports (e.g., reminders, prompts, mini-schedules) can also enhance instruction.

**Shift the focus of CBI as an individual grows older** - CBI evolves to meet the demands of new environments that require increasingly advanced skills. For example, using CBI to teach an individual how to use public transportation looks very different across development. In elementary school, the focus will be on learning how to ride a bus with a teacher or caregiver (e.g., how to choose a seat, how to get on/off the bus). Skill acquisition may evolve to purchasing bus passes, mapping routes, and developing plans to visit new locations. In adulthood, these combined skills will pave the way for greater comfort and confidence in using transportation options that foster community engagement (e.g., work/school, club/activity, friend’s house). The amount of time that each individual spends in CBI will typically increase, especially in middle and high school. By 16 years old, most individuals should spend some time in the community for CBI and community-based employment training each day.

**Utilize other resources** - Resources are available to assist teams in creating their own CBI programs and to plan for logistical considerations like staffing ratios, transportation, and liability (Florida Department of Education Bureau of Exceptional Education and Student Services, 2018; McDonnell, 2009).

CBI Through the Years: A Case Study

At age 5 years, “Mark” joined in his first CBI outing with classmates to a McDonald’s fast food restaurant. During these first visits, one staff ordered food while two staff members instructed students on selecting a seat and waiting patiently for their meals. Mark and his classmates repeated trips to McDonald’s, each time adding another step to the beginning of the routine (using a backward chaining instructional process) until they were able to order and pay for their own food, take the food to the table, eat the meal, and safely exit the building and board the bus. Mark and his classmates practiced at McDonald’s for some time before generalizing purchasing and waiting skills to other fast food restaurants as well as to grocery stores, the mall, and convenience stores. The students also went on leisure outings to places like bowling alleys and on hikes. By the end of that school year, Mark and his classmates were going into the community to practice skills 2-3 times per week.

As Mark got older, CBI targeted advanced transition skills to adulthood. Mark built employment skills by working at a retirement home and practicing the tasks of setting tables for meals, inputting computer data, and making copies. He also completed filing at two other centers, as well as at his school, where it was discovered that Mark was particularly skilled at tedious detail work that challenged others. CBI efforts were also geared toward increasing Mark’s participation in leisure and recreational skills (e.g., going to the gym, arcade, miniature golf, etc.). As Mark approached graduation, he found work at a retirement home that was in the community closer to his home. Mark and his team worked diligently on generalizing all of his skills to other settings to ensure a successful transition to adulthood. Mark’s program has shifted to be almost entirely CBI. He is currently working on expanding his employment skills and enhancing meaningful relationships in the community.

Recognized both in research and anecdotally, the effective implementation of CBI results in enhancing an individual’s skills across community settings and, thus, improving that individual’s quality of life throughout the life span. The challenge our field faces is identifying effective and efficient ways to increase the use of CBI for students across public and private school settings.

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References


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1. Holiday Meals: Many people look forward to the traditional meals of the holiday season, but for those individuals on the spectrum, holiday meals can be quite disruptive to their usual routine. If dining at a restaurant or someone’s home, call ahead to inform of any dietary restrictions and inquire about the menu in advance. Researching menus and allergies can help prepare for any potential sensory challenges. Also, do not hesitate to ask if you can bring a preferred dish or food item for everyone.

The holidays should be a festive season that everyone has the opportunity to enjoy. While the holidays can cause disruptions for the routines and behaviors of individuals on the spectrum, those individuals and their families can mitigate many of the disruptions with communication, planning and patience. Happy Holidays!

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This article was in the Fall 2018 issue of AHA’s print publication On The Spectrum (OTS). AHA is now joined with AANE - Asperger/Autism Network www.aane.org.
access to recreational and leisure activities. Most agree that there are many benefits of leisure and recreational activities for individuals with ASD. As one parent reported in Schleien et al., (2014, 66), “We were restraining <child’s name> every day to prevent him from doing property damage or harm to himself. When we started a program of intensive physical activity, these things melted away.” It’s really hard to explain how important the benefits are. It’s true our lives changed.” Other benefits noted by researchers, beyond the health benefits of recreational activities, include the increased opportunities for social interactions, increased feelings of self-esteem and belonging, as well as overall improvement in quality of life (Schleien et al., 2014; Thompson & Elmiro, 2011). These benefits to the individual may also lead to increased opportunities for community involvement for others with ASD and more recreational and leisure programs developing resources to successfully include individuals with ASD.

Another benefit of home and community-based programs is the opportunity for skill generalization. Generalization of skills from the home to the community occurs across both skills taught to parents and to the individual with ASD. Parents are coached through applying principles in the community while supported by trained professionals. For example, a young man who was trained at home to ask for time to follow a written “to do” list for his morning routine at home. Initially the behavior was maintained in the home, but was not maintained when children were later observed to perform the task at the dentist’s office. Once children are able to use the skill in the community, they are more likely to use the skill independently of the presence of the parent or therapist.

Barriers

Despite the increasing prevalence of ASD and growth in scientific understanding as well as public awareness, there continues to be work to do in the community engagement for this population. Parents often struggle with limited access and feelings of isolation. Thompson and Elmiro (2011) note, “how one squares the circle between the principal of full inclusion and meeting practical needs of family is uncertain” (p. 75). Data from parent focus groups on the topic of community engagement uncover similar themes. Families report frustration and fatigue at constantly needing to fight for their children’s right to participate while they also fear negative attitudes toward their children and worry about their safety. Additionally, they are concerned that professionals in community agencies are not well trained to deal with their children, and rarely make accommodations or modifications in order to facilitate participation. Therefore, they continue to work toward full participation or settling for participation within specialized settings in the community. Even within specialized settings, parents state that they continue to run into obstacles such as inadequate understanding of ASD and inability to manage challenging behaviors. However, parents continue to value and advocate for opportunities for their children to have what one parent described as those infrequent yet magical moments of complete acceptance by their community (Russell, 2003 LaVigna, & Willis, 2005, Thompson & Elmiro, 2011, Schleien, et al., 2011).

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Dental Care from page 11

about how to help your child through this, but it’s important to be aware of it so you can know how to prepare.

Tips for a Successful Dental Visit

There are many ways to have a successful dental visit for you and your child, but it’s mostly about finding what works best for both of you. Here are just a few ways I believe work best for preparing and ensuring a great dental visit.

Practice at Home - Practicing at home is one of the best things you can do to prepare for a successful dental visit. Use visuals like story books and videos to help your child visualize the experience. You can also play games such as role-playing dental visits to give your child an idea of what a dental visit is like.

Familiarization Appointment - To help your child feel less overwhelmed the day of their appointment, consider scheduling a familiarization appointment ahead of time. These appointments are an opportunity for you and your child to see the dental office and meet the staff before any dental work is done on your child. This can help them feel more familiar with the environment for when it’s time for their actual appointment.

Accommodations - Your dentist will be able to accommodate your child to make their visit the best it can be. Some common accommodations that may help your child include an early morning appointment or a specific flavor of toothpaste. You can also ask to bring your child’s favorite toy or book to the dentist’s office. You can also ask for a distraction to help distract them a bit from the dental work and what’s going on around them.

Dental care is extremely important for all children. However, sensory issues may make it more difficult for children with autism to visit the dentist. Luckily, choosing the right dentist, knowing what to expect, and preparing for their visit can help make the experience better. Never give up on your child’s dental health and embrace the learning experience that comes with it. It is possible for your child to be comfortable at the dentist with patience, love, and dedication.

Dentably’s team, Dr. Grillo is able to share his expertise with you to make your next appointment at the dentist a comfortable experience.

For more information, visit http://www.dentably.com.
ID Cards from page 16

behavioral differences and how they may appear or be misinterpreted by others, such as stereotypic behavior like rocking, vocalizing, abrupt physical movement, walking away, not maintaining eye contact, etc.

• They can provide needed information for someone that may be nonverbal or have limited verbal communication skills or ability

• They can potentially prevent tragedies in very intense situations

• They can provide critical information for first responders in an emergency, especially if the parent is not there or not able to communicate on their behalf

• They can help in cases of wandering (also referred to as elopement)

• Information on the front of the card is general but information on the back can be individualized to the person which is extremely important

• Individuals can be taught to carry these cards and present them upon request or if they are in need of help or assistance

• The OPWDD IDD/ID cards are standardized and uniform across the state which helps emergency personnel become familiar with them during trainings and interactions in the community

In recent weeks, I have had the opportunity to collaborate with Town of Hempstead, NY, Town Clerk, Sylvia Cabana and Deputy Town Clerk Dolores Sedacca. They were eager to figure out a way to get information to families as well as to possibly have Town of Hempstead staff assist families and individuals right there in the main town office. Together we discussed the OPWDD I/DD ID cards as well as ways to get the information to individuals and families that may benefit from the cards. After our initial meeting, we set up an NSSA Community Information Session so that I would be able to come to the main Town of Hempstead building to meet with key staff from the clerk’s office. During this meeting, I introduced those in attendance to NSSA, autism spectrum disorder, applied behavior analysis, OPWDD and of course these new I/DD ID cards. In addition to these topics, we discussed tips for understanding and working with individuals with autism as well as their families. I also provided them with a detailed task analysis that could be used by the clerk’s office staff or anyone that wanted to complete the process for getting the ID card.

The Town Clerk’s office provides assistance for many things including passport ID processing and providing senior ID cards. Now, they will also include assistance for completing the process in order to obtain the OPWDD I/DD ID card. They will have designated staff to assist as needed as well as designated areas of the office with added privacy and support if needed. The staff will now be knowledgeable about ASD, OPWDD, and the ID cards. Most importantly they will have a sensitivity and understanding to the challenges many individuals with autism and their families face on a daily basis. It was great meeting with Town Clerk Sylvia Cabana and her dedicated staff. I applaud their effort and determination in leading the way on autism acceptance and inclusion in the Town of Hempstead and I look forward to additional opportunities to provide these valuable information sessions to other local government offices, community organizations, and other interested members of the community.

For more information on obtaining an OPWDD I/DD ID card, visit the OPWDD website at opwdd.ny.gov/iddcards, Nassau Suffolk Services for Autism’s website at www.nssa.net, or contact the Town of Hempstead Clerk’s office.

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Coexist from page 16

A tool that will help guide our treatment interventions.

With streamlining and simplifying the identification process of comorbid disorders, we can now look at the treatment implications. Typical treatment modalities are not geared specifically towards the Autism population, which creates a whole new set of issues for providers and clinicians. Where psychopharmacology is beneficial for the neurotypical individual, those on the Autism spectrum can be more susceptible to side effects of medications, reducing its effectiveness and can lead to medication non-compliance. Traditional, non-medication treatments such as insight-oriented or classic Cognitive Behavioral Therapy (CBT) show limited benefit due to the concrete nature of an Autistic individual’s thought process. This makes identification, verbalization and exploration of one’s feelings more challenging. Additionally, these therapies rely on an individual’s willingness and ability to tolerate uncomfortable feelings and thoughts, something that individuals with ASD find exceedingly difficult. A key feature of Autism is a generalized sense of discomfort in their daily lives. Social-emotional discomfort is a daily struggle for these individuals and the impulse to avoid further sources of discomfort is strong. As such, there is less overt motivation to engage in treatment (National Autistic Society, 2018).

According to the Anxiety and Depression Association of America, careful and selective psychopharmacological inter- ventions combined with aspects of Cognitive-Behavioral Therapy can be beneficial in reducing depression and anxiety in individuals with ASD. They specifically recommend mindfulness-based treatment combined with emotional literacy skills in order to improve their ability to regulate their emotions as well as increasing their ability to tolerate emotional discomfort. Concrete examples as well as visual aids and even virtual reality scenarios can help individuals recreate a situation without necessarily triggering their anxiety. New medication treatments, such as Oxytocin, vasopressin receptor 1A antagonists and cannabinoids are being researched by ADAA for possible future use. If there is one take-away from this article, it is that the research on this topic is severely lacking. Much of the data and treatment formulations are based on meta-analysis and anecdotal data. In order to have appropriate and effective treatment for comorbid anxiety and depression with Autism, specific research needs to be done. This leaves clinicians with the dilemma of identifying and treating these individuals. But, as we have discussed in this article, using a whole-person, family-systems approach and individualizing assessment of functioning, we are better equipped to identify those in need. And by modifying existing treatment modalities by thinking out-of-the-box in terms of the tools we use, we can make measurable and sustainable differences in our client’s lives.

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music, and iPads. They learn about history, royalty, politics, literature, sports, and the processes and materials used in making what they are looking at.”

“Traveling beyond the boundaries of the campus of the Chapel Haven Scheifer Center has broadened their world and provided confidence for many to continue these explorations,” Friedlaender noted. “A few students have learned to take public transportation to the museum, and some even come on their own just to look around or attend a public lecture.”

Over time, Chapel Haven and the Yale Center have presented at national conferences on this unique partnership and have identified five common elements that make the program a success for the special needs population.

First, and most important, is that all staff are engaged. The museum spends a lot of time training its own staff, so that when an individual steps through the front door, they feel welcomed.

“When teachers, security and information volunteers greet students by name as soon as they enter the museum, students feel that they are welcome,” reported Lynne Horoschak, a professor at Moore College of Art and Design.

Second, the instruction is differentiated. “Sound and movement activities give all students the chance to respond, even if they struggle verbally,” she reports. “Students are treated like adults, but lessons are no-fail and geared to a range of cognitive abilities.”

All lessons have multi-sensory elements and each class includes hands-on studio activities. Students may sit in on a lecture about Constable or Turner and then will have the chance to make some art in response to what they’ve heard and seen.

The end result, according to Menchetti, is visible in the students. “Their posture is stronger, their heads are held high. They have really risen to the occasion of being in a world-class museum,” she noted.

Eric Chessen, founder of Autism Fitness, is a believer in recreation activities that build physical fitness and wellness. He blends in repetition, social stories and a menu of choices.

“Regular, vigorous, progressive physical activity should be a staple in any educational, recreational, and vocational program,” he said. “For both proactive and reactive health and psychological/emotional benefits, exercise and being outdoors should not be a privilege but a cornerstone of life skills.”

Chapel Haven community member Ellen Rosenbaum is a big believer in fitness. She recently placed second in the agency’s Biggest Loser competition, which drew 43 participants. She lost a total of 35 pounds during the campaign.

“I’ve been drinking a protein shake every day,” she said. “I have fruit for breakfast and chicken or fish for dinner with salad and vegetables.” Ellen gave up carbohydrates such as pasta, potatoes and rice. “I feel good,” she said, vowing that next year, she intends to take the top slot.

There is also an art to creating a successful exercise program for adults with disabilities. Chessen offers these recommendations:

1) Always assess an individual’s ability levels with specific activities. Knowing the baseline skills are important for effective teaching and mastery.

2) A new/novel activity may not be enjoyed immediately. Revisit new exercises, movements, and activities often and in small or limited amounts of exposure.

3) Social narratives can be a game-changer for alleviating anxiety and letting an individual know “what’s coming next.” They can also be used to develop new language.

4) Whenever possible, offer choice. In Autism Fitness programming, he said, “we do this all the time. ‘Do you want to do hurdle steps first or push throws first?’ It provides our athletes with a measure of control and autonomy.”

Along with having an active and social calendar on the weekend, Andy Auerbach has blended a fitness regime into his week with great success.

Chapel Haven Trainer Kim Stack says, “Andy has lost a total of 40 pounds over the past few years. He works out with me twice a week and usually comes into the fitness center twice a week on his own in addition to that. Andy has kept a food journal for years of every single thing he eats and drinks every day. He is an incredibly hard worker!”

References


Small Village from page 14

from Village leaders, committee members, businesses and organizations has strengthened over time. As a result of people willing to learn, open their hearts and do just one thing in the Village of Rhinebeck, people with autism and their families (and people with other disabilities, too) will increasingly encounter patience, understanding, respect, acceptance and inclusion. And hopefully, the Village of Rhinebeck will become a model for other communities interested in evolving into a supportive community. Katy Kollar, a parent of a teenager on the spectrum shared, “As a family, we are so grateful for this culture of compassion. Small changes give children like our son a chance to be wholly integrated into our community, which fosters his growth and development and in turn, helps everyone become better.”

Clearly, this is just a small, first step toward more substantive social inclusion of people on the autism spectrum. Research offers varying definitions of “social inclusion” or “social participation” by those with ASD and their families. Simplican, Leader, Kosciulek and Leathy (2015) offered helpful models to consider, especially for the areas of Interpersonal Relationships and Community Participation. Anderson Center Consulting is considering methods by which basic community participation data may be captured to inform further development of the Autism Supportive Community endeavor.

Perhaps Mayor Bassett summed it up best: “The outpouring of support for this project has been truly extraordinary. It just takes one simple thing to make a difference in someone’s life; I’m proud of our local businesses and organizations for recognizing the impact they can have.

For more information about Anderson Center Consulting and Autism Supportive Program options, contact AndersonConsulting@andersoncares.org.

Dr. Killion went on to attain an M.Ed. in Special Education and a PhD in Developmental Psychology. He previously had his own ABA that serviced many areas of South Carolina, and he has served as adjunct psychology professor and consultant to psychiatric and behavioral facilities for behavioral plans for children and adults with Autism and other developmental disabilities. Dr. Killion is a frequent national speaker on ABA and how to address significant negative behaviors.

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monthly contact with all supports. Staff also educate the individuals on their rights.

Group Home - A Group home is a facility where individuals live all together. Individuals who live in this type of setting are not related to each other, but have similar disabilities. The house is staffed 24 hours a day, 7 days a week. The staff are trained to provide life skills training such as personal hygiene, food prep, and health and safety. Staff are trained in medication management and behavior assistance training, if needed. The individuals who live in this supported and community-based housing attend a day training program and/or in the community with supports. This type of housing is owned by a licensed provider agency. A licensing agent monitors the Medication Administration Record (MAR) as well as the Registered Nurse. The home is required to have residential monthly meetings where the residents communicate what social activities they would like to participate in and how they want their house run. All individuals who live in the home are educated on their rights. A monthly fire drill is conducted in the home. Staff drive the individuals in the group home van or the miniature school bus.

An Intermediate Care Facility - An Intermediate Care Facility is similar to a group home. However, this facility is surrounded by similar facilities. This is also known as a “Cluster” on campus which houses individuals with similar disabilities and ages together. Some homes are co-ed. Intermediate Care Facilities have 24-hour nursing, case management as well as behavioral staff if applicable. Intermediate Care Facilities provide transportation to day programs and shelter workshops. The Intermediate Care Facility receives medical care, occupational therapy assessments, and physical therapy assessments. Unless otherwise requested by the family, the Intermediate Care Facility uses one staff doctor who sees all of the residents.

Rights

Does my young adult with autism have rights? There are several laws designed to protect individuals with Autism when it comes to fair housing. The Olmsted Community Integration was made in 1999 by the United States Supreme Court. The court stated in Olmsted v. LC that unjustified segregation of persons with disabilities constitutes discrimination in violation of title II of the American with Disabilities Act. The Court held that public entities must provide community-based services to persons with disabilities when, (1) such services are appropriate; (2) the affected persons do not oppose community-based treatment, and (3) community-based services can be reasonably accommodated, taking into account the resources available to the public entity and the need of others who are receiving disability services from the entity.

The Americans with Disabilities Act (ADA) is a federal law that prohibits discrimination against people with disabilities in employment and mandates that these individuals have the right of public accommodations as well as access to programs of public agencies.

The Office of Fair Housing and Equal Opportunity (FHEO) administers and enforces federal laws and establishes policies that make sure all Americans have equal access to the housing of their choice.

When looking for supportive and community housing, it is imperative that families and individuals with autism conduct thorough research. Families should apply for disability services early as there is a long wait and can be cumbersome. When it comes to exploring whether a group home or living with a roommate and minimal staff assistance is best, it is imperative that families tour the group home to get a feel of it. The tour is an opportunity for staff and families to ask and answer questions regarding supportive and community living. Just like a parent releasing a child to school for the first time, you want to be informed and confident in all of your decisions.

Tavesha Guyton is a social worker who works with autistic children and adults. Tavesha Guyton can be contacted at Werfamile.org.

References


Public Housing Authorities: Helping to End Homelessness through Permanent Supportive Housing. Journal of Housing and Community Development, 2008, p. 18

Public Housing Authorities: Helping to End Homelessness through Permanent Supportive Housing. Journal of Housing and Community Development, 2008, pp. 18–21
food in the cafeteria, working at the staff copy center, delivering mail, staffing a school store, re-shelving books in the library, or completing light custodial work.

Research shows that a combination of on-site job training and simulation training is most effective (Lattimore, Parsons, Reid, 2006). For those beginning to explore work options, internships and volunteer opportunities are an excellent place to start. Consider volunteering in libraries, animal shelters, nursing homes, civic organizations and small businesses in your community.

State Labor Laws will dictate how much time a student can work per week, depending on their age. For young teenagers, it is often 1-2 hours per week. This time scales up to 20 hours or more for young adults 18 or older.

To best prepare individuals for transition from school to adult programs at age 21, the vocational training program should begin to focus on developing career goals and securing long-term paid employment. Typically, this will begin around age 18. Programs should offer individuals the opportunity to sample a variety of work environments, observe jobs in action, and review occupational handbooks/overviews, as appropriate.

Fostering Employer Partnerships

Relationships with employers can be established by networking with your organization’s board members, employees, friends, and family. Sharing information and providing a tour of your school or organization are also effective strategies. Volunteer opportunities or internships may precede paid employment. With internships, keep in mind Federal Department of Labor regulations. Discuss with employers the needs of their organization or business and how your job candidate can help them meet those needs. Address the practical advantages of hiring individuals for short shifts. Students with autism should receive the same pay, reviews and raises as typically developing employees.

Retail chains are particularly valuable employer partners. These contacts should be cultivated with care and attention. Oftentimes, district managers can direct or influence HR decisions across a region, providing more opportunities for your job seekers. Students may be able to work at one location during their time in school and then transfer to their local community after graduation.

Ensure that the initial employer experience is optimal. Start with one promising student and an experienced on-site job coach to make sure the experience works well for both the student and employer. After one student has achieved ongoing success, explore expanding the hours and/or days per week for that individual or bringing on an additional student. Job coaches should support the student until they demonstrate mastery of the required skills.

Vocational training is a critical component of autism services that also serves as an excellent way to assimilate those with autism into the community. Local businesses, families and the general public all benefit from working alongside individuals with autism.

Julie Weiss, MSED, BCBA, LABA, is Director of Vocational Services and Julie LeBlanc, MS, BCBA, LABA, is a Vocational Specialist at The New England Center for Children.

For more information on vocational services programs, contact Julie Weiss, jweiss@necc.org, or visit The New England Center for Children at www.necc.org.

References


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

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

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

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

Socialization and Life Skills Group For Asperger’s Syndrome and High Functioning Autistic Adults

Focused on: Employment and Vocational Issues, College Coaching and Supports, Socialization, Self-Advocacy, Dating, and Relationships

For more information, visit www.ASDGroupsWestchester.com or contact the facilitators:

Robin Kaufman, PhD, and Lauren Greiner, PhD  |  ASDGroupsWestchester@gmail.com  914 497-1590


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The Gleeson-Israel Gateway Center

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All Teaching Families go through a rigorous training process and receive ongoing observation with direct feedback measured against quality standards. This ensures programmatic integrity for both quality instruction and for the family philosophy inherent in this novel shared living experience. Brad Walker, a supervisor for Teaching Families for more than a decade, views the importance of quality supervision as imperative. “The training process within the Professional Family Teaching Model provides for monitoring of key performance indicators against which staff performance is evaluated. The data collected through this observation experience allows the team to focus directly on needed performance areas, dramatically improving their performance, consequently delivering high quality services,” says Walker.

This community-based, shared living model utilizes varied Medicaid funding models, often dependent upon the local region’s funding structures, and it has been shown to decrease costs (Strouse, Carroll-hernandez, Sherman & Sheldon, 2003). One of the primary reductions in costs is due to decreased turn-over of direct support workers. Onboarding new professionals affects outcomes and is expensive. In the state of Kansas, where this model has been in operation for several decades, the current annual staff turnover is 35%.

Given the nationwide shortage of housing for adults with autism, and a commitment to innovative programming, NEXT for AUTISM is working with New York State to pilot this programmatic model and are hopeful this type of program will spread to other states as well. The overall project promises great success. NEXT for NEIGHBORS is in its early implementation phase in Westchester, New York, utilizing the Family Teaching Model as its staffing support structure and emphasizing community inclusion and engagement for clients. The Family Teaching Model can help to address this critical need for community living options for adults with autism, especially those with higher needs. It holds great promise not only in New York, but across the country.

Interested in learning more about the Teaching Family Model and/or NEXT for NEIGHBORS? Please contact Patricia Wright at pwright@nextforautism.org or visit www.nextforautism.org.

3) Visit the Airport

As autism awareness has increased, airports across the country have developed rehearsal programs like Wings for Autism/Wings for All (https://www.tsa.gov/news/top-stories/2016/10/25/tsa-supports-wings-autism) where individuals with special needs and their families can go to practice air travel. These programs are specially designed for individuals with autism spectrum disorders and individuals with other special needs. The rehearsals seek to minimize the stress that families who have a child with autism or intellectual/developmental disabilities experience when flying. Some of the rehearsal activities include entering the airport, obtaining boarding passes, walking through security and boarding a plane. The Wings for Autism/Wings for All also gives the opportunity for airport, airline, TSA professionals, and other personnel the opportunity to observe, interact, and deliver their services in a structured learning environment so that they develop increased fluency and competency when it comes to accommodating all passengers. Lastly, some families with whom we’ve worked have shared that booking a short and easy flight can help parents to control their child for longer, more challenging trips as they get exposed to the various stimuli and enable their children to experience success with a shorter flight.

4) Take Advantage of Pre-Existing Supports and Resources

Many airports and airlines have supports in place to provide additional resources for families who may need extra support. You can request some additional resources when you book your flight online (e.g., when booking for other states as well since it holds, food or dietary requests when flights offer meals, etc.). It’s a good idea to print boarding passes at home and have the mobile version downloaded to your phone to cut down on time spent standing in line once you arrive at the airport. Also allow yourself additional time to give yourself a time cushion to cut down on your stress. It can be helpful to research ahead of time to see if there is special parking or drop off closer to the terminal. Request the full body scanner for your child so he or she doesn’t need to be patted down or scanned with a detection device. Avoid wearing belts with metal buckles, and make sure to wear shoes without laces that are easy to slide on and off for a less stressful screening experience. When possible, one parent should go through the security check point first, while having the other parent waiting with your child. That way you can be comfortable with the process as he or she is covered in both directions.

5) Have fun!

Airports can be exciting and fun places to visit. Recently, at JFK in New York, TWA opened a new “re-opened” terminal with a hotel, restaurants, a rooftop infinity pool and observation deck with runway views. Many airports have a variety of retail shopping options and they keep up with favorite food trends; there are now Shake Shacks at several local airports. Many flight staff are being trained to work with and accommodate special needs individuals and are happy to explain fun facts about air travel. You might even get a free pair of wings or model airplane from one of the airline staff. While traveling by plane may present some obstacles and challenges, it can also be very rewarding as flying can reunite families and friends who live far apart. Hopefully, these tips will let you enjoy the experience as planning ahead helps to ensure you anticipate as many challenges as possible. Just remember to bring that phone charger!

Dr. Braden Josephson is a clinical psychologist and board-certified behavior analyst (BCBA-D) and is founder and chief executive officer of NeurativeMind Psychological Services, a private evaluation and ABA program based in New York City that is part of Autism Care Partners. For more information, visit http://cityprogroup.com/, contact the author at bjoepson@cityprogroup.com or call (718) 769-2698, ext. 261.
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