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Becoming an Ally: How Communities Can Empower and Embrace Individuals with Autism Spectrum Disorder

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Becoming an Ally:

How Communities Can Empower and Embrace Individuals with Autism Spectrum Disorder

Hillary Adams and Eugenia Damron

Introduction

There is a demographic shift going on in the United States. The Centers for Disease Control (2015) estimates that one in sixty-eight children are diagnosed with Autism Spectrum Disorder (ASD). In just ten years, the prevalence has increased from one in 150—a huge leap from the 1960s and ’70s when the diagnosis was approximately one in two thousand (Centers for Disease Control 2015). As the number of individuals with ASD rises, average citizens must realize the responsibility to embrace this growing population and better engage in personal efforts to assist individuals with autism to integrate effectively into their communities. Individuals with autism are isolated, often trapped by their own self-doubt, challenges with communication, and trepidations of fitting a societal mold. Average citizens have the keys to open these doors by opening their minds to those who are different. People with ASD need allies to support them to connect, exchange, and make a positive impact within the community.

Autism Spectrum Disorder is identified through two main indicators. The American Psychiatric Association, through the Diagnostic and Statistical Manual 5 (2013), lists the first indicator as persistent deficits in social communication and interaction; these deficits can manifest through atypical social-emotional reciprocity, lack of nonverbal communicative behaviors, and deficits in developing, maintaining, and understanding relationships (27-28). The second indicator of ASD is restricted, repetitive patterns of behavior, interests, or activities (28). These symptoms play out through repetitive motor movements, use of objects, or speech; insistence on sameness, routines, or patterns of verbal or nonverbal behavior; restricted, fixated interests that are abnormal in intensity; and hyper- or hypo-reactivity to sensory input (28). Autism Spectrum Disorder can range in severity, from Level 1 (requiring minimal support) to Level 3 (requiring very substantial support). No matter the severity, adults diagnosed with ASD often yearn to lead meaningful lives on their own terms. A quality life involves varying levels of independence, postsecondary education, employment (Hansen 2015), socialization, and romantic or sexual relationships (Hellemans et al. 2006, 94).

An average of fifty thousand individuals with ASD will turn eighteen each year in the United States; however, adult services continue to be sparse (Roux et al. 2013, 931). As many families plan to celebrate high school graduations as a joyous event, families of graduates diagnosed with ASD will face the daunting question, "What's next?" Families must face the edge of a cliff, wondering what services their state can provide, whether their family will qualify for these services, as well as if college or independent living are options for their sons and daughters. Across the United States, adult services are available, but limited. In West Virginia, there are several initiatives in place to serve adults with ASD: the West Virginia Developmental Disabilities Council assists with training and grants to enhance community partnership; the WV Division of Rehabilitation Services helps individuals with ASD reach vocational goals; and the WV Autism Training Center provides a variety of Positive Behavior

Support direct services and has established the Marshall University College Program for Students with Autism Spectrum Disorder. In addition, Title XIX Home and Community Based waivers can assist with service payment for low-income families, providing things like private nursing, care management, and medical equipment for those who are limited in functioning. Wait lists, family income, provider criteria, or lack of funding, however, can inhibit involvement or depth of services provided. Given the current inadequate number of services, everyone has a powerful obligation to create change: We can embrace individuals with ASD by developing citizen understanding and skill sets related to the diagnosis. Change can happen by a conversation at the dinner table, advocating in a workplace, or a simple hello. We empower those around us to accept individuals with autism if we challenge ourselves to connect.

Evolution of Autism Services

The twentieth century progressed from institutionalizing and sterilizing individuals with ASD to emphasizing concepts of self-determination and inclusion. Service providers stopped labeling the population “unworthy of life” and now, instead, discuss “quality of life.” For our communities to continue to make positive steps in advocacy, we must also recognize how far we have come. Beginning in the 1920s, the United States saw the legalization of sterilization in seventeen states and the rise of eugenics, while the 1930s and 1940s encouraged the institutionalization of children deemed “defective” (Donvan and Zucker 2016). In the 1950s and 1960s, when autism was believed to be a personality disorder, the serotonin-inhibiting drug, LSD, was a focus of experiments. Additionally, the “refrigerator mother” theory, depicting a lack of maternal warmth shown to a child, also became a popular theory for the development of autism (Baker 2013, 1090). In the 1970s, electric shock therapy was practiced on children with autism as a type of aversive punishment. The late 1970s and early 1980s saw massive deinstitutionalizations, and mental health treatment shifted from hospitals to the community. Neuroscience had an increasingly important role in mental health in the 1990s and 2000s, while autism awareness and research increased dramatically. Today, Applied Behavior Analysis (introduced in the 1960s) and Positive Behavior Support (introduced in the 1980s) are two of the most widely used therapies for Autism Spectrum Disorder. Both Applied Behavior Analysis and Positive Behavior Support focus on the science of Behavior Learning Theory—reducing undesired behavior and reinforcing the positive ones. Many believe the difference in the two interventions relies on Positive Behavior Support's emphasis on quality of life, normalization, and choice (Weiss et al. 2009, 428).

Before this evolution of thinking, Leo Kanner of Johns Hopkins University sought to understand the unique behavior of a patient who was displaying what is now called Autism Spectrum Disorder. In 1942, Kanner used the phrase, "autistic disturbances of affective contact," pulling from a portion of the schizophrenia diagnosis, to describe his patients' inability to relate themselves to other people. Kanner was calling for the humanization of the mentally feeble, while others were calling for mercy killings (Donvan and Zucker 2016). In the 1950s and 1960s, autism was identified as a form of childhood schizophrenia. Kanner made important strides in his career to distinguish autism from schizophrenia, as well as from mental retardation. In 1980, his efforts were realized in the DSM-III, when autism was listed as a pervasive developmental disorder with three basic criteria, which was then expanded upon in 1987 with the DSM-III-R listing eight to sixteen criteria (Baker 2013, 1091).

A significant cultural shift originally began in the 1970s with the advent of the self-advocacy movement, giving voices to the previously stifled. This movement really took shape in the 1990s and 2000s, as the use of the Internet became more prevalent, tying autism communities together. For the first time, individuals with autism, and their families, were able to unite with one another in a broader sense to create connections. These communities, as described by Holland et al. (1998), are "figured worlds," giving meaning to people's interaction and changing historically due to political or social values of the community. Figured worlds are socially organized encounters in which an individual's position matters (45). This discourse amongst the autism community provided a contrast to the biomedical definition, and, instead, focused on neurodiversity (Bagatell 2010, 38). Finally, individuals with ASD were not lesser humans to be cured or isolated, but people with differences worthy of support and understanding.

Integrating individuals with ASD into our communities through education is vital so that we can reach into the culture and world in which they live. To take an ethnographic view, we first need to understand the complexity of mapping the diverse world of autism. Imagine you are from a non-English speaking country and you arrive in the United States to study American culture. You decide that New York City is a good place to begin. Upon arrival, you realize the cultures within the Bronx, Manhattan, Brooklyn, Queens, and Staten Island are vastly different. Not only that, but your translator can only vaguely communicate and interpret the events in which you are submerged. To simplify the experiences of individuals with ASD as the same would be like depicting the same cultural experiences of Manhattan and the Bronx. Additionally, due to typical barriers in communication, asking an individual with ASD to depict their world experience may be like relying on poor translation in a foreign land. This is why we must educate each other to recognize commonalities within the diagnosis first and welcome opportunities for deeper understanding of the human experience of individuals with ASD as a result. By creating a conceptual framework of autism through training and education, forming meaningful, working relationships with individuals with ASD becomes less intimidating. We must build a community that is open to change, and immerse ourselves in a world where difference is not scary—it is just different.

Ally Recruitment: Removing the Double-Edged Sword

Communities have the ability to reshape societal standards for a more inclusive and compassionate environment for those with ASD. Howlin (2000) expresses that for individuals with ASD, there is "constant pressure to 'fit in' with the demands of a society that fails to understand their needs or difficulties. Inability to meet these demands may lead to stress and anxiety and even psychiatric breakdown" (79).

Within the United States, our prevailing culture screams, "dance to the beat of your own drum," "different is beautiful," and "don't be afraid to be yourself!" Then, society leans in to whisper, "don't dance too loudly, don't be too different, and only be yourself if we approve." Our culture cherishes uniqueness in theory, but we hand out puzzle pieces to individuals with ASD, reminding them they do not quite fit the mold of society. As citizens, however, we must meet them somewhere in the middle, not only to support quality lives for this growing population, but so we can grow as individuals, as communities, and as a society.

Our nation, like many others, has nurtured an ableist society—the notion that people are automatically better, have better lives, or have better brains or bodies because they are not disabled. Even more defeating, is how those with disabilities internalize ableism. Individuals with ASD learn they are tolerated in society, rather than accepted.

By gaining understanding and then including individuals with ASD, we can tap into a completely underutilized resource. The following personal narrative illustrates this point:

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> I recently helped a young man, diagnosed with autism, to fill out an application for a railroad switch operator. He is a recent graduate with an affinity for all things railroad and would be an ideal candidate. He can stay up for long hours, does not mind tedious or seemingly mundane tasks, and would absorb his roles efficiently and enthusiastically. As we neared the end of the application, however, we faced the inevitable double-edged sword: to disclose or not to disclose. Most individuals with ASD, and with the capacity to work, will face this dilemma. By not disclosing, he could face an interviewer who would not understand his pauses in speech, his interrupted eye contact, or his lack of work history. To disclose means he could face stigma and discrimination, never receiving the invitation for an interview. As a young adult well versed in ableism, he clung to not disclosing. After weighing the pros and cons, however, he gambled on disclosure, hoping his true self would be enough.

Passing on disclosing, as described by Leary (1999), cited in Campbell (2007, 10), "represents a form of self-protection that nevertheless usually disables, and sometimes destroys, the self it means to safeguard." Individuals with disabilities should not have to mask themselves to feel included. By resisting the ableist mentality and adopting the ally mentality, we can provide an environment where individuals with ASD can openly discuss their diagnosis without hesitation and without fear of backlash.

The resistance against an ableist society, additionally, comes with its own double-edged sword. Because our society is so resistant to discussing limitations as a result of a disability, we extinguish honest conversations. We believe that to identify and openly discuss how a disability affects someone's everyday life is to diminish him or her as a human. This is not so.

ALLIES SUPPORTING
AUTISM
SPECTRUM
DIVERSITY

WV Autism Training Center

As allies, we want to have that honest conversation—to connect with each other as members of communities with shared interests. The West Virginia Autism Training Center, located at Marshall University, created the "Allies Supporting Autism Spectrum Diversity" training to help with common misconceptions regarding individuals with ASD. Checking out in a grocery store, applying for a job, or eating at a restaurant can be a daunting task for an individual with ASD. But it does not have to be. What if the grocery cashier understood that not being able to purchase a brand of cereal could throw off desired routines? What if the job interviewer recognized that speech delays are due to slow processing speed, not low IQ? What if the restaurant server showed empathy to the patron overstimulated by clanging dishes and loud chatter? The Allies Supporting Autism Spectrum Diversity training works to inform and educate individuals who wish to provide a safe and accepting environment for individuals living with Autism Spectrum Disorder. Our mission is to advocate for diversity and promote understanding in order to support and develop ASD awareness.

The ally mentality is being quickly embedded into Marshall University, and we are spreading our ideals through our Huntington, West Virginia, home. Winner of the national competition and named "America's Best Community," Huntington, West Virginia, stands as an example that change is not only possible, but also wanted by our citizens. As our city works to revitalize and beautify its outward appearance through the Huntington Innovation Project, we seek to revitalize and beautify our city from the inside. Through the understanding, acceptance, and inclusion of a misunderstood and underutilized population, we can help to nurture productive members of society. Individuals with ASD wish for independence, employment, friendships, and community inclusion. It is our job to meet them halfway by learning what we can do to support those goals. We need citizen involvement to create change—to shift responsibility from mental health experts to citizens who wish to spread autism advocacy into our communities. Our hope is to chisel away at the rock and hard place individuals with ASD are stuck between. They should be able to openly discuss the need for support, disclose without fear, and grow up understanding they are capable of living meaningful lives absent of ableist attitudes.

"America's Best Community" competiton
(Photo by Lori Wolfe, *The Herald-Dispatch*, Huntington, West Virginia)

Societal Stigma

Due to misconceptions caused by a lack of understanding of Autism Spectrum Disorder, there is often stigma associated with the diagnosis. This obloquy follows myths and stereotypes that are inaccurate and often unkind. ASD stigma can inhibit educational opportunities, employment, socialization, and independent living. Awareness is growing, but stigma continues to exist, and individuals with ASD are affected in a variety of ways. Some individuals avoid disclosing their diagnosis for fear of being placed in a box, leading to different or unfair treatment. Others diagnosed with ASD may absorb that stigma, creating self-doubt and untapped potential. Because they are misunderstood, individuals with ASD are avoided, leading to reduced learning opportunities in socialization and communication, as well as loneliness. As humans, we resist actions that may lead to discomfort or uncertainty, but relish in moments when we take those risks. These tiny "risks" for communities, however, could lead to life-altering impacts for individuals with autism.

In a research study by Jacoby (2015), seventy-seven community members were surveyed regarding "comfortability" with individuals with ASD. Responses on a zero to ten scale, zero being extremely uncomfortable and ten being extremely comfortable, had varying results dependent on social situation. Jacoby (2015) explains that the more ongoing contact with someone with ASD, the more likely an individual was to feel comfortable with interactions (30). Participants showed the lowest comfort levels in professional settings (cashier, coworker, waiter, or doctor) with average comfortability being 6.60—the very lowest being if the individual with ASD were their doctor, with an average 4.82 comfortability. When searching as to whether the type of previous experience with individuals with ASD effects comfort levels, two experiences showed positive correlations: "I have learned about autism at school or work" had a .27

positive correlation, while "I have had a job related to working with people with autism" had a .28 correlation with higher comfortability (Jacoby 2015, 26). It is clear the more exposure and one-on-one interactions community members allow themselves to engage in, the higher comfort they will feel in future exchanges with individuals with ASD.

Previous research regarding efforts to reduce autism stigma within the elementary education setting provides further evidence that exposure to people with autism can lead to less stigma. Campbell (2006) sought to encourage persuasive communication through autism disclosure of children in order to create attitude and behavioral change in the classroom. Research suggests that by initially introducing ASD to classrooms, we can create inclusive education and positive initial attitudes of peer responses toward individuals with ASD (Campbell 2006, 268-269), which could potentially lead to a more knowledgeable and accepting society.

In a 2010 study at the University of Hong Kong by Ling, Mak, and Cheng, an examination of attitudes of "frontline workers" (123 teachers and faculty who worked directly with students with ASD to age eighteen) was conducted to empirically investigate the stigma of students with autism. Results showed that better knowledge and longer working experience with autism correlated with low intentions to punish the student. Those who previously received special education training were more confident in how to handle situations with students with ASD, therefore indicating training was important to frontline staff. Although training was linked to better preparedness, stigma toward ASD was still apparent. The role of emotions, like anger and sympathy, appears to have a direct influence on the behavioral intentions toward students with autism, suggesting training on emotion regulation and alternative teaching methods could be useful.

Staniland and Byrne (2013) aimed to bridge the gaps in ASD anti-stigma literature by evaluating the effects of an anti-stigma program on adolescent boys regarding their peers with ASD. The study involved a multi-session intervention with direct contact and videos displaying individuals with ASD. Results indicated that knowledge and attitude had a positive correlation with the training, but not behavioral intentions to engage with peers.

Gillespie-Lynch et al. (2015) conducted a brief online training with college students in order to increase knowledge and decrease stigma. Similar to Staniland and Byrne's outcomes, immediate increases in knowledge were shown. However, changes in knowledge were relatively greater than changes in stigma, suggesting stigma is more difficult to alter. Common misconceptions of typical college students found in this study state that ASD is associated with the following: cognitive difficulties or lack of intelligence, vaccinations, the inability to engage in romantic relationships, and the likelihood of pursuing STEM subjects. This research saw marginal improvement of these stigmas post-training (Gillespie-Lynch et al. 2015).

Although trainings and up-to-date knowledge regarding ASD are shown to improve understanding, a theme has emerged from this research that although positive change is often seen in mindsets, behaviors and actions toward individuals with ASD are less susceptible to change. Our understanding and initiatives to reduce stigma and cultivate more inclusive communities must continue to develop.

Postsecondary Education

Higher education is a daunting prospect for individuals with autism and their families; it is particularly scary for those looking to move away from home. Individuals with ASD often need very tailored and structured support, therefore making it difficult for traditional disability service programs within higher education to meet the true

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needs of students with ASD. Of the 190 to 192 higher education institutions surveyed, based off the *Benchmarks of Effective Supports for College Students with Asperger's Disorder,* 12.5 percent have fully dedicated staff who assist instructors in improving academic outcomes for students with ASD, while only 7.3 percent have staff dedicated to working directly with the students (Ellison 2013, 61). These support programs vary significantly in format, practices, and prices, but provide hope to many students and their families in pursuing the dream of a college degree. The higher education community is seeing a significant increase in the admission of individuals with ASD, which comes with a unique set of challenges; collaborative practices that foster growth are pertinent to the development of best practices to serve these students with ASD (Ackles, Fields, and Skinner 2013).

Based on the National Center for Educational Statistics' nationally representative sample of two- and four-year colleges and universities, data indicated that 2 percent of students registered with a disability reported having ASD, and 56 percent of colleges and universities reported at least one enrolled student with ASD (Raue and Lewis 2011, 18). This likely underestimates the true numbers of individuals with ASD enrolled in higher education (Matthews, Ly, and Goldberg 2014) due to lack of diagnosis or lack of disclosure. Shattuck et al. (2012) found the rate of postsecondary education among those with ASD, particularly within the first two years after high school, was lower than for those with a speech/language impairment or learning disability, but higher than those with mental retardation (1046).

As students with ASD enter college campuses in higher numbers, the need for more comprehensive services grows. Students, by disclosing their diagnosis, can receive accommodations through their disability office; typical auxiliary services include extended time on exams, notetaking, taped text, and private testing space (US Equal

Employment Opportunity Commission). These accommodations, however, are not often the comprehensive support that these students need. Cai and Richdale's research (2016) noted that "of the twenty-two students attending higher education with ASD that were interviewed, most students (63.6%) felt their educations needs were satisfied, however their social needs were not met. Fifteen students lost interest in university activities or coursework; ten of these students mentioned wishing they had someone to motivate them" (34). Additionally, students who may have difficulty in academics or socialization in higher education often do not seek assistance, possibly because they are concerned with stigmas attached to their diagnosis. A participant in the Cai and Richdale (2016) focus group noted that he or she had no help and "didn't want to be treated differently, I didn't want to be treated like I had some kind of disease, which I think sometimes we are treated like, like we're lesser people" (35). This type of internalized ableist thinking is common among individuals with ASD. Research shows, however, that knowledge of a diagnosis may actually improve attitudes toward college students with ASD.

Matthews, Ly, and Goldberg (2014) conducted a study of 224 college students' perceptions of vignettes depicting ASD behaviors with either the label of "High Functioning Autism," "typical college student," or "no label." They found that students reported a more positive disposition toward hypothetical peers given the label of High Functioning Autism as compared to those having no label (96). It is possible that with more disclosure and campus community awareness, individuals with ASD will experience more inclusion. It is important for policy-makers and administrators to be aware of the positive attitudes of college students towards the inclusion of individuals with intellectual disabilities in order to encourage the expansion of inclusive programs in colleges and universities (Griffin et al. 2012).

With a more accepting and understanding higher education community, students may feel inclined to be open about their diagnosis, leading them to the supports, accommodations, and personnel that can help them succeed. Persistent concern of stigma and isolation due to a diagnosis means students will continue to enter campuses without disclosing, often becoming a number in a university retention rate. Research on retention notes that feelings of belongingness achieved through involvement in activities inside and outside the classroom are integral to learning, and ultimately to the students' success (Matthews, Ly, and Goldberg 2014). Marshall University, year after year, strives to create a community where students with autism belong, feel included, and have a network of allies. It is important for this dedication to students with ASD to spread throughout the higher education communities of the United States, and infiltrate the towns they call home.

Employment

Post high school and college employment for individuals with disabilities continues to be one of the most pressing concerns for adults with Autism Spectrum Disorder. It is clear that the majority of individuals with disabilities do not attain a satisfactory level of career development consistent with their capabilities (Brolin and Gysbers 1989). Developing students to their maximum ability is one of the foundations of education in order to prepare for employment, develop social skills, and function independently (Brolin and Gysbers 1989); however, addressing unemployment continues to be a struggle.

One of the most powerful ways community members can effectively create meaningful change is through providing employment opportunities for individuals with autism. By simply gaining basic knowledge of the diagnosis through training, community members are more likely to recognize that behaviors linked to ASD do not discredit the ability to do a job well. According to The Autism Society of America (2015), in 2014, only 19.3 percent of people with disabilities in the United States were participating in the labor force (working or seeking work). Of those, 12.9 percent were unemployed, leaving only 16.8 percent of the population with disabilities employed, compared to 69.3 percent of those without disabilities.

Shattuck et al. (2012) found that young adults with ASD, particularly within the first two years after high school, have a lower rate of employment relative to those diagnosed with speech/language impairment, learning disabilities, or mental retardation. Within the first two years, post high school graduation, less than 50 percent of individuals with ASD were employed or enrolled in postsecondary education.

Hansen (2015) researched the preparedness needs of students with ASD by surveying employers, parents, and college students. Notably, the biggest concerns reported by both employers and parents revolved around social communication issues, including the following: workplace etiquette and norms, reciprocal dialogue, networking skills, personal insight, and nonverbal communication (Hansen, 2015). College students, however, did not see social communication issues as a primary concern. Because theory of mind, which entails placing oneself in someone else's shoes, and social communication are two significant problems for individuals with ASD, these types of workplace issues must be expressly explained. We need better mutual understanding of employer and employee needs for successful integration.

Kaye, Jans, and Jones (2011) noted that a significant amount of prior research showed positive attitudes and success stories regarding the hiring and employment of those with disabilities since the enactment of the American with Disabilities Act. The unemployment rates of individuals with disabilities, however, starkly contrasts this rosy picture. Researchers, therefore, surveyed human resource professionals and managers regarding their opinions as to why other employers fail to hire or retain employees with disabilities, eliminating the dishonesty that may stem from discussing one's own workplace. Of the 468 questionnaires completed, the three primary barriers that arose included (1) ignorance in how to accommodate those with disabilities and the notion they will be a burden; (2) concern over the cost of accommodations (although studies have shown generally inexpensive accommodations); and (3) the threat of legal liability. Also highly noted was continued discrimination. The most highly-endorsed solution for these concerns was increased, high-caliber training for supervisors and managers on disability issues, including exposure to successful employees with disabilities (533-534).

Research conducted by Butterworth et al. (2012) looked at training and mentorship interventions in employment outcomes, noting that training is a key component for employers and employees in ensuring professionals have access to updated knowledge. Additionally, the mentorship component played a large role in successful outcomes due to individualized and tailored support (Butterworth et al. 2012).

Although a few large national chains and small local stores are considered "autism-friendly," the need for widespread employer training, understanding, and acceptance of individuals with ASD is great. "People with autism have unique talents and they can be some of your best employees . . . they don't need to be micromanaged or get special treatment. Simply give them a challenge and the support that they need" ("Work and Autism" 2013).

Socialization

Abnormal social approaches, difficulty with typical back-and-forth conversation, lack of proper social responses, and deficits in verbal and nonverbal communication are at the heart of Autism Spectrum Disorder (American Psychiatric Association, 2013, 27). Most individuals with ASD have a desire to engage in social activities, but social skill deficits make interactions a challenge, which can lead to feelings of loneliness and isolation (Koegel et al. 2013). The program, Playground Partners, developed by Touchstone Behavioral Health, works to improve the communication and socialization of children diagnosed with ASD, ages six to twelve, through playground interaction (Scott 2011). According to Scott (2011), program coordinators collect data prior to and after program implementation, and have seen success with increased interaction and gained friendships. The goal of Playground Partners is to familiarize typically developing children to children with ASD early so that they can increase their understanding of how ASD affects social behavior. This level of inclusion and peer modeling aims to reduce negative perceptions of the diagnosis through early disclosure and practical experiences. The resulting increased understanding of the condition helps to foster communication amongst all students, on and off the playground.

Although many are socially engaged and included in social opportunities in K-12, challenges occur when adults with ASD try to find belonging without structured support. Myers et al. (2015) point out that once individuals with ASD leave the school system, community connections are often lost; teachers, peers, and extracurricular activities that accompany education quickly disappear. Important social skills for adults, such as understanding disguised or nonverbal cues in conversations, are especially difficult to master in the absence of direct support or educational settings (Matthews et al. 2015). Because of this absence of professional support for adults with

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ASD, acceptance and inclusivity must come from non-professionals, citizens with the untapped potential and unknown skill sets who can create positive change.

With several previous studies focused on the outcomes of peer networks, Hochman et al. (2015) sought to find the effects of peer interventions on the social engagement of four high school students with ASD interacting at lunchtime with their non-ASD peers. While looking at baseline data, researchers noted the very limited interactions of individuals with ASD during lunchtime. Peers without disabilities may have shown reluctance to speak to those with ASD due to attitudes or stigma attached to the diagnosis, as well as lack of structured opportunities to interact. "The primary barrier to social interaction for students with ASD in this study may have been not social-related skill deficits but, rather, limited structured opportunities to connect with peers without disabilities" (Hochman et al. 2015, 113). Results of the peer networks showed substantial increases in peer interaction and social engagement for all four students, although researchers noted they could not distinguish which parts of the peer networks were responsible for these improvements. Additionally noteworthy, however, is that researchers found peer interaction and socialization were not generalizable to days when no networking was scheduled. This may have been due to non-ASD peers choosing to spend lunch with preferred friends, or not understanding the ability to meet outside of scheduled lunches. Non-ASD peers expressed that they considered their partners with ASD to be their friends at the end of the semester, but those without ASD must further initiate communication to continue development and foster consistent social interaction.

Research conducted by Asselt-Goverts et al. (2014) sought to find differences between the social networks of those with ASD, intellectual disabilities (ID), and the general population. Participants with ASD reported being less satisfied with their social networks as compared to the research reference group. Participants with ASD and ID reported fewer network members than the reference group; those with ASD expressed desire for the expansion of their social networks. For example, a thirty-five-year-old participant with ASD noted, "I long for many more contacts, but there is so much fear if someone actually comes closer that you clam up and it usually goes wrong again. . . . To say things wrong. Not to respond in time. Not to have an answer when it is expected from you" (Asselt-Goverts et al. 2014, 1198).

Research denotes that individuals with ASD rely on others to involve them in community and social opportunities, leaving them potentially poor results if no advocate is present (Myers et al. 2015). Hans Asperger expressed how, amongst his patients, it was often their special interests or skills that would lead to social opportunities (as cited in Howlin 2000, 64). Individuals with ASD often do not possess the skills to develop meaningful close friendships sporadically, but through family coordination of social activities (Myers et al. 2015), or via special interest groups which connect with pervasive interests (Howlin 2000). The Autism Society of America (2014) suggests that individuals with ASD may have luck in finding friendships through clubs revolving around the individual's special interest, because finding those with the same interests in the area can be limited.

A study conducted by Carter et al. (2013) explains that although techniques and communication skills must be expressively taught, we should also place responsibility upon community members who interact with those diagnosed with ASD. Interventions should focus on equipping others with the skills, opportunities, and confidence to interact socially with their coworker, classmate, teammate, or partner with ASD. When there is hesitation or uncertainty about how to interact with someone with ASD, providing basic information and guidance may increase their confidence and capacity to seek out and maintain interactions (Carter et al. 2013). "Absent intentional and coordinated efforts spanning school and community contexts, many adolescents with ASD will struggle to connect to individualized experiences that might enable them to flourish as adults" (Carter et al. 2013, 889). It is crucial to provide opportunities for individuals with ASD to socialize regularly. Community members have a responsibility to spread inclusivity, acknowledge and rebuke myths that perpetuate fearfulness, and provide a welcoming environment.

Independent Living

Individuals with Autism Spectrum Disorder face stigma, limited higher education support, minimal employment opportunities, and difficulty connecting socially—these challenges funnel into issues directly related to independent living skills, often made even more problematic with lack of executive functioning ability. Executive functioning can include things such as organizing, sustaining attention, prioritizing, and maintaining a schedule. "Both paid employment and postsecondary education were associated with better living skills and there was at least some indication that community skills may be related to living independently" (Gray et al. 2014). Because many individuals with autism do not earn college degrees, face unemployment, and lack the skill set to become actively involved to remedy these issues, they face burdening family members to care for them.

Krauss, Seltzer, and Jacobson (2005) collected data regarding the positive and negative effects of co-residence versus out-of-family living on individuals with ASD and their mothers. The families of 133 adults (twenty-two years or older) with ASD were sampled; in eighty-four of the families, the son or daughter lived outside of the family, with the remaining forty-nine individuals with ASD living at home.

For those whose son or daughter lived outside of the home, mothers noted significant positive benefits for the individuals with ASD (56.6%)—particularly reports of personal growth, new skills, and social benefits for their sons or daughters. Families reported fewer benefits for their sons or daughters (34.7%), aside from security, if he or she resided in the family home. Krauss et al. (2005) conveyed that mothers reported positive outcomes for their son or daughter living independently outside the home with ASD, while they told a much more complex story about themselves. Mothers who lived with their son or daughter reported more peace of mind and assurance that their child was cared for, but displayed high strain from the caregiving. In contrast, mothers who did not live with their children reported more free time and less exhaustion, but held deep worries for their child's future. As Field and Hoffman (1999) point out, individuals with ASD face many barriers to become self-determined, a key aspect of living independently. Parents of those with ASD, therefore, hold the extremely important role of providing the opportunities and support for the self-determination of their child. These family members and individuals with ASD need community support to foster this development.

Howlin et al. (2013) note the reliance on aging parents as the primary caregivers for adults with autism is particularly concerning, and efforts to enhance accommodation provision is required. Of the social outcomes presented by Howlin et al. (2013), surveying fifty-eight adults diagnosed with ASD, most participants were rated "poorly" concerning residential status, heavily reliant on others to support their daily lives. From a longitudinal study of eighty-nine participants with ASD from 1991 to 2009, the majority were either living with their parents or were in residential care. More than half (61%) of the individuals were living with their families, with only eight adults living independently (9%) (Gray et al. 2014).

Interestingly, Farley et al. (2009) reported a high rate of positive outcomes regarding independent living in their longitudinal study of adult outcomes with ASD. The sample for this study drew from a unique population, where 94 percent of participants were involved in the Church of Jesus Christ of Latter Day Saints, creating several advantages—a focus on family, along with several weekly, structured social opportunities and yearly mission trips (Farley et al. 2009). The successful independent living outcomes of those studied is likely attributed to the inclusive religious community in Utah. This research may point toward hope that as community members understand and embrace individuals with autism, adults with ASD will see their futures as promising, rather than scary.

The Importance of Training and Becoming an Ally

Allies Supporting Autism Spectrum Diversity aims to provide an understanding of ASD in order to press the importance of citizen involvement in assisting a misunderstood population. Many mental health professionals are looking to involve community members in helping individuals with mental illness through training opportunities. Additionally, social justice inequalities, like LGBTQ discrimination, are proactively combated through trainings on campuses. These initiatives are fruitful in developing awareness and providing citizens with a basic tool belt of knowledge that can provide the confidence and gumption to get involved.

Mental Health First Aid (MHFA) is a program offered across the nation, originally developed by an Australian couple, which seeks to train citizens to recognize symptoms of distress in order to provide immediate reassurance and helpful resources. As Baruchin (2015) notes, trainees range from social workers, to police officers, to doctors, and teachers. One Rhode Island police officer, post MHFA training, recalled a scene where a man with schizophrenia was upset and breaking things in a public area. Once on the scene, the officer remembered his training, reassuring the man that officers were there to ensure he received proper help, not to arrest him; he stated the training made a significant difference in resolving the situation (Baruchin 2015, 72). As the autism community grows, so should our community involvement. MHFA is a shining example of the type of positive change that can infiltrate our businesses, emergency services, schools, and overall public perception.

The inspiration for the Allies Supporting Autism Spectrum Diversity drew from the successful format of the LGBTQ Safe Zone Trainings. These trainings were created to develop and maintain supportive environments for LGBTQ (lesbian, gay, bisexual, transgender, and queer/questioning) individuals to express acceptance of diversity, equality, and inclusion (Gay Alliance 2016), primarily in school settings. Research regarding the effectiveness of these trainings exists, although it is limited. Byrd and Hays (2013) completed a study surveying school counselors and counselors in training. An overall analysis of the Safe Space training on LGBTQ competency noted a significant relationship between trainees and increased knowledge, awareness, and skills. Byrd and Hayes (2013) explained, through their research, that LGBTQ individuals would know effective training reduces homoprejudice and heterosexism, making schools safer for all students. Evans (2002) and Poynter and Lewis (2003) assessed the Safe Space Program at Iowa State University and Duke University. Respondents from both locations noted more awareness, increased comfort level, and overall improved campus environment for the LGBTQ community. Additionally, Scher (2008) reported favorable changes in knowledge and specific attitudes, and noted positive increases in perceived levels of understanding regarding LBGTQ individuals amongst doctoral students of psychology. Participants also expressed support for mandatory Safe Space training for incoming students (Scher 2008). Because of the positive response and results of trainings such as Safe Zone and MHFA, the Allies Supporting Autism Spectrum Diversity training emerged.

Allies Supporting Autism (Photo courtesy of the Marshall University Program for Students with Autism Spectrum Disorder)

The Allies Supporting Autism Spectrum Diversity training has a primary focus to serve and create awareness regarding individuals with Autism Spectrum Disorder—to enable campuses and communities to deepen their support by enhancing understanding of the disorder, discovering strategies known to be helpful, and creating welcoming spaces to foster development. Started in 2015, the ally initiative is already deeply rooted in Marshall University's campus in Huntington, West Virginia. Trainers identify individuals, campus departments, community programs, and local businesses who wish to provide support. The goal is to expand this training nationwide.

In this one-hour interactive training, trainees are provided with a basic understanding of ASD severity levels, common patterns of behavior, and deficits in verbal and nonverbal communication, which often coincide with the diagnosis. Difficulties with theory of mind, sensory overload, stimming, and processing speed are described, while practical tools and methods of support are provided.

Post-training, allies receive a sticker with the Allies Supporting Autism Spectrum Diversity emblem. This emblem is a message to individuals with ASD that those who display it are advocates, are supportive, and are trustworthy. They will know that they can come to these allies for assistance, advice, or just to talk to someone who is considerate of their diagnosis. Trained allies will promote understanding and acceptance of individuals with ASD in their professional and personal lives in order to spread the ally mentality. When applicable, allies should be open to providing employment opportunities for qualified individuals with ASD.

According to the Bureau of Labor Statistics (as cited in Butterworth et al. 2014) West Virginia had the lowest employment rate for individuals who have cognitive disabilities of working age (eighteen to sixty-four) at 16.5 percent. This leaves a significant number of adults with ASD relying on Supplemental Security Income (SSI) Benefits—many of whom do not wish to rely on federal money. In 2005, over sixty-eight thousand disabled West Virginians received SSI (Social Security Office of Policy), and the average check for an individual receiving SSI in 2016 in West Virginia was $733 per month. By incorporating training for our community members regarding how to best support and empower individuals with ASD, we can reduce the number of individuals forced to depend on SSI, weaving this population into the fabric of our community.

As the population of individuals with ASD increases, understanding community and social functioning of the individual is important. Schools, families, caregivers, professionals, and legislators must focus on the outcome that low involvement in community and social opportunities may have on the ASD population (Myers 2015). Societal responsibility must shift—growing numbers of individuals diagnosed with Autism Spectrum Disorder points to the need for more than awareness. We need involvement.

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