Autism Across the Lifespan: Embracing and Redefining Disability

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The Diagnostic and Statistical Manual of Mental Disorders (DSM-5) defines autism spectrum disorder as a neurodevelopmental disorder that “is characterized by persistent deficits in social communication and social interaction across multiple contexts, including deficits in social reciprocity, nonverbal communicative behaviors used for social interaction, and skills in developing, maintain, and understanding relationships” (American Psychiatric Association, 2013). This definition encompasses the meaning of autism, but only in a strictly scientific sense. For a full understanding of what autism is and the implications it carries, one must take the time to consider a variety of perspectives. The purposes of this multiple-component research study were 1) to investigate current scientific research findings, study advocacy organizations, and gather information about the personal experiences (of both individuals with autism and those who teach them); and 2) to integrate these perspectives to determine future directions for better supporting individuals with autism to flourish and lead rich, meaningful lives.

**Early Signs of Autism**

The first component was a live, online training that presented research on the 16 early signs of autism that are typically noticeable by 16 months of age, as well as video analysis of young toddlers (13-20 months of age) exhibiting these early signs. Since prior research has shown that the sooner young children with autism receive early intervention services the better, it is crucial that parents and physicians are aware of the early signs. The list of early indicators can be broken down into two parts. The first group of eight are related to the limited social domain and lack of typical communication, while the second group of eight are associated with the focused interaction with objects and repetitive, restricted actions that is reflective of autism (Baby Navigator and Autism Navigator LLC, 2019). The more characteristics a child is
displaying, the more urgent the need for evaluation for early intervention services that will provide them with the proper support.

**Parental Perspective on Autism**

To begin to understand a parent’s perspective on autism, a book study was conducted focusing on a nonfiction work entitled *Ten Things Every Child with Autism Wishes You Knew* by Ellen Notbohm, the mother of a son diagnosed with autism. Notbohm outlines attributes shared by many individuals with autism, ranging from the differences in how they understand language to the commonplace triggers for sensory difficulties. There were three overarching themes. The first theme that Notbohm presents is the idea that all humans have differing ranges of ability and disability, and that those with autism are no different. Rather than forcing those with autism to learn and engage with the world in a “normal” way, one should embrace their child’s different abilities and allow them to perform the way that they do best (Notbohm 2019). The second theme was that the goal of providing services to children with autism should be to prepare them for adulthood. She stresses that “the closer they [draw] to maturity, the more critical is [becomes] that they be able to shoulder a larger share of the decision-making, that they learn how to articulate their needs and identify the choices therein. The ability to do so, to be an effective self-advocate, [will] make or break their success as adults” (Notbohm 2019). The third theme was that helping to boost someone’s self-confidence is one of the most important things to do, and it starts with one’s own attitude (Notbohm 2019). In order for children (with or without autism) to believe in themselves, their parents, teachers, coaches, and any other influence in their lives must first believe in them and foster an environment that is supportive and encouraging.

**Scholarly Research Articles**
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A third component involved analysis of scholarly research articles focused on the lack of services for young adults with autism. The ten articles that were chosen following a literature search, overall, revealed consistent findings. First and foremost, the research affirms a need for autism-specific adult programs for all those across the autism spectrum, regardless of ability, ethnicity, or socioeconomic status. One study cited that “more adults reported an unmet need to speech/language therapy, one-to-one support, occupational therapy and social skills training” than any other age group (Turcotte et al., 2016). This has an impact on the health of these adults, as “. . .there is some evidence of that lack of appropriate support in adulthood can have a much greater impact on outcome and quality of life than factors such as the person’s IQ” (Howlin & Moss, 2012). The adult programs that are developed should partner with the parents and/or caretakers of those with autism to help lessen their stress and workload in trying to provide adequate services for their children (Anderson & Butt, 2018). These adult programs need to focus on continuing therapy started in childhood as well as preparing and assisting the individuals with ‘adulthood tasks’, such as socialization. A study of the PEERS social skills training for young adults with autism showed promising results: “an overall improvement in social skills. . .[including] increases in cooperative social behavior with peers and caregivers, social assertiveness. . .and self-control” (Gantman et al., 2012). However, these programs should also fit whatever level of functioning the adult possesses in order to effectively help them reach any and all goals, such as: attending college, living independently, and employment (Taylor & Seltzer, 2011). In other words, autism services should not be ‘one size fits all’; some young adults with autism will be able to live independently and hold a career position, while others may be better suited to a community living program.

Advocacy Group Perspective
The fourth research component focused on arguably the most important group of all: those with autism. Researching various autism advocacy groups revealed that adults with autism feel strongly about the services that should be provided for them. Autism Speaks, a resource for families of children with autism and people with autism, had two articles that share information on federal legislation and state legislation that recommend adult programming, but also highlights how funding is lacking (Autism Speaks, 2019). The Autistic Self Advocacy Network (ASAN), a network of individuals with autism that aims to acquire more support for those with autism, has a page devoted to their position statements that shared common themes: more financial support from the government, more training for those working with autistic individuals, and more resources in public places to support autistic individuals (ASAN, n.d.). These same themes are echoed in their policy brief on the transition to adulthood, which provides recommendations for implementation of a medical home model, expanded funding for transition services, and focused outreach on groups that are at more of a risk of not receiving services, such as racial minorities and those considered low-income (ASAN, 2013). The International Society for Autism Research (INSAR), a collaboration between researchers and individuals with autism, emphasizes that employers “matching the interests, skills, and strengths of an autistic person with a particular job” will improve job outcomes, and the need for businesses to adjust their workspaces for those with autism (INSAR, 2018). Overall, it is clear that the concerns raised by those with autism echo those of parents and the findings from research that a “service cliff” precedes adulthood for individuals with autism.

**Classroom Perspective**

The final component of this research project involved observing a Life Skills class for special needs students ages 14-21 at a local high school to analyze how students with special
needs are supported as they prepare to transition into life after public school. The day included a mix of both basic instructional learning (math, science, reading, etc.) and preparing the students for independent living (learning household maintenance skills such as cooking, cleaning, etc.). During a portion of the day, students go out into the community and complete jobs at different facilities, such as organizing books at a library. One important takeaway from the observation is that the class encouraged students to be confident in their abilities despite their struggles and the stigma of learning disabilities and special needs. The teachers and aides continually gave positive reinforcement to the students, and the students also encouraged one another if they saw signs of struggle with a particular task. Another takeaway is the social connection that this class facilitates between students will help them practice their social skills in a “safe place” before applying their skills to the overall social world. This could particularly be helpful for students with autism, who may struggle more with socializing with their peers. Overall, the observation of the Life Skills class reinforced many of the other perspectives gathered in this study: students who may be classified as having a disability are no less capable of success; they just need to be given the right supports and the opportunity to apply their skills.

Conclusion

It is clear from the research from all perspectives that despite any difficulties that an individual with autism may experience, they do have the ability to lead fulfilling lives. Through proper supports such as early intervention services, school-based services, and adequate adult programs, they will be able to flourish in environments that encourage them to set goals and overcome struggles. Much like any other individual, when given the opportunity to lead a meaningful life, those with autism can accomplish just that.
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References


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