

Autism spectrum disorders in adolescence and early adulthood: Characteristics and issues

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Abstract. Much has been written about the diagnostic characteristics that distinguish autism spectrum disorders (ASD) from other disorders of childhood for toddlers and elementary school age children. There is a paucity of description of the characteristics and needs of youth and young adults with ASD. This paper presents a description of the characteristics of ASD in adolescence and young adulthood and presents three case studies to illuminate the issues confronting individuals with ASD, their families and support providers.

Jason McElwain shot his way into history at Greece-Athena High School one cold February day in 2006 by scoring six three-point shots and one two-point shot in the waning minutes of the last basketball game of his senior year [15]. What made his 20-point feat particularly stunning was that Jason was the team's manager, not a regular roster player. His coach put him on the roster and let him play at the end of the game as a thank you for his service to the team. While his shooting prowess was notable, Jason made the national news and met the President of the United States because he has autism. The juxtaposition of his accomplishment in the face of his disability made his story newsworthy.

In fact, some saw his interview on CNN or saw pictures of him meeting LeBron James and other celebrities and thought that perhaps Jason was misdiagnosed, or that Jason was unique among individuals with autism. Jason did not appear to flap, he seemed to make occasional eye contact, and he was able to answer questions from the reporter who interviewed him [3]. In short, Jason did not display those classic behaviors

that have become emblematic of a young child with autism. Yet those who understand autism in adolescence and adulthood saw the signs. While Jason answered the reporter's questions, his vocal 'prosody' was different. When he described the game, he was not as enthusiastic as another senior might have been. He seemed more polite, maybe even pedantic, for a young man his age.

Today, Jason works 14 hours a week at a local grocery store stocking the bakery shelves with bread and lives at home with his parents. He does not receive benefits at his job and may not be working to his full potential. He is also a volunteer coach for the junior varsity basketball team at his alma mater [15]. The promise that he showed in those final minutes of that basketball game seem lost in the underemployment he is experiencing now. In order to help Jason and others like him achieve their full potential in adulthood, we must understand the characteristics of autism spectrum disorders (ASD) and the issues in providing rehabilitation services to adolescents and young adults with ASD that lead to improvement in employment and community living outcomes.

Jason represents the beginning of a wave of students with ASD working their way through school. During his time in school, the recorded prevalence of ASD's has

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increased significantly. The most recent figure places the prevalence of ASD in school aged children at 1% of all children [4]. Early intervention providers and elementary school teachers have been most affected by the increased prevalence [12]. Thus, most of the research data describes characteristics and interventions for very young and elementary aged children [7]. Despite this fact, ASD is a collection of lifelong disabilities that continues to impact affected individuals in all areas of living, yet there has been a paucity of literature describing these disorders in late adolescence and adulthood [9]. The purpose of this article is to describe how the symptoms of autism, Aspergers disorder, and Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS) change in late adolescence and early adulthood and to present three case studies illuminating those characteristics. Finally, the authors will discuss the impact of the disorder on transition aged youth and young adults and identify issues for future research.

1. The characteristics of autism in adolescence and early adulthood

Autism Spectrum Disorders is the diagnostic category that includes autism, Aspergers disorder, and PDD-NOS (APA, 2001). These three represent a spectrum from autism where most individuals are affected by many more communication challenges and are more likely to have an intellectual disability to Aspergers disorder where individuals acquire language in toddlerhood, and tend to have higher measured IQ's. PDD-NOS represents those individuals on either end of the spectrum who display many but not all required behavioral symptoms of either Aspergers disorder or autism. Table 1 presents a comparison of the three disorders across symptom patterns.

These three disorders have behavioral characteristics in three areas; communication deficits, social skill deficits, and restricted, repetitive, and stereotyped patterns of activities, interests, behavior [9]. In addition to these primary characteristics, many individuals with ASD experience secondary characteristics including displaying sensory sensitivities, behavior challenges, and additional mental health diagnoses such as anxiety disorders and depression [2, 9, 16].

The primary characteristics of autism are most salient in young children [12]. That is, those characteristics most associated with autism including difficulty acquiring language, unusual motor movements, and avoidance of interacting with others, are most prob-

lematic between the ages of 3 to 6. With education these characteristics are mutable and the individual's communication and social skills improve, while their stereotypic patterns of responding subside [13]. Therefore, by adolescence and early adulthood, the symptoms that lead to diagnosis usually have changed [14]. Nevertheless, there are usually enough symptoms present to validate the diagnosis of ASD in adolescence and early adulthood [5, 6].

Gilchrist et al. found that, by adolescence, individuals with Asperger syndrome show similar behavioral characteristics to individuals with high functioning autism in adolescence [5]. They found that delays in language development for individuals with high functioning autism were ameliorated by adolescence; leading to the finding that individuals with Asperger disorder were similar to individuals with High Functioning Autism. Seltzer et al. suggest that, while there is an abatement of symptoms, the developmental trajectory for individuals with ASD is splintered with improvement in some behaviors that define autism. They also noted that some individuals with ASD experience periods of regression in the areas of behavioral challenges and insistence of sameness. Finally, they note that some individuals experience a worsening of symptoms [13]. Thus, the developmental trajectory for individuals with ASD through adolescence is neither uniform nor linearly ascending. They report findings indicating improvement in communication, but continued impairment, particularly in social communication, persists into adulthood. Seltzer et al. also note that, as they age, individuals with ASD adjust to change and decrease the presence of stereotyped behavior, but impairments in social interaction remain into adolescence and adulthood [13].

On the point of social interaction, McGovern and Sigman note that individuals with ASD who were more socially engaged with their peers without disabilities gained more adaptive skills than their peers with ASD who were not socially engaged with non-disabled peers. They conclude that "engagement with peers improves the social skills of children with autism as is true for typically developing children" ([5], p. 407.) Further, they note that as children with ASD enter adolescence, they show increased social interest.

Thus, the literature indicates that through adolescence and early adulthood, most individuals with ASD continue to display the behavioral characteristics of ASD. Additionally, many individuals with ASD show improvement in communication and decreases in challenges related to stereotyped movements and patterns

Table 1
A comparison of characteristics between autism, Aspergers disorder and pervasive developmental disorder-not otherwise specified (PDD-NOS)

Characteristic	Presentation in Autism	Presentation in Aspergers disorder	Presentation in PDD-NOS
Cognitive and intellectual ability	More individuals display intellectual disabilities. Cognitive abilities range from gifted to severely impaired	More individuals display average to above average abilities. Cognitive abilities range from gifted to mildly impaired	Individuals with PDD-NOS display abilities across the entire range of intellectual ability
Social interaction	Social skill deficits in all areas of interaction. Social skill errors and misunderstandings can present as problem behavior	Social skill deficits in all areas of interaction. Social skill errors and misunderstandings can present as problem behavior or social language difficulties	Individuals display social skill deficits, but may not meet full criteria in this category for either autism or Aspergers disorder
Communication	More individuals display late acquisition of language and lifelong language delays and disorders including increased use of idiosyncratic and echolalic language. Most individuals have significant challenges displaying and understanding non-verbal communication	Most individuals acquire language on time, but display significant challenges with the social use of language (also called pragmatics). Many display difficulties with reciprocity in communication and understanding and using non-verbal communication	Individuals display communication deficits, but may not meet full criteria in this category for either autism or Aspergers disorder
Patterns of behavior	More individuals display unusual motor movements and stereotypies such as flapping hands, rocking, jumping, etc. Many individuals resist changes in routine and engage in non-functional rituals	Many individuals converse about intense interests to the exclusion of reciprocal interaction with others. Some individuals display motor stereotypies, but to a lesser degree than those with autism. Many individuals resist changes in routine and engage in non-functional rituals	Individuals may display restricted and stereotyped patterns of behavior, but may not meet full criteria in this category for either autism or Aspergers disorder
Secondary characteristics	Many individuals display challenging behavior including aggression, self injurious behavior, darting or wandering away, and over activity. Some individuals with higher intellectual abilities may also experience anxiety disorders and depression. Many individuals also display varying patterns of hyper and hypo responsiveness to sensory stimulation	Many individuals display challenging behavior including aggression, self injurious behavior, darting or wandering away, and over activity. Many individuals may also experience anxiety disorders and depression. Many individuals also display varying patterns of hyper and hypo responsiveness to sensory stimulation	Some individuals display challenging behavior including aggression, self injurious behavior, darting or wandering away, and over activity. Some individuals with higher intellectual abilities may also experience anxiety disorders and depression. Many individuals also display varying patterns of hyper and hypo responsiveness to sensory stimulation

of behavior. Finally, while many individuals with ASD continue to struggle with social interaction, those who have had engagement with peers without disabilities show more improvement in social skills. Table 2 shows a listing of symptom patterns and how they change through adolescence into early adulthood.

Despite these general findings, individuals may respond differently. There are some individuals who demonstrate noteworthy improvement to the point where they no longer display the symptoms of the disorder. Likewise there are some individuals who continue to display significant debilitation by the disorder. Nevertheless, the majority of individuals on the autism spectrum display a varied pattern of improvement into adolescence and early adulthood. The next section of

this article will present three case studies to further illuminate the disorder in adolescence and early adulthood.

2. Three case studies of adolescents and young adults with ASD

2.1. *Mary Ann*

Mary Ann is 20 years old. She had a diagnosis of PDD-NOS. While she met all of her motor milestones on time, she did not speak her first word until she was 5 years old. She did not compensate for her lack of spoken language with gestures or facial expressions. Her parents described her as “in a world of her own”. Once

Table 2
Changes in behavior and characteristics in ASD in adolescence and early adulthood

Characteristic area	Behavioral characteristic	Type of change
Impairment in social interaction	Engaging in reciprocal social interactions	There is little documented change in this area
	Non-verbal social communication such as eye contact, gestures, and body position	Individuals who have higher engagement with peers without disabilities show improvement in these behaviors. Others show less improvement in this areas
	Sharing interests and being attentive to others Develops same age peer relationships	There is little documented change in this area There is little documented change in this area
Impairment in communication	Developing language and or, when words are not present, compensating with gestures or other non-verbal communication methods	Individuals with autism show some progress by adolescence with many individuals acquiring words or another alternative form of communication
	Engaging in age appropriate spontaneous make believe or imitative play	There is little research in this area
	Using echolalia to communicate or using idiosyncratic speech	Individuals with autism show some progress by adolescence
	Ability to engage in social communication and sustain conversations with others	Individuals who have higher engagement with peers without disabilities show improvement in these behaviors. Others show less improvement in this areas
Repetitive and/or stereotyped patterns of behavior, activities and interests	Playing with and attending to parts of objects rather than the whole object e.g.: repeatedly spinning the wheels on a car	There is evidence that this subsides as the person develops into adolescence
	Stereotyped motor movements like rocking, flapping hands, twisting fingers	There is evidence that this subsides as the person develops into adolescence
	Insistence on following non-functional routines and rituals	There is evidence that this subsides as the person develops into adolescence
	Displaying an all encompassing, intense interest in one or more topics	There is evidence that this subsides as the person develops into adolescence
Secondary symptoms associated with ASD	The Presence of Aggression, Self Injurious Behavior, Darting or wandering away, and/or Excessive over activity	After an initial increase in early adolescence, and with intensive positive behavior supports, these behaviors subside
	The presence of anxiety disorders and/or depression	There is evidence that these increase in adolescence
	The presence of sensory hyper and/or hypo responsiveness	There is little research in this area

she began to talk, though, she also became more interested in interaction with others, although her attempts to play were uncoordinated and awkward. She is currently performing slightly below grade level in school. Her greatest challenge in academic work is comprehension of written material. On her individualized education program (IEP), she is receiving services under the category "other health impaired".

As a young adult, Mary Ann is unique in her classroom. She is the only girl out of 6 students in a senior year transition program for youth with ASD modeled after Project Search at Cincinnati Children's Hospital in Ohio [8]. Upon first meeting, Mary Ann seems overly polite and engaging. After a few moments, however, a few issues stand out. First, Mary Ann sounds different when she speaks. Her vocal prosody is at times pedantic and monotone, and other times sing song in nature. When she laughs, her laugh is very giggly and louder than expected. While she makes eye contact, her eye contact is fleeting and uncoordinated with her conversation. She frequently looks through rather than at persons

with whom she speaks. Finally, she is dependent on her conversation partner to maintain conversations. She responds to questions but does not initiate topics or ask questions that would extend a conversation. Thus, she displays communication differences that indicate the possible presence of an ASD, but they are not currently excessive or severe.

Her social skills are a little different as well. Her parents report that she has only one friend that is her age. Most of her friends are either younger or older than she is. She has difficulty relating to friends her own age. Otherwise, she is able to share enjoyment with others appropriate to her age. Because of her social differences, she displays behaviors that are further evidence of a possible ASD. In the final category of symptoms for autism, Mary Ann displays few restricted or stereotypic behaviors. While she does not like change, she is able to adjust to changes in her routines with relative ease. She does not engage in any motor stereotypies. She also does not display any excessive interests that frequently characterize Aspergers disorder. In short, she displays

symptoms consistent with an ASD in the areas of communication and social skill deficits but not in the area of stereotypic and repetitive patterns of behavior, interests, or activities. Thus, the best diagnostic match is PDD-NOS. Regardless of the specific diagnostic category, it is perhaps more important to discuss Mary Ann's future goals and how to improve the likelihood that she will achieve those goals.

When Mary Ann graduates, she wants a job. She has not defined her particular career interest, but is clear that she doesn't want to go to college. While attending high school, she took classes at the technical center in printing and print shop. She had difficulty learning all of the computer programs and struggled with the social aspects of the job. In short, she has limited knowledge of her strengths and skills, and an even more limited knowledge of work and adulthood. Her parents worry about her future and are anxious to find services and supports that will help her become successfully employed.

While Mary Ann is not quite ready for her transition out of school and into work, the clock is ticking and time is running out. Thus, her participation in the specially designed "Project SEARCH" modeled classroom seems particularly important. In this classroom, she will rotate through three internships that, together, will result in her having marketable skills toward a job in patient care, materials management, or specialized room and cart stocking. The program is located in the hospital and will result in repeated 'trials' where she will practice employment skills and social behaviors as well as experience working. She will develop a portfolio where she will list her skills, strengths and further identify desired future careers. She will interact regularly with job coaches and adult services case managers. Finally, she will network with potential employers through her internships at the hospital. These types of experiences will increase the chances that Mary Ann will achieve her graduation goal.

Mary Ann's case raises a number of questions. She has not developed an understanding of career development and therefore will struggle with making good decisions regarding her job and career paths. Thus she will likely have difficulty displaying the behavioral components of self determination. She is typical of many individuals with ASD. While she does not display many of the most debilitating challenges associated with the disorders, she also does not initiate requests or see herself as an actor in her own life. Thus, the question raised by Mary Ann's case is what instruction and interventions would result in increasing her career

awareness and self determination? These interventions would likely be implemented across her entire school career and would change the priorities from becoming compliant to becoming self determined [9].

2.2. *Patrick*

Patrick was diagnosed with autism at the age of four. He developed some language by 18 months, but lost most of his words by two years old. He was severely withdrawn and avoided interaction with peers and adults alike. He displayed temper tantrums whenever his routine was changed unexpectedly or when he was rushed through a favored task. He lined all of his toys up in his bedroom and never played with them. He spent most of his childhood leisure time pacing and flapping his hands. Thus, he displayed all of the classic signs of autism before he turned three. Although his diagnosis at the age of four was delayed by today's standards, at the time his diagnosis in the early 1990's was as early as most.

Patrick has made progress in communication and behavior since that time. Specifically, Patrick uses words to communicate, although he continues to display communication deficits. He can make requests and respond to direct questions. He has difficulty engaging in conversations and frequently uses phrases in a rote fashion. For example, he asks to use the restroom in the same way, even when he is not required to ask. He also uses echolalic phrases to express his emotions. Sometimes it is difficult for the unfamiliar person to understand those phrases. For example, when he repeatedly says "Your Fired!" that generally means that he is frustrated or unhappy with a person or situation. That phrase usually precedes darting.

He will occasionally dart when his schedule changes, when he is rushed to stop a desired task, or when he encounters an unexpected problem. There were two episodes of this behavior across four months. Nevertheless, his team is working on developing a positive behavior support plan to teach him how to accept changes in his routine and to teach him a "calm down" strategy when he becomes frustrated or upset.

Patrick prefers solitary activities such as playing computer games, looking at preferred books about NASCAR racing, or playing on his Nintendo DS. Additionally, Patrick still struggles with minor changes in his schedule or routine. For example, he became upset when he missed completing a page in his work book because he was absent from school.

Despite these challenges and deficits, Patrick has many strengths. He is an excellent typist and is able to transcribe notes and text with a high degree of accuracy. His reading ability is measured at the 4th grade level, while his comprehension of written material is somewhat lower. He is also able to complete basic mathematical operations and is skilled at using a calculator and an adding machine.

Patrick is also in Mary Ann's classroom at the local hospital. His internship rotations have been in materials management and nutrition. In materials management, he counted inventory in floor supply closets and uploaded that data to a central computer system. He was skilled at the rote aspects of the job, but struggled with activities that required decision making. At this particular internship, there were tags that required rote counting and tags that required a decision based on an estimation of the number of items used in a day. Patrick was fast and accurate when inputting rote counts into the computer system, but was not skilled at completing the estimations required in each closet.

To address this aspect of the task the team worked to make this decision algorithmic. They took pictures of the bins at full, three quarters full, half full, one quarter full and empty. Then they affixed each picture to a page in a 'picture dictionary'. Next to each picture of the bin, they put the number that Patrick should enter on the inventory counter he used. For example, if, when a bin was empty Patrick should input the number 500 to order 500 units of the supply in the bin, then the dictionary would have a picture of an empty bin next to an equal sign "=" and the number 500 next to it. That way, instead of making decisions, Patrick just had to match the bin to the picture in his dictionary and input the number listed. Patrick performed best with visual supports like this including a visual schedule and written instructions. His team anticipates using more visual supports in all aspects of Patrick's internships.

Patrick's case review also raises questions related to supporting individuals with ASD in transition and at work. Specifically, there are few studies that describe positive behavior supports in work place settings [10]. What are the types of interventions that are most effective in the context of work? What types of supports are necessary to implement these interventions? Does implementation of positive behavior supports in the work place change because of the unique nature of the environment? How does a person like Patrick access those supports when there are few funding options for behavioral services for adults? Access to positive behavior support is critical to the successful employ-

ment of individuals like Patrick who display many work strengths, but also have intensive support needs. There is a critical need for research in this area to assure the successful transition of youth and young adults with ASD.

2.3. Jackson

Jackson is 19 years old. Throughout his life, he has had numerous medical complications that resulted in him receiving an IEP to address his learning needs related to these complications. For example, he has a heart defect and scoliosis that resulted in multiple surgeries. In addition to a hearing loss, he also had learning, behavioral, and social skill problems that were attributed to anoxia due to heart complications in infancy. Over time though, it became clear that the medical complications and subsequent learning problems did not explain all of Jackson's needs. In fact, at the age of 17, Jackson's mother requested a re-evaluation due to on-going social and behavioral challenges. That re-evaluation resulted in a diagnosis of Aspergers Disorder. This diagnosis seemed to provide closer match and helped account for the behavioral and social difficulties that Jackson displays. Jackson's story is common among individuals his age with Aspergers disorder. That he received this diagnosis in adolescence is not unusual. After all, the disorder was not well understood in his youth and teams failed to consider other explanations for his learning problems. It was only when his mother requested further evaluation that this diagnosis was considered. This is an issue of which transition and adult services should be aware. That is some individuals with Aspergers disorder were not diagnosed as youngsters because their early diagnostic evaluations predated full understanding of the disorder [11]. Thus, transition and adult services teams should be alert to the possibility of under diagnosis or misdiagnosis of Asperger disorder in youth who's learning, social, and behavioral characteristics seem to match this profile.

Like Mary Ann, Jackson does not know what he wants to do upon graduation from high school. While he performs adequately in school, he does not want to go to college. He would like to work, but does not have a clear idea of a career that he likes or a job that would match his skills and strengths. He has a penchant for data entry and but has never tried work in a data entry position. Unlike Mary Ann and Patrick, Jackson has worked menial jobs in fast food, and a large retail store. These experiences did not result in advanced insight into his future career.

While working at these jobs, Jackson also appeared vulnerable to inappropriate suggestions from co-workers and acquaintances who attempted to take advantage of his position to acquire free food and goods. In all of his jobs, he had to be taught to say no to peers who sought to take advantage of him. Other social behaviors included misunderstanding verbal directions and failing to ask for help or clarification. His mother reports, "he doesn't seem to know what he doesn't know!" Finally, Jackson can sometimes exasperate his supervisors. While he doesn't argue often, if he perceives he is right and his supervisor is incorrect, he will insist that the supervisor correct himself, even on small points of disagreement.

Jackson also attends school in the hospital based transition program. He is currently in his second internship rotation. His first internship capitalized on his visual organization skills and his data entry abilities. He was assigned to a cardiac care unit where he stocked carts, entered patient and inventory data into an electronic record, and organized patient charts at the nurses' station. His success in this environment was likely due to the nature of the job. That is, he was able to capitalize on his strengths and avoid public interaction where peers might take advantage of him. The next step in his career development is to have Jackson evaluate his performance and identify why he was successful in this environment. This would be the beginning of is developing a portfolio of his skills.

Like Mary Ann and Patrick, Jackson presents unique challenges for his transition team. He also requires intensive supports. He especially requires in depth social skill instruction. His vulnerability is of particular concern. Because he is vulnerable to suggestion and may not be able to discriminate between friends and acquaintances who would do him harm, he requires instruction combined with monitoring. Thus, his support needs are different, but equally intensive. Again, the issues for Jackson require further research to assist the service community in understanding the types of supports that result in successful independent or supported employment and independent living.

3. Conclusion

The purpose of this article was to explore the characteristics of ASD in adolescence and early adulthood and to present three cases to illuminate the spectrum. All three case studies pose important issues related to

transition to adulthood and employment. Specifically, all three individuals require higher intensity services than are typically offered to transition aged youth. Also, they require intensive services and instruction in communication and social skills. Research in the area of transition services is becoming critical. As the first wave approaches graduation, there are at least four times as many students identified with ASD who are in elementary and middle school. In order to change the outcomes for this group of individuals, we have to develop scientifically-based practices now.

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