

Doctoral Student Research Briefs

School of Education
Drexel University

Research Brief no. 12

**A Qualitative Case Study: Exploring Parents' Support Needs When An Adolescent With
Autism Spectrum Disorder Is Preparing To Transition To Adult Services**

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Volume 2 Number 12 March 2, 2018

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Abstract

Autism spectrum disorder (ASD) is a pervasive disorder that impacts an individual's ability to interact appropriately with others. Individuals with an ASD diagnosis struggle with communication impairments and restricted behaviors that cause them to be isolated from others. Individuals with more severe diagnosis of ASD are reliant on others for daily care throughout their lifetimes. Parents of individuals with the more severe ASD diagnosis assume the responsibilities of managing this life-long disorder.

This study will seek to understand parents' support needs when an adolescent with a more severe ASD diagnosis is preparing to transition to adult services. While juggling the daily responsibilities of running a household and managing social skill deficits and challenging behaviors, parents are also working as advocates for their child. Therefore, parents of adolescents with an ASD, when compared to parents of non-disabled peers, experience a need for greater support from special education teams as their child moves from a traditional high school program into adult services.

Problem

Currently, there is no system in place to assist parents of adolescents with a more severe diagnosis of ASD during the transitional phase from a high school certificate program to working with an adult services agency that will provide supported employment and independent living skills training (McDonough & Revell, 2010). Prior to high school completion, parents need to be connected with knowledgeable high school special education teams to avoid situations where individuals with a more severe ASD diagnosis may "fall through the cracks" (Taylor & Seltzer, 2011, p. 572). High school special education teams are best positioned to provide families and future related service providers with information about routines and strategies that benefit the individuals with ASD.

Purpose

This qualitative case study is being conducted to explore parents' support needs when an adolescent with a more severe ASD diagnosis is preparing to transition to adult services that provide supported employment and skill training programs.

Significance of the Problem

This research seeks to describe the complex difficulties that face adolescents with ASD and their parents during the transition from traditional secondary school to adult services agencies. As Carter (2014) noted,

On the brink of adulthood, most youth aspire to pursue a range of personally important

experiences, relationships, and outcomes in the years after high school. Although youth with more severe intellectual and developmental disabilities share many, if not all, of these aspirations for their futures, having a significant disability continues to be a powerful predictor of the degree to which desired outcomes will materialize in early adulthood. (p. 245)

Adolescents with ASD are experiencing the same hormonal and mood changes as typically functioning adolescents with the added complexity of social skill deficits and restricted behaviors. These complex forces can directly impact these adolescents' ability to maintain appropriate social behaviors and function independently in workplace and community settings. Therefore, the responsibility falls to the parent to ensure that the individual with ASD can maintain a high quality of life.

In addition to managing the stresses that are associated with adolescence, parents of individuals with more severe ASD to play the role as an advocate into adulthood as well. This researcher used the literature review to examine prior research findings on the challenges that are associated with being an advocate for a person with ASD, and to understand how IEP teams need to work together to create meaningful transition plans. The problems that exist in the post-secondary transitional phase have been identified as needing significant attention from policy makers and local communities to ensure that quality services are provided for adolescents with ASD and their parents. In the meantime, parents and educators need to continue to work together to alleviate the stresses that are prevalent for adolescents with ASD and their families.

Conclusion/Discussion

Parents of adolescents with ASD have many support needs as their children with a more severe ASD diagnosis transition from high school certificate of completion programs to an adult service agency. If the gap is not bridged between secondary certificate of completion programs and acceptance into an adult services agency, this population of parents are likely to experience stresses that may be toxic to themselves and their families. In today's modern society, educators need to be working more closely with these parents and adult service agency providers to support the responsibilities and alleviate the concerns of parents of adolescents with more severe ASD diagnoses.

Research Implications

Research findings from this study will allow high school special education teams to have a better understanding of the problems that exist for students with a more severe ASD diagnosis, and their families, leading up to high school graduation from a certificate program. With this knowledge, high school special education teams can create more meaningful transition plans that will allow individuals with more severe ASD to reach their greatest potential.

Future research will be needed to explore the transition process for adolescents with more severe ASD diagnoses. Specifically, researchers should investigate the most influential factors (ex. community-based learning, related service therapies, parental support, job coach, etc.) that allow individuals to achieve their greatest sense of independence. These factors need to be better understood by policy makers, high school administrators, curriculum specialists, and special education teachers to create more comprehensive transition planning for students with more severe ASD diagnoses. Additional research is needed to identify therapies and community services

that would better support parents and families of students with more severe ASD diagnoses during this transitional time leading up to high school graduation.

References

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Author Biography

Rebecca has been a Special Education Teacher at Kennedy Krieger High School (KHHS) in Baltimore, MD for the past four years. She works primarily with students with more severe diagnoses of autism spectrum disorder (ASD) and intellectual disabilities. For the past two years, she has been the chairperson of the PBIS (Positive Behavioral Intervention and Supports) committee. This committee works to implement and support a school-wide positive behavioral system that meets the needs of a diverse population of students. Prior to working at KHHS, Ms. March worked with at-risk students at the Upper Merion Vantage Academy located in Bridgeport, PA.

In addition to teaching special education, Rebecca is currently pursuing her doctorate in educational leadership from Drexel University. Her dissertation will explore parental anxieties as adolescents with more severe diagnoses of ASD transition from a traditional public school settings to placements with adult service agencies. Through her work at Kennedy Krieger, Ms. March has repeatedly seen the difficulties that adolescents with more severe ASD diagnoses and their parents experience during this transitional phase leading up to graduation. Once Rebecca finishes her doctorate, she hopes to work with future special education teachers at the undergraduate and graduate levels.