

Review Article

Educational Success of African Americans with Autism: An Exploratory Study

Tremaine Riley¹, Shanika L. Wilson^{1*}, and Christopher Solomon¹

¹Department of Social Work, North Carolina Central University, USA

***Corresponding author:** Shanika L. Wilson, DSW, LCAS, LCSW, Assistant Professor, Department of Social Work, North Carolina Central University, 1801 Fayetteville St., Durham, NC 27707, USA, Tel: 919-423-7952; Fax: 919-530-7924; E-mail: swils108@ncu.edu

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Abstract

The proposed study explores the educational success of African Americans with Autism. Research and interventions are immense in the early stages of diagnosis of Autism however, not emphasis not is placed on programs for post-secondary educational success. Currently there are hundreds of thousands of people in America with Autism who could benefit from transition interventions and services that would enhance chances of educational success in post-secondary educational settings.

Keywords: autism, african americans

Introduction

The proposed study will examine the effects of early diagnosis on the educational success of African Americans with Autism. Autism is a developmental disability which can affect children and adults [1]. Autism, has become a well-known developmental disorder as it affects 1 out of 68 families in America [2]. A Century ago those with Autism were “slow”, mentally retarded or incapable of being independent and successful. Today individuals with Autism live full and successful lives. Though the cause of Autism remains a mystery, it has been proven that early diagnosis can make a tremendous difference in the overall success of an individual with Autism.

A great emphasis has been placed on the significance of early diagnoses and interventions however, limited research show effects of those interventions on the long term educational success of individuals with Autism. This study will analyze and bring awareness to collegiate support programs created for college students with Autism. This study will also view how successful these programs are in assisting students with Autism in transitioning from secondary to post-secondary educational institutions.

This findings from this study could allow secondary education programs to reevaluate curriculum and expectations for students with Autism. Currently many students with disabilities are not required to obtain a diploma to graduate from high school but a certification of completion [3]. This may prevent individuals with Autism symptoms from being eligible for admission into post-secondary institutions. This study can assist post-secondary organizations in understanding the need for specific interventions so college students with Autism symptoms can be successful.

Included in this proposal one will find a literature review examining studies that found a correlation to disparities of early diagnosis of Autism and the effects on the educational success of African Americans. The theoretical framework in this proposal provides an analysis of the systems theory. The proposed study will attempt to fill the gap on the secondary and post-secondary levels of education with the need for sufficient interventions allowing success in higher educational environments for individual with Autism. Included in this proposal, the methodology of the proposed study examines the design, data collection and tools needed to replicate the study.

Literature Review

Roughly 750,913 individuals under the age of 20 in the United States have a form of Autism [2]. Autism Spectrum Disorder Diagnosis has grown tremendously within the last twenty years [2]. The age that individuals are diagnosed with Autism is crucial in their development. This literature review will focus on the disparities of early diagnosis effects on African Americans with Autism and how these disparities affect their educational success. This literature review contains a summary of the history of Autism. It also reviews the parameters of the term early diagnosis with special attention to the disparities among African Americans. Interventions towards the overall educational success of those diagnosed with Autism is presented throughout this literature review as well. A theoretical framework concludes this literature review to support the need for further studies for transition interventions and services that would enhance chances of educational success in post-secondary educational settings.

Definition of autism

The word Autistic is a Greek based word with the root meaning auto or self [1]. Autism is a developmental disability which can affect children and adults [1]. In 1943 Leo Kranner highlighted key factors and the conditions of early infantile autism [1]. According to Kranner, characteristics include: lack of desire to communicate verbally, echolalia, fear of unexpected situations, lack of imaginative play skills, and demonstration of repetitive behaviors [1].

Autism, as defined in the Diagnostic and Statistical Manual of Mental Disorders 5th Edition [4] contains three levels of severity, which are composed of different symptoms. Criteria for an Autism Diagnosis are based on “social functioning and communication impairments with restrictive, repetitive patterns of behavior” [4]. Persistent deficits in social communication and interactions occur within several different contexts. The deficits could include social-emotional difficulties and social exchanges, the lack of age appropriate speech abilities. Lack of interest in social exchanges and the inability to respond to or initiate social interactions present issues in social communication. Among several communication difficulties, individuals diagnosed with Autism have deficits in interpreting nonverbal communication in social settings [4]. The understanding and performance of body language such as eye contact, gestures, and facial expressions, depending on the level of severity, is a major deficit. For example, eye contact is a sign of respect in some cultures however, some individuals with Autism have difficulty with eye contact [1].

Along with social communication difficulties, restrictive and repetitive patterns of behavior also affect functionality. Repetitive behaviors include the obsessive use of objects and speech like lining up toys and echolalia, which refers to repeating words and phrases out of context. Insisting on the same routines and inability to be flexible with transitions and change are also noted as difficulties [4]. Rituals include but are not limited to social greetings, food choices and rigid thinking patterns. Sensory sensitivity to temperatures, sounds, textures, smells, tactile stimulation and visual fixations with lights and moving objects affect functionality as well.

Levels of autism spectrum

Autism Spectrum has 3 levels which are determined by the severity of persistent deficiencies in the areas of communication and social interaction [4]. Studies show that students who engage in meaningful communication have a sense of purpose and understanding for succeeding in college [5]. Lack of the ability to engage in appropriate social interactions or the ability interpret social cues may enable students from being successful in an educational setting.

Level 1 on the Autism Spectrum shows deficiencies in the ability of initiating interactions and clear exchanges within a communication opportunity [4]. Providing appropriate responses to said interactions are noted difficulties as well. With level one Autism, verbal communication may be age appropriate yet the exchange and holding meaning within the interactions are rare. Under the repetitive and restrictive behaviors noted, functionality difficulties include problems with organizational skills as well as difficulties with changes in routines [4]. These issues do require some support and intervention.

Level 2 of Autism Spectrum Disorder (ASD) may require “substantial support”. As with level one Autism, verbal and non-verbal communication skills are deficiencies [4]. Even with support, initiations of social interactions are limited [4]. Speaking may include simple sentences and the exchange in social interactions is odd at times and include specific interests which result in odd exchanges. The restricted and repetitive behaviors include inability to cope with change as well as difficulty with changing one’s focus from one activity to another [4].

Level 3 of ASD requires “very substantial support”. Verbal and non-verbal communications cause serve impairments in functionality. A person with Level 3 ASD will only respond when communication is directed and will not initiate social interactions. Limited speaking abilities where also noted. The restrictive behaviors include the inability to be flexible and extreme coping difficulties when changes occur. Also, one will have an extremely difficult time with changing focus from one activity to another.

Disparities in early diagnosis

African American children are diagnosed an average of one and a half years later than White children with symptoms of Autism [6]. Studies show that early diagnosis of Autism provides optimal developmental outcomes and success with family coping and community planning [7]. Studies show that intensive early intervention can improve the abilities; cognitive, language and adaptive behavior in children with the Autism Spectrum Disorder [6]. However, several barriers may interfere with families gaining an early diagnosis. Factors that spark earlier diagnoses may include symptom severity, high socioeconomic status, and the education levels of parents [8]. Disparities in early diagnosis include access to quality health care, cultural expectations and parental awareness of Autism Spectrum Disorder [7].

The average age of Autism Spectrum Disorder diagnosis is 3.1 years old [8]. Asperger’s syndrome, a higher functioning type of Autism, is diagnosed later at 7.2 years of age [8]. Autism is generally diagnosed between the ages of 38 to 120 months [8]. Children who show signs of Autism are referred by a health care provider to address significant speech and language delays [1]. The initial process consists of a speech and language evaluation, followed by an Ear Nose and Throat evaluation eliminating any concerns of hearing loss. If no hearing deficiency is observed, the child is then referred for a full developmental assessment. Families who can afford the full developmental exam in a timely manner are met with earlier diagnosis [1]. African American children require three times the number of visits to complete the initial assessment before receiving an ASD diagnosis (Mandell, 2002). However, families who may not have access to quality health care, wait weeks or even months for the initial developmental assessment, albeit a complete ASD diagnosis.

Quality Care

Delays in diagnosis and treatment of African American children prove a health care disparity in the United States [9]. Disparities are presumed to be due to the cultural differences in health care received by African Americans [9]. It has been assumed that health care providers test for ASD less in minority children [6]. General diagnostic assessments by physicians who use clinical judgements followed by a more explicit diagnostic assessment is needed to fully assess Autistic characteristics [10]. Berger [10], stated “bias is present among physicians who provide general assessments in the early stages of minority children”. General assessments spark the need for explicit diagnostic assessments, though health care providers spend less time with patients of lower socio-economic status, preventing them from receiving the explicit diagnostic assessment that leads to earlier diagnosis.

Access to health care or the lack thereof has been proposed as a major factor in the diagnosis delay of Autism. According to research, conflicting findings were presented about socioeconomic status being a greater contributing factor to early diagnosis, than poor health care [7]. However, other studies that examined the correlation between socioeconomic status and ASD diagnoses found that lower income families were consistently diagnosed later. Studies also have shown that lower income families have access to adequate health care, yet quality was not examined [9]. Studies that found children living in lower income areas were diagnosed early and this continues to contribute to the correlation of ecological measures of socio-economic status and the age of diagnoses [6].

Cultural Sensitivity

“The Black community does not believe that autism happens in Black families” [9]. Individuals from different cultures may not be willing to use health service or prefer to keep problems in the family, leaving concerns unaddressed [7]. Based on research conducted by Burkett, families and professionals believe that cultural influences delay diagnoses and treatment when receiving and seeking appropriate care for African Americans with Autism and African American children are 2.6 times more likely to be misdiagnosed than White children [9].

A study on influence of culture on early ASD diagnoses conducted cultural focus groups of African American families to share ideas, observations, active listening and interviews to collect data. The process took place at families’ homes and other natural settings. They shared that families lack acceptance of disability in the African American community [9]. Their lack of knowledge of Autism Spectrum Disorder kept them from gaining appropriate diagnosis and treatment for their children [9].

During the study, families shared they had to act in support of their child’s development. However, many families went to their own family members when initially concerned about their child’s development [9]. The participants shared concerns with their family members as a point of reference to gauge if their child should have met certain benchmarks in development such speaking or walking. A few participants in the study expressed how as a culture they would “just deal with it” or “pretending that nothing was wrong” [9]. Participants shared that after an ASD diagnosis was given, they did not reach out for help. The families were unaware of any other families in their community who were affected by Autism.

With potential bias, Caucasian children being diagnosed most frequently at early ages while many African Americans did not utilize professional diagnostic and therapy services [11]. The study highlights health care professionals’ feedback about it being more difficult for African Americans caring for an ASD child to tap into resources because their network of family resources were not as large as Caucasians. African Americans tend to be “overwhelmed” by the emotional and physical care, limited economic resources and untrustworthy professionals [6].

Interventions and educational success

Early diagnosis sparks the initiation of intervention plans and specialized instruction for students to be successful. The Individuals and Disabilities Act provides special education and services to all students with disabilities [12]. Parents, psychologists and educational professionals build the teams to create Individualized Education Plans. The Individualized Education Plan (IEP) contains individualized goals and interventions to meet the needs of the child for educational success [1]. IEPs are revised and amended once every year and transitions with the child as they matriculate through each level of education or until the individualized plan is no longer needed. Goals outlined on the IEP are implemented by special education and general education teachers. Research shows that it is likely that many teachers are not adequately trained on how to educate a student with Autism in order to meet their individualized needs [13]. Lack of teacher trainings creates an environment where a student's potential may never be reached.

Challenges for high school students with autism

Through qualitative research, studies show that high school students with ASD struggle in complex social and academic environment [14]. Little research has been conducted to examine the impact of social and academic challenges and the affect those challenges have on post-secondary education. Previous studies have been conducted using focus groups to understand the inconsistencies, difficulties with interpersonal connections and the knowledge breakdown of educational success of students with Autism [14]. In the study, parents of students with Autism voiced concern of social challenges and the academic outcomes as being a major impact on educational achievement. Research tells us that post-secondary outcomes for those with Autism are generally poor [15]. Researchers have suggested that the poor outcomes are partially due to the lack of support students receive in high school [12]. Studies show that more than half of high school students with Autism receive modification to curriculum and alternate exams [14]. These accommodations mean students with Autism will not graduate with a regular high school diploma [14].

Functional curriculum is an option for some students with ASD [13]. This curriculum focuses on the life skills students with Autism need to work and live and to be inclusive in the community [13]. Conflicting results show a need for functional skills curriculum while others feel too much emphasis is given to non-academic and non-vocational curriculum for autistic students [13]. Research shows a poor connection between functional curriculum and post-secondary success of students with Autism [13]. Both functional and academic curricula can be implemented to successfully support students as they transition to post-secondary opportunities. Parents must advocate for their high schoolers' IEP to include functional, academic and social skill goals.

Transitioning to post-secondary education

The number of students with learning disabilities who enrol into post-secondary education has increased over the past 20 years [16]. Yet studies show that post-secondary success of students with ASD is generally poor [14]. Poor success for students with ASD have been partially due to lack of support in high school [14]. Students with ASD inclusive in the general education classroom setting may not be eligible for the transition goals needed for post-secondary success [12]. Students who have become dependent on a special education environment experience challenges in a post-secondary education setting [16]. Studies show that family members become lifetime caretakers of their ASD children because they were unable to realize and meet their full potential. This study was conducted with a sample consisting of parents, educators, students with ASD who attend a college or who are living independently. Parents found that the IEP and transition process were unsatisfactory due to ineffective communication between the families and school personnel.

Many factors contribute to successful transition to post-secondary education. Studies show that family and student characteristics and the transition planning are prerequisites of successful post-secondary opportunities [12]. Studies show that of the sample 43% (4 out of 10) of autistic post-secondary students participate in post-secondary

education after high school [12]. In successful transition parent expectation and annual household income were major factors of the high school students with ASD who attend post-secondary educational settings. Attendance at a high school in the general education setting and the student's academic performance were also major factors. Above average academic performance was key for high school students to graduate and participate in post-secondary education [12]. Including the ASD student during the transition planning process was found to be a key factor in the success in the post-secondary education transition. The study did acknowledge the limited sample and found much of high school "leavers" did not attend post-secondary education [12].

Autism Spectrum Disorder students have great difficulty with the initial transition from the high school setting to post-secondary education. Students with ASD who attend post-secondary education programs generally do not have academic concerns but, are met with social interaction challenges. This also affects their transition into post-secondary education [2]. With support of learning centres and disability student services, students who attend comprehensive support which may include individual or group support, have been more successful [16]. Once enrolled in post-secondary education, studies show supportive learning environments allow students with disabilities to be most successful [16].

Policy changes have been passed by the United States Legislator as the Higher Education Opportunities Act allows students with intellectual disabilities to apply for federal student financial aid [2]. The students must be enrolled in a comprehensive transition and/or post-secondary program [16]. Normally only full-time students are awarded federal aid [16]. Families with higher functioning autistic students are now eligible for federal grants [16]. Disability service departments at colleges and Universities must continue to make changes to their invention models to provide services to a new population of learners.

Theoretical framework

Urie Bronfenbrenner developed the ecological theory in 1917 to understand defining relationships that form a person's environment [17]. The theory states that a person's environment affects a person's development and the environment can too, affect the person [17]. The theory creates a framework to understand students by assessing the environment: home, school and culture of the child [18]. Complex systems within ecological theory create ecological systems theory. The ecological systems theory supports the study of the disparities of early diagnosis of Autism and the effects of those disparities associated with the educational success of African Americans.

Microsystems in the ecological theory refer to the students, parents and family members of the student. It also includes teachers, administration and the community of the students as well. The parent is the child's first advocate. In some cases, a person's environment prevents them from even knowing the symptoms of Autism or how to seek services. Many behavioral concerns are misinterpreted and are symptoms of autism [9]. Cultural influences correlate with the ecological theory as families do not think Autism affects African American families. Not only do parents should be aware, they should have access to quality care. Health care professionals in their community must provide adequate service and make time for all patients. Health Care professionals initiate the early diagnosis process. However, if African Americans are not provided with the same assessment tools, early diagnosis will continue to show disparities.

Mesosystems connect to microsystems consisting of parents, students and school [17]. As students matriculate through high school, expectations teachers have of students with Autism can affect their educational success and their transition into post-secondary education. It is of the utmost importance that schools, teachers and health care professionals collaborate to meet the needs of the student. Teachers and staff need to be held accountable for meeting the goals outlined in the IEP. School personnel's expectations of students, especially students with

disabilities, alter the learning environment of the student. The school culture and classroom behavior of peers also affect the learning environment.

The Exco-system represents a larger social system which continues to develop around special education. The exco-system consist of decision making and policy changes that affect the community [17]. Policy makers make changes based on the needs of the community. Policy contributes to the rights and access to resources for individuals with Autism. An increase in Autistic students pursuing secondary education has created a need for policy changes. Legislators are constantly changing laws to meet the financial strain on raising a child with Autism. The Federal Government now provides financial support for students with Autism transitioning into post-secondary education learning institutions. Policy changes are game changers for the educational potential of students with Autism.

Conclusion

Early Diagnosis provides optimal potential in the development of a child with Autism. The lack of access to quality care, cultural influences, and lack of awareness has created a disparity in the early diagnosis of African American children with Autism. Although, some studies have concluded that race and socio-economic status do not contribute to ASD, these factors do contribute to the age at which children are diagnosed. Secondary education students continue to struggle with obtaining academic success because their matriculation through the educational ecological system is not meeting the needs of the students' potential. The educational system has low expectations of students with Autism as they focus too much on functional skills and do not equip students to be successful in post-secondary educational settings. Policies and opportunities have been created for students with Autism, yet the expectations of their community hinder their potential success. With further research, the current study will explore the effects of the disparities of early diagnosis and the educational success of African Americans with Autism.

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