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Parents of Children with Autism in Baltimore, MD.

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COUN 6785: Social Change in Action:
Prevention, Consultation, and Advocacy

Social Change Portfolio

Aneah Young

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OVERVIEW

Keywords: Parents of Children with Autism in Baltimore, MD.

Parents of Children with Autism in Baltimore, MD

Goal Statement: My goal is to increase parents' awareness about the stress that comes with raising a child with ASD as well as provide parents with resources on how to navigate this new journey.

Significant Findings: Parents of children with Autism spend most of their focus on their children and less on their mental health. Parents of those children, who experience depression can impair their ability to be present with their child (Vital et. al., 2023). Parents might also have difficulty setting boundaries with their children, causing certain behaviors to be negatively reinforced (Vital et. al., 2023). The focus is on the children and less on the parents. Parents need access to more resources to assist their children. Programs within schools, in the community, and changes in program requirements federally will help parents with the stress that comes with raising a child with autism.

Objectives/Strategies/Interventions/Next Steps: The next steps include making parents aware of the stress and resources available to them. This would include programs or discussions with the diagnosing professional about what to expect. Schools and teachers need more assistance and resources for children with autism. The parents should be able to rely on the schools as well as other professionals to assist with their child. Schools should partner with programs such as FACES, which is a training program that provides training on autism for African-American families (Pearson & Meadan, 2021). Parents should be educated on the

symptoms of depression, anxiety, and burnout as well as where to go when they need help.

Lastly, we should shift focus to program requirements at the state and federal levels that include more families based on their socioeconomic status.

INTRODUCTION

Parents of children with ASD

Autism is a neurodevelopmental condition that is characterized by difficulties with social communication and interaction by behavior that is considered restricted or stereotypical (Shtayermman & Zhang, 2022). To assist with living their daily lives, it requires a lot from the parents of children with ASD to adjust their parenting style to raise a child with ASD. This can cause a lot of strain and a lot of stress on the parent. In the sections below, I will discuss the mental health rise of parents of children with autism. It is suggested that parents of children with ASD have higher levels of mental health outcomes related to the severity of their child's symptoms (Shtayermman & Zhang, 2022).

PART 1: SCOPE AND CONSEQUENCES

Parents of children with ASD

The population I would like to discuss is parents of children with ASD. The mental health and coping skills of parents of children with ASD are not prioritized because the focus is typically on the child with ASD (Vital et. al., 2023).

Although there wasn't much information on the prevalence, there has been a lot of research on the correlation between ASD symptoms, and the mental health of a parent/caregiver. Vital et. al (2023) mentioned a study that stated that caregiving for a child with ASD who

presents with more challenging behaviors impacts, not only the caregiver's role, but other relationships, finance, work, family life, and mental health. In addition, Vital et. al (2023) reported on a study that found depression was more severe in parents with children with high-functioning ASD, who reported low levels of benefit finding. Vital et. al (2023) found in their study, that greater ASD challenging behaviors were associated with a higher likelihood of depressive symptoms in parents of children with ASD. These studies show a relationship between the child's symptomology and the parent's mental health. Due to ASD symptoms being on the spectrum, there's no way to know or regulate what symptoms each child has, or will not have. It creates a lot of stress for the parent.

Parents are typically responsible for the facilitation of the behavior interventions of their child (Vital et. al., 2023). If a parent is struggling with mental health, such as depression, it can impair the parent's ability to engage in appropriate social interactions with the child (Vital et. al., 2023). Vital et. al (2023) also states that parents who are depressed may have difficulty setting boundaries with their child as they may be too exhausted or unmotivated. This will leave a lasting effect on the child whose behavior is being negatively reinforced. Research shows that negative feedback cycles can diminish positive improvements, and can create more stress for parents of children with ASD (Vital et. al., 2023). My goal is to increase parents' awareness about the stress that comes with raising a child with ASD as well as provide parents with resources on how to navigate this new journey.

PART 2: SOCIAL-ECOLOGICAL MODEL

[Parents of children with ASD]

The social-ecological model tells us the overlap between individual, relationship, community, and societal factors (CDC.,n.d.). It shows how one factor can influence another (CDC.,n.d.). I will use this model as it pertains to parents of children with autism.

At the individual level, the risk factors for parents include income, any pre-existing mental health, education, and age. Some protective factors would be having positive attitudes, beliefs, and behaviors (CDC.,n.d.). At the relationship level, the risk factors include being a single parent or lack of family nearby (CDC.,n.d.). At this level, protective factors may include having a close group of friends, and family nearby and having a 2-parent or co-parenting household (CDC.,n.d.). At the community level, the risk factors include unsafe neighborhoods, underserved schools, lack of resources in neighborhoods and schools, as well as lack of employment (CDC.,n.d.). Some protective factors would be safe neighborhoods, and schools with appropriate resources to assist children with autism (CDC.,n.d.). Lastly, at the societal level, a risk factor is how low the income requirements are to qualify for federal and state assistance. Another risk factor is how tight the rules and regulations are within those programs with an increased likelihood of being cut off. Many people receiving assistance on behalf of their child with autism could risk losing their eligibility for a program, for something as simple as not receiving mail on time. Some protective factors are schools that assist parents with finding programs and resources that they qualify for. Another protective factor would be parents receiving referrals, and the next steps once their child is diagnosed.

This model shows that to prevent parents of children with autism from burning out and mental health strain, it is necessary across multiple levels (CDC.,n.d.).

PART 3: THEORIES OF PREVENTION

Parents of Children with ASD

Two theories would be useful in serving my population, Social Cognitive Theory and Diffusion of Innovation. SCT describes a process where personal factors, environmental factors, and human behavior all influence one another (National Cancer Institute, 2005). If individuals have self-efficacy, they can change behaviors even with obstacles (National Cancer Institute, 2005). When a person gets new behaviors, this causes changes in the environment and the person (National Cancer Institute, 2005). Diffusion of Innovation suggests that it is not enough to create new programs but that these programs must disseminated (National Cancer Institute, 2005). It addresses how practices that are perceived as new are spread throughout society (National Cancer Institute, 2005). It's used for multi-level change in diverse settings, through different strategies (National Cancer Institute, 2005). It includes the media, advancing policies, or starting initiatives (National Cancer Institute, 2005). This theory focuses on dispensing information and resources increasing the likelihood that they will be adopted (National Cancer Institute, 2005). This theory has been used to study programs such as smoking cessation and condom use (National Cancer Institute, 2005).

These two theories would work well with a prevention program for parents of children with autism due to the combination of both assisting parents with their self-efficacy and focusing on getting information out to parents that they need. An example of an evidence-based prevention program is the California Mental Health Services Authority. This coalition implements prevention and early intervention programs to reduce negative outcomes for those experiencing mental illness (Promising Practices Network, 2014). This program is focused on stigma and discrimination reduction (Promising Practices Network, 2014). My target population also needs assistance with, the stigma around mental health in general.

PART 4: DIVERSITY AND ETHICAL CONSIDERATIONS

Parents of Children with ASD

The subgroup within the population of parents of children with autism that are directly impacted differently are African-American parents of children with autism. The CDC reported that African-American children are less likely to be identified with ASD than European-American children, even though the risk of developing ASD is consistent across racial guidelines (Pearson & Meadan, 2021). Although there has been an increase in promoting empowerment and advocacy for services for children with autism and their families, there have been no parent advocacy training programs that have been specifically designed to address the needs of African-American parents of children with ASD (Pearson & Meadan, 2021). With current interventions, many early dropout rates have been correlated to lower socioeconomic status, increased parenting stress, and minority racial status (Machalicek, 2022). I should also note that the recruitment of parents of children with ASD may be challenging due to how time-intensive these interventions are (Machalicek, 2022). There is a need for an increase in knowledge and awareness of ASD in the African-American community, as well as the resources to help parents advocate for the services and support for their children and families (Pearson & Meadan, 2021). Minorities having to fight for diagnoses and lacking necessary interventions and programs to find resources can cause even more parental stress and can cause a strain on their mental health.

FACES is a six-session 18-hour parent training program that is specifically designed to address the needs of African-American children with ASD (Pearson & Meadan, 2021). Pearson and Meadan (2021) did a study on the FACES program and found that parents were able to gain

more family empowerment, the ability to address and debunk myths related to ASD, and a community of African-American families navigating the same thing. Parents were also able to learn about resources that were available in their community (Pearson & Meadan, 2021). All three of these mechanisms are important to address within the African-American community as it surrounds ASD.

One of the ethical codes we should keep in mind as it pertains to prevention programs is informed consent, which is code A.2.a. This code states that clients have the freedom to choose whether to enter, or remain in a counseling relationship (American Counseling Association, 2014). Pearson and Meadan (2021) mention that during their informed consent process, all participants were assured that their participation was voluntary, and their information would be kept confidential. In the results section, the participants' identities were also protected by using pseudonyms (Pearson & Meadan, 2021). Lastly, code C.2.a talks about our professional responsibility to have boundaries of competence. This code expresses that counselors should only practice within the boundaries of their competence, education, training, and specialized experience (American Counseling Association, 2014). In a prevention program that is dedicated to minority groups, we must make sure that those who are leading the program have the full knowledge of what's needed to run a program for minorities. It could do more harm than good if we don't have the right people in the room to communicate the correct information.

PART 5: ADVOCACY

Parents of Children with ASD

According to the ACA Code of Ethics code A.7.a, when appropriate, counselors should advocate at the individual, group, institutional, and societal level (American Counseling Association, 2014). However, there are barriers at these levels that impede addressing the mental health of parents of children with autism. A barrier at the institutional and community level, is children with autism have a high non-attendance rate at school, missing 22% of school (Adams, 2022). Many factors can contribute to the non-attendance including bullying, school refusal, or anxiety around schooling in general (Adams, 2022). Adams (2022) found the most frequent reason was for medical or therapy appointments. Due to their needs, it is likely parents are using multiple interventions or therapies for their children (Adams, 2022). Adams (2022) study also found that 1 day every two months, on average, the child is being sent home due to their behavior or the child is being asked to stay away from school due to the school's lack of ability to support the child. At the institutional level, schools are just not equipped with the support needed for children on the spectrum. Parents are forced to pull their kids out of school for them to get the help they need. Parents have to arrange their schedules around appointments. Most appointments are during the school day, which puts the parent in a position to have to make a choice. When kids do go to school, both the parents and children are anxious and worried about classroom performance (Adams, 2022). At the community level, due to a lack of support institutionally, children on the spectrum are being excluded from school because of a lack of resources and due to not behaving “appropriately”. All of this in mind, can cause a lot of stress on the parent who might be worried their child won't be able to get through a school day.

An action to take against the institutional barrier is connecting clients with supportive individuals within social institutions who can help alter the inequity (Multicultural and Social Justice Counseling Competencies, 2015). This action will help the children get the extra help and attention they need without missing valuable schooling time. There should be resources available within schools so parents aren't forced to decide which is important, therapy or school. An action we can take at the community level is by "utilizing the norms, values, and regulations of the families to shape community norms, values, and regulations" (Multicultural and Social Justice Counseling Competencies, 2015). There is no reason these children should be outcasted from school. They are already anxious and nervous to go, with the knowledge that they are different but are punished for it. That puts so much more stress and pressure on the parent to find the perfect school that understands their child's needs. How can they learn, if they're constantly being sent home? This is also why I combined both levels. The community won't change if we don't fix the problem institutionally.

At the public policy level, most of the resources available for children on the spectrum are for families who are at the poverty level or below. Middle-class families are stuck in this grey area of not having enough but having more than someone else. So they're forced to pay out of pocket for expenses. As discussed above, parents are having to miss work for their child's necessary appointments. Also, if parents wanted to place their children in a better school or institution, without funds or resources it's next to impossible. So, they become stuck doing it on their own. Adams (2022) states that child anxiety is associated with the parents. If the parents felt supported, that could also trickle down to the child. An action to take at this level is to initiate discussions with privileged and marginalized clients regarding how they shape and are shaped by local, state, and federal laws and policies (Multicultural and Social Justice Counseling

Competencies, 2015). We must have these conversations around the inequalities to make a push for change in guidelines and program requirements so more people can have access to the resources.

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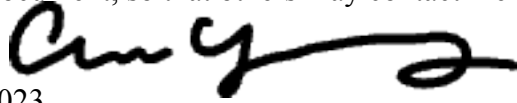
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