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**SOCIOECONOMIC STATUS AND AUTISM SPECTRUM DISORDER: CAREGIVERS'
SOLUTIONS TO OVERCOMING SERVICE BARRIERS**

A project based upon an independent investigation,
submitted in partial fulfillment of the requirements
for the degree of Master of Social Work

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2017

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Socioeconomic Status
and Autism Spectrum
Disorder: Caregivers'
Solutions to Overcoming
Service Barriers

ABSTRACT

This study attempted to remedy the existing research gaps by asking: How does SES of caregivers for children with ASD influence their ideas of service barrier solutions? The purpose of this study was to examine caregivers' perspectives of service barrier solutions and how SES influences their ideas of solutions. It was hypothesized that high SES caregivers would report experiencing less service barriers than low SES caregivers; therefore, there would be a difference in their ideas of solutions. This study explored sources of information, service barriers, ideas of solutions to barriers, and how solutions may improve caregivers' abilities to care for their children. The findings concluded that high SES caregivers experience more service barriers than low SES caregivers and suggested more solutions. It is recommended that a social justice framework be used in any future ASD research. Implications for practice highlight the need for further research so clinicians can better assist.

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CHAPTER I

Introduction

Autism Spectrum Disorder (ASD) has been the focus of a variety of studies. ASD is defined as "...a developmental disorder that presents with atypical language and social behavior, along with restrictive and repetitive behaviors and unusual interests" (Johnson, Burkett, Reinhold, & Burtas, 2016, p. 16). In the DSM IV-TR, ASD was originally known as pervasive development disorders (PPD), and was divided into three possible diagnoses: autism, PPD – not otherwise specified, and Asperger syndrome (Johnson et al., 2016; American Psychiatric Association, 2000). In the DSM-5 these three diagnoses were collapsed into one, known today as ASD (Johnson et al., 2016; American Psychiatric Association, 2013). All of the previous separate classifications are now considered to be on one spectrum. According to the DSM-5, it is referred to as a spectrum because manifestation of the disorder varies greatly based on the severity of the autistic condition, developmental level, and chronological age (American Psychiatric Association, 2013).

Research suggests that various social issues can impact a caregiver's ability to meet the needs of their child with autism (Pickard & Ingersoll, 2016). A child with a disability often has needs that children without disabilities may not have (Reichman, Corman, & Noonan, 2008). The child may need to be a part of a variety of supportive programs in the community or have in-home services. These resources not only exist to help the child, but they also exist to assist the caregivers in meeting the child's needs (Reichman et al., 2008). However, there are a plethora of families of children with autism who struggle to meet the needs of their child due to several barriers (Pickard & Ingersoll, 2016). Some of these barriers include transportation, long wait lists, finances, insurance, or scheduling issues (Pickard & Ingersoll, 2016).

A significant barrier includes the socioeconomic status (SES) of the caregivers of people with autism. SES has been defined as the current social and economic situation a person is in, and it can change at any time (Rubin et al., 2014). The SES of a family could potentially influence knowledge of and accessibility to resources that could help support the child and the family (Pickard & Ingersoll, 2016). Research has documented the differences in accessibility of resources between low and high SES families, and how both low and high SES families struggle in their own ways (Pickard & Ingersoll, 2016). For example, low SES caregivers report having difficulty in advocating for their children because they do not have the finances or transportation to access services for their child. It can be difficult for some caregivers to find means of transportation to get to and from appointments or to qualify for insurance to cover the costs of services. High SES caregivers typically do not qualify for Medicaid or state insurance coverage due to a high income, and, therefore, end up paying for services out of pocket, which can be an added financial strain (Pickard & Ingersoll, 2016).

There is a need to examine solutions to reported service barriers. Existing research has explored the different barriers faced by high and low SES families, but has not specifically focused on solutions to the service barriers caregivers experience. This is important to study so service providers can better assist caregivers to meet the needs of their children with ASD. Caregivers are more likely to report their negative experiences rather than their positive ones (Pickard & Ingersoll, 2016); therefore, it is imperative to intentionally ask about both their positive and negative experiences to understand what is going well and how services could be more easily accessed.

How the caregivers identify their own SES versus how they are identified by objective demographic factors, such as education or income, has not been examined either (Rubin et al.,

2014). People are usually identified either objectively or subjectively, not as both, but it is possible for someone to be labeled as high SES based on education but identify themselves as low SES because of their experiences (Rubin et al., 2014). It will be beneficial to study how objective measures of caregiver SES (e.g., education, income, occupation, material possessions, etc.) interact with subjective measures (i.e., how the caregiver identifies their SES) in order to understand whether or not the interaction of the two impedes meeting the child's needs. It will be valuable for social workers to understand caregivers' ideas of service barrier solutions so they can work from a strengths-based perspective in assisting them in meeting the needs of children with ASD. It will also be valuable for social workers to understand the differences that exist between high and low SES families to better accommodate them.

This study attempted to remedy one of these existing research gaps by asking: How does SES of caregivers for children with ASD influence their ideas of service barrier solutions?

CHAPTER II

Literature Review

Introduction

The purpose of this literature review is to examine what is already known about caregivers' experiences with service accessibility, caregivers' ideas of service barrier solutions, and disparities among high and low SES caregivers' ideas of solutions. Examining what has already been discovered by researchers will assist in understanding the research gaps that remain. I will also discuss the relevance of this study and how it can be beneficial to people who influence the lives of children with ASD (e.g., service providers or caregivers). I will use a social justice framework to discuss the literature because the social discourse created from the stigma of the intersection of disability and SES significantly influences the experiences of caregivers.

Existing literature represents the plethora of barriers that caregivers experience in accessing and receiving services. Caregivers often find themselves taking more time off from work because of the struggles of balancing work, family, services for their child with ASD, and any other daily responsibilities (McEvelly, Wicks, & Dalman, 2015). Caregivers find themselves so busy making sure their family is taken care of, that they are sometimes unable to find time to care for themselves. Many caregivers find it very stressful to access services in general. Navigating the system can feel lonely when providers are unavailable to assist and can make it very difficult for caregivers to find necessary services for their child's treatment (Brookman-Frazer et al., 2012). The ways the system is structured is significantly based on oppressive perceptions of disability. Historically, disability has been viewed as a problem that needs to be fixed and something that is a burden to the non-disabled. This is exactly how ASD tends to be

perceived. It is often presented as a negative diagnosis (Wendell, 1996), and the ableist reactions from others in society can create feelings of shame, embarrassment, or depression for caregivers.

Literature about caregiver's ideas or recommendations of solutions to service barriers is quite limited. Some research has examined the ways in which service providers can improve in assisting families of children with ASD (Solomon & Chung, 2012). However, there is very limited qualitative research examining perspectives of caregivers. After extensive research, only two studies were discovered regarding this topic. Existing research suggests that caregivers and providers have the same concerns about service barriers and make recommendations based on their individual experiences with the system (Sperry, Whaley, Shaw, and Brame, 1999). More qualitative research examining the caregiver's perspective can be helpful in improving service accessibility because caregivers are primarily impacted by the obstacles created by systems of oppression. Caregiver's voices often go unheard. If those who experience the obstacles had the opportunity to voice their concerns and to voice how the system could be improved to make it more accessible to them, the answers to improvement may become clear.

One of the most significant barriers reported in the literature is financial obstacles. Therefore, examining the intersection of SES and ASD is important in the research of solutions to service barriers. Existing literature suggests that there are disparities among high and low SES caregivers when accessing services (Durkin et al., 2010; Pickard & Ingersoll, 2016). It is more difficult for low SES caregivers to gain knowledge about service; therefore, it is more difficult for them to access services. However, literature has also examined the various ways that both high and low SES caregiver struggle to access services for their children with ASD.

Caregiver Experiences with Service Accessibility and Other Barriers

To understand solutions to services barriers, existing barriers must first be understood. Children with ASD tend to have an immense amount of needs, which requires more attention from caregivers than a child without ASD would require. Research has discovered frequent use of sick leave by parents of children with ASD. McEvelly et al. (2015) examined the difference in the use of sick leave by parents who have a child with ASD and parents whose child does not have ASD. The authors focused specifically on families living in Stockholm, Sweden. A total of 149,567 families with children ages 4 to 17 participated in the study. They found that parents of a child with ASD were likely to be on sick leave more often and participate less in work than parents of a child without ASD. The authors suggested higher levels of stress, anxiety, and depression exist in parents of children with ASD and concluded that these parents require the need for more time off from work; as a result, these parents were more likely to have lower incomes. It was suggested that a qualitative study may be better suited for further exploration of caregivers' personal experiences with service barriers and what their ideas of solutions to those barriers would be (McEvelly et al., 2015). This study is a representation of the unique situations and the struggles caregivers experience. However, this study does not examine solutions to these obstacles. It would be beneficial to explore how a child's unique needs can be better accommodated, so service providers can find ways to improve their services.

Services can often be inaccessible or difficult to navigate for caregivers. In another study, the accessibility of mental health services for children with ASD was examined. Brookman-Frazer et al. (2012) conducted a qualitative study examining parent perspectives on community mental health services. A total of 23 parents of children with ASD participated in semi-structured interviews to provide their perspectives of the effectiveness of outpatient community mental health services. The authors concluded that parents of children with ASD

find it difficult and confusing to navigate the service system. Their children are most often recommended to services through the educational system prior to ever receiving a diagnosis and children were typically referred to services because of behavior issues in school. It was also concluded that the time and effort put into accessing services put a financial strain on families, and created a disruption in the family system (e.g., marital discord, feelings of guilt, or no time for other children). When parents were finally able to access services, they discovered there are few, if any, service providers who possess specialized training in working with children with ASD. ASD can sometimes be comorbid with other diagnoses (e.g., intellectual disability, anxiety, or mood disorders). The authors concluded that a comorbid diagnosis creates stress for the caregiver because of the difficulty in finding services that meet the specific needs of their child (Brookman-Frazer et al., 2012). This qualitative approach provided in-depth exploration of the caregiver's experiences with community mental health services. It highlights the parts of the service system that are worsening the experiences of caregivers. However, like other studies, it lacks a focus on caregivers' ideas of solutions to this problem or the types of services caregivers believe would help their families. Caregivers are the experts of their children's needs; however, as this research gap suggests, little is known about what caregivers believe would help ameliorate these service issues.

A significant barrier that caregivers of children with ASD face is the stigma attached to the diagnosis of a disability. ASD is documented in the DSM-5 as a neurological disability (American Psychiatric Association, 2013). The stigma attached to disability creates social discourse that influences how people perceive it. The social discourse created by the non-disabled suggests that a person with a disability is imperfect, weak, and a failure to control the body, which leads to the false conclusion that disability is bad (Wendell, 1996). This discourse

not only influences how caregivers may react to the news of their child's diagnosis of ASD, but it also influences the way the news of the diagnosis is delivered by a service provider (e.g., the service provider may deliver the diagnosis as if it were bad news). ASD is a diagnosis in the DSM because the children with this diagnosis do not fit the standards of "normal" development. Therefore, they are ultimately treated as "The Other" (Wendell, 1996). With the label of "The Other" a child with ASD is treated different from children without ASD.

Stigma is not a one-time offense. It constantly impacts the ways in which we function daily. It influences our thoughts, our decisions, and our actions. When the news of an ASD diagnosis is delivered to a caregiver in a sympathetic way, the service provider is attempting to be emotionally supportive, but is also unconsciously sending the message that the diagnosis of ASD is unacceptable. This is unfortunate because "...the manner in which a diagnosis of childhood disability is communicated may have significant implications for parents' ability to cope in future" (Potter, 2016, p. 96). The research has failed to acknowledge the influence of social injustices on the experience of caregivers of children with ASD, which suggests a gap in existing research. Per the NASW Code of Ethics, social justice is a core value of the work that is done with clients, particularly vulnerable and oppressed populations (NASW, 2008). Therefore, it is imperative to consider a social justice perspective when examining disability to understand the social influences and the intersection of other social identities on the experiences of caregivers and what they believe would be possible solutions to the plethora of barriers they face.

Caregiver's Ideas of Service Barrier Solutions

There is very little existing research that examines solutions to service barriers from the caregiver's perspective. Some existing research reports on ways that service providers can improve in working with children with autism. Solomon and Chung (2012) report on the ways

in which a systems-oriented therapist can assist families of a child with autism. It is suggested that for a family therapist to have the skill to work with families of children with ASD, the family therapist must understand comprehensive treatment planning for children with autism (Solomon & Chung, 2012). Research suggests that a therapist may help a family by supporting them in prioritizing and balancing daily activities and responsibilities that may create stress (Solomon & Chung, 2012). The therapist can also work with caregivers in telling their child's story to create meaning, connection, and empathy with the hope that this would cultivate deep acceptance for difference among family members (Solomon & Chung, 2012). For the early stages of diagnosis, a family therapist may support caregivers by validating the emotions that accompany the diagnosis of their child (Solomon & Chung, 2012). Although created by stigmatization, as previously mentioned, it is still difficult for a caregiver to cope with the discovery of their child's disability, and lack of support can make the experience feel more difficult; therefore, a family therapist may be essential to the support system of a family of a child with ASD (Solomon & Chung, 2012). However, finding a family therapist for support could even feel inaccessible to caregivers, especially if insurance does not cover it. It is crucial that the caregiver's perspective be examined to understand their individual needs and how services and accessibility can be improved.

Existing research has studied the caregiver's perspective, but most studies examine the struggles of caregivers. More recently, studies have begun to examine the caregiver's recommendations for solutions to the barriers they experience in receiving or accessing services for their child with ASD. Only two studies were found that specifically examined caregiver recommendations to service barriers (Dymond, Gilson, & Myran, 2007; Sperry et al., 1999). Sperry et al. (1999) compared the recommendations of service providers and caregivers of

children with ASD for solutions to service barriers. The researchers held four focus groups that provided the opportunity for caregivers and service providers to share their hopes, expectations, barriers, and effective practices they encountered in accessing services (Sperry et al., 1999). Focus groups were used as a qualitative approach to gain insight on the personal experience of caregivers and service providers and what their ideas of solutions were based on their own unique experiences.

Results suggested common themes among the caregiver and service provider groups, which included issues of finance, training, family support, early identification, parent-provider collaboration, advocacy, equity, and inclusion (Sperry, et al., 1999), even though each group assigned different degrees of importance on each of these factors. Parent-provider collaboration appeared to be significant for both caregivers and service providers. Caregivers expressed needing more patience and willingness from providers to hear the concerns of caregivers and to be treated as “viable team members.” Providers expressed needing more active engagement from parents in the child’s treatment. Their expressed needs were different, but the ultimate goal of collaboration was the same.

Another major concern for providers and caregivers was financial barriers. It can be frustrating for both groups when financial obstacles make it difficult to access services, or even prevent accessibility to services. Sperry et al. (1999) found that caregivers reported going into severe debt and experienced issues with being denied insurance coverage for services. Providers expressed similar concerns about insurance coverage for clients. Providers reported that insurance companies claimed ASD is not a “medical necessity,” but is considered an “educational necessity” and needs to be paid for by the school district (Sperry et al., 1999, p. 27). It is just as difficult for providers as it is for caregivers to assist in getting coverage for a client’s

services. If caregivers are unable to obtain insurance or any other form of financial assistance to pay for their child's services, they could be required to pay out of pocket, which can lead to the severe debt caregivers mentioned in this study. The Sperry et al. (1999) may be an old study and the experiences reported may not align with experiences caregivers have in the present, but it is a representation of the long-term financial struggle caregivers have had.

Dymond et al. (2007) conducted a similar study as Sperry et al. (1999). Researchers asked caregivers of children with ASD ages 0-22 years of age for recommendations on solutions to service barriers in school and community-based services. Participants were recruited from schools across the state of Virginia and were asked to complete a paper survey. Participants were also recruited from various support services for caregivers of children with ASD; facilities sent out announcements in newsletters encouraging caregivers to participate. Results presented a total of 28 recommendations for solutions to service barriers; these were divided into four separate categories. The four themes discovered were 1) Improve the Quality, Quantity, Accessibility, and Availability of Services; 2) Educate and Train Individuals to Work Effectively with Children with ASD; 3) Increase Funding for Services, Staff Development, and Research; and 4) Create Appropriate School Placements and Educational Programs for Children with ASD (Dymond et al., 2007).

For Theme 1, caregivers made recommendations for things such as a need for more and better services, more accessibility for services, more individualized programs, and more collaborations among parents, professionals, and organizations. For Theme 2, caregivers made recommendations for more education and training for school personnel, parents, people (unspecified), service providers, the public, and students without disabilities. For Theme 3, recommendations included increased funding for both school and community services, requiring

insurance companies to cover more services, therapies, and treatments, provide funds to hire more school personnel and service providers, and many other recommendations. For Theme 4, recommendations included more one-on-one support for children with ASD, provide more inclusion with non-disabled peers, provide more challenging curriculum and prepare students to be contributing members of society, ensure more continuity in placement location and staff, and several other recommendations (Dymond et al., 2007).

These studies present a solution-focused perspective that most studies do not have. They provide a means of improving the flawed system that caregivers of children with ASD often find difficult to exist in and navigate. They provide an opportunity to caregivers to voice their concerns that typically do not get heard from busy, over-worked service providers. However, the limited solution-focused research examining caregiver's ideas of solutions to service barriers is a problem in the field of ASD research. Improvements cannot be made if there is no evidence suggesting a need for improvement, and the individual concerns of caregivers are less likely to be heard without qualitative research. More qualitative research can validate what has already been found by existing studies or present new ideas for solutions. For example, this study focuses on discovering whether SES has an influence on ideas of service barrier solutions.

Disparities Among High and Low SES

Justice cannot be served for people with disabilities if it is not examined from an intersectional perspective. Research suggests that financial concerns are a significant barrier to accessing services (Durkin et al., 2010; Dymond et al., 2007; McEvelly et al., 2015; Pickard & Ingersoll, 2016; Sperry et al., 1999). Therefore, it is important to examine the ways in which socioeconomic status and ASD intersect in the experience of caregivers.

Durkin et al. (2010) conducted a cross-sectional study to explore the association of SES with the prevalence of ASD among children. The study was conducted using data from 12 different sources from the Autism and Developmental Disabilities Monitoring Network. The study focused specifically on 3,680 8-year-old children with ASD. The authors categorized SES as “Low SES,” “Medium SES,” and “High SES,” and defined it based on objective measures such as federal poverty level, education, and household income. Researchers concluded that high SES children were more likely to be diagnosed with ASD than medium or low SES children. However, the researchers suggest ascertainment bias significantly contributed to these results. In other words, data was collected from a database that only had information about families who had access to services. Therefore, researchers concluded that high SES families are more likely to have access to services than low SES families, which suggests SES disparities in families accessing services for children with ASD. However, like the other studies, this study lacks solution-focused interventions. Another limitation is that the researchers relied on data sources to identify SES of children with ASD, but failed to identify caregiver SES and the influence that had on ASD prevalence and SES disparities. It was unclear whether the child’s SES was the same as their caregiver’s or not. The use of a qualitative approach will provide further exploration of SES disparities between high and low SES caregiver’s ideas of solutions to service barriers.

Pickard and Ingersoll (2016) conducted a mixed methods study that examined the relationship between SES and accessibility of services to families of a child with an ASD diagnosis. A quantitative approach was used to examine what services parents had heard of as treatment options and what services parents were currently accessing. It was hypothesized that parents of higher SES would have greater awareness of resources and have accessibility to more

resources than parents of lower SES. There was a total number of 244 parents with children between ages 2 and 17 with an ASD diagnosis. Parent education level was used to determine SES: parents with less than a 4-year college education level were considered low SES and parents with a 4-year college education or higher were considered to be high SES. Results suggested SES was a predictor of service knowledge and service use. High SES families were more likely to have more knowledge of services and utilize services more, whereas low SES families were limited in knowledge and service use. Results also suggested that both high and low SES families report the quality of services as good, but there were not enough services available or being recommended by service providers. Researchers concluded that parents clearly understand the needs of their children, but would like more education on services and have more of a variety of services recommended. Low SES families in particular reported a need for more education of services, respite care, in-home services, and parent training available in their area. The authors also used a qualitative approach to examine parents' perceptions of service needs and barriers to service accessibility. The qualitative portion of the study showed both similarities and differences between low and high SES families. Both types of families expressed wanting more frequent recommendations of services that could benefit their child. However, low SES parents seemed to be less knowledgeable about available services than high SES parents and expressed work and transportation as difficult barriers to overcome. Children with autism and families could benefit from more knowledge about solutions to service barriers from the perspective of families of high and low SES.

There is clearly a plethora of existing research examining the struggles and barriers caregivers face in accessing or experiencing services for their children with autism. There is even research regarding the differences of service accessibility among high and low SES

families. However, existing research presents few solution-focused perspectives to understand solutions to these existing barriers from the caregiver's perspective. Now that it is understood what is not going well, there needs to be further exploration of what can be done about service barriers, so service providers can be of better assistance and make services more accessible.

This study fills a gap in existing knowledge for clinicians about working with high and low SES families of children with autism. Clinicians and other service providers will be able to better understand disparities between high and low SES caregivers' ideas for potential to remedy some of these barriers. This will assist clinicians and other service providers in finding ways to better accommodate their clients, assist in improving services, and provide more frequent educational trainings so caregivers can hold a more direct role in their child's therapy.

Caregivers of children with ASD will also benefit from this study by having the opportunity to voice their perspective on solutions to service barriers that would most help their families. This study also explores where caregivers get information about services, and whether high and low SES caregivers are utilizing the same support for information about services available to their children. This will help service providers to understand if there is a difference in the ways high and low SES caregivers are being assisted in meeting their children's needs.

Chapter III

Methodology

Purpose of Study

This qualitative study is an exploration of the following question: *How does SES of caregivers for children with ASD influence their ideas of service barrier solutions?* The purpose of this study was to examine caregivers' perspectives of service barrier solutions and how SES influences their ideas of solutions. This study examined where caregivers receive information about available services, experiences with service barriers, caregivers' perceptions on solutions to service barriers, and their perspectives on how these solutions will help. It was hypothesized that high SES caregivers experience less service barriers than low SES caregivers.

There are many strengths in using a qualitative approach to research. A qualitative method informs practice with the population being studied (in this case, caregivers of children with autism); it gives clinicians more insight into the caregivers' personal experiences (Engel & Schutt, 2013). There have been studies that have used mixed methods to examine the relationship between SES and ASD (Pickard & Ingersoll, 2016), and there have also been studies that have strictly done qualitative work to examine this topic (Brookman-Frazer et al., 2012). It would be beneficial to expand knowledge about the relationship between SES and ASD through a qualitative design to replicate existing results to confirm caregivers' experiences with service barriers, which would strengthen the reliability of this study. It would also be beneficial to use a qualitative approach to discover new themes other studies may have missed. This method is beneficial for understanding potential service barrier solutions directly from the population that personally experiences these barriers. Theme analysis will be used to analyze the data. Survey questions will be completed first, then data will be coded for themes (Engel & Schutt, 2013).

Sample

Participants in this study were adults 18 years of age or older who met the following inclusion criteria: currently care for a child with ASD, have legal guardianship over the child, and the child with the ASD diagnosis is between the ages of 2 and 17. If there were two caregivers for one child who both met the requirements, it was possible for both to participate individually since they may have had different perspectives to share. To determine eligibility, participants were asked to answer screening questions regarding the inclusion criteria previously listed. Participants were also asked to review and sign a consent form prior to completing the online survey. Once the consent form was reviewed and electronically signed, participants were directed to the survey questions.

To narrow down the eligibility criteria, there were some exclusion criteria that restricted who could participate in this study. Caregivers who used to care for children with ASD in the past but no longer do were not eligible as this study is looking at current experiences and not retrospective experiences. Those who did not have access to a device with internet that allows access to the survey were also not eligible to participate, and anyone under the age of 18 was also not eligible.

Those interested in participating in this study and fit the inclusion criteria were asked to answer online demographic and open-ended survey questions (Appendix F). Participants' level of education was used as an objective measure of SES. In this study, participants who have obtained a 4-year college degree or higher were considered high SES and participants who have completed less than a 4-year degree were considered low SES.

A total of 38 anonymous people attempted to participate in the study. There were 19 participants who passed the screening, agreed to consent, and completed the survey. One

participant's responses were disqualified because this person identified as a teacher, and did not fully identify with the inclusion criteria. Participants were provided contact information for the opportunity to ask questions, express concerns, or discuss the study further; however, no one reached out. Therefore, all participants remained anonymous.

Recruitment

Prior to recruitment for this research, this study was approved by the Smith College School for Social Work (SSW) Human Subjects Review Committee (HSRC) (Appendix A). Convenience sampling was used to recruit participants through Facebook and Instagram. Convenience sampling is also known as availability sampling and is commonly used to recruit a population that is easily accessible or not difficult to find (Engel & Schutt, 2013). An electronic recruitment flier was created; it included the title of the study, the purpose of the study, inclusion criteria, exclusion criteria, the survey link, and the researcher's contact information (Appendix C). The recruitment flier was posted on to Facebook along with a recruitment message (Appendix D) four times and the same was posted on Instagram two times. On Instagram, the account was made public so anyone could see the post, and hashtags were used to make it more likely for people searching ASD related terms to see the post. Many friends and family shared the original Facebook post on their own Facebooks to spread the word, and some of their Facebook friends shared the original post as well. It is not known whether Instagram had the same effect or not.

Use of Networking

The networking I have done and the various contacts I have gained over the years from working with people with ASD was a great advantage to conducting this study. My social networks are made up of people involved in the autism community, whether they are family

members of someone with autism, know someone who has a family member with autism, or have friends with autism. This significantly helped in recruiting participants for the study. The information was spread around via social media to the community that was being recruited. It was also helpful to have very supportive friends and family members willing to share the information about the study on their own social media sites to further spread the information to potential participants. The recruitment process occurred in a timely manner.

Data Collection

Participants were provided with a link to the online survey from an electronic recruitment flier. Those who wished to participate clicked on the link to the survey via a Facebook or Instagram post and were directed to a screening questionnaire to determine if they qualified or not. If they did not qualify, a message appeared informing them of this. They were thanked for their time, and they did not have access to the survey. If they did qualify, participants were directed to an electronic consent form, which they were prompted to review. If they did not consent to participate they had the option to opt out by exiting the website. If they did consent to participate, they electronically signed the consent form. Contact information for myself (the researcher) and the school was provided should participants have any questions before consenting. Once the consent form was signed, they were directed to the survey consisting of open-ended questions and demographic questions. Participants had the option to opt out of participation at any time during the survey process if they changed their mind. A total of 18 participants completed the demographic and open-ended questions of the survey (Appendix F).

CHAPTER IV

Findings

This chapter documents the findings from 18 anonymous semi-structured interviews conducted with caregivers of children autism via an online survey. Results suggest that high and low SES caregivers experience many of the same service barriers, but high SES caregivers report more variety of service barriers than low SES caregivers. Both groups shared some ideas of solutions to service barriers; however, high SES caregivers presented significantly more service barrier solutions than low SES caregivers. High SES caregivers provided more detailed answers to the open-ended questions with a plethora of service barriers they have experienced; whereas, low SES caregivers provided short answers containing less variety of service barriers.

Demographics

Overall, the demographics showed that most participants were age 31-49 (n=12), their child was age 5-12 (n=12), they were married or in a domestic partnership (n=15), they identified as White (n=15), and had a four-year college degree or higher (n=11). More than half of the participants were identified as high SES (four-year college degree or higher; n=11); less than half were identified as low SES (trade school/specialized training or lower; n=7). The demographics were divided into two different groups per their SES identification.

There was a total of seven low SES identified participants (n=7). Of those seven people, five participants were between the ages of 31 and 49 (n=5), one person identified as being between the ages of 18 and 30 (n=1), and one person identified as being between the ages of 50 and 69 (n=1). Most of their children were between the ages of 5 to 12 (n=6), and one child was identified as being between the ages of one and four (n=1). Most of the participants identified as being married or in a domestic partnership (n=6), and one participant identified as being

widowed (n=1). The majority of low SES participants identified as White (n=6), and one person identified as being Hispanic or Latino (n=1). Four participants identified their highest level of education as a high school degree (n=4) and three people identified as having completed trade school or specialized training (n=3).

There was a total of 11 participants identified as high SES (n=11). Seven of these people identified as being between the ages of 31 and 49 (n=7), two identified as being 18 to 30 (n=2), and two identified as being 50 to 69 (n=2). The majority of the participants identified their child being between the ages of 5 and 12 (n=6), four people identified their child being between ages 13 and 17 (n=4), and one person identified their child being between ages 1 and 4 (n=1). More than half of the participants identified as being married or in a domestic partnership (n=9), and two people identified as being single (n=2). Most of the participants identified as being White (n=9), and two participants identified as being Asian or Pacific Islander (n=2). Nine out of the 11 participants in this category identified as having a 4-year-college degree (n=9), and two people identified as having a graduate degree (n=2).

The next sections will discuss participants' answers to the open-ended questions asked in the second part of the survey. Participants were asked five open-ended questions, and were given space to type out their answers. They were asked about the sources they get their information about resources from and their satisfaction with those sources, the barriers they may have experienced in accessing resources for their child with ASD, their perspective of possible service barrier solutions, and how they feel their suggested solutions will improve their experience in accessing necessary resources for their child.

Sources of Information and Satisfaction with These Sources

The first question of the open-ended portion of the survey was stated as follows: Some caregivers receive information about services for their child with autism from school officials such as a counselor or teacher. Others may receive information from the child's therapist, a friend, family member, an autism support group, or even the internet. Where do you receive the majority of your information about available and the most beneficial services for your child with autism? How would you describe your satisfaction with this/these referral source(s)? Explain.

The results present common sources of information for both low and high SES caregivers. High and low SES caregivers appear to gain information from several of the same sources. Some of these sources include, military EFMP (Exceptional Family Member Program) (n=2), independent research (searching the internet, reading books, etc.; n=11), referrals from therapists (n=4), in-person or online support groups (n=7), the child's school (n=2), the local regional center for people with developmental disabilities (n=3), or the child's physician (n=2). Although they shared these various sources, high SES caregivers reported more sources than low SES caregivers. High SES caregivers also reported sources such as resource fairs for people with disabilities (n=1), the child's case coordinator (n=2), the hospital social worker (n=1), and friends who work in the field and have knowledge of resources for the caregiver to refer to (n=1).

High SES caregivers provided more detailed answers about their sources of information and satisfaction levels. Some of the things they reported dissatisfaction with include confusion about what professional opinions will benefit their child most (n=1), feeling aggravated not knowing search terms related to autism (n=1), and sources being unhelpful in giving information (n=4). Caregivers expressed that they were unable to obtain helpful information unless they actively advocated for their child. One participant stated, "I have found that most organizations do [not] share information up front. They only provide information once the parent pushes for

it.” Both low and high SES caregivers expressed concern for the lack of knowledge and experience many service providers seem to have. Another participant shared about their experiences with various service providers:

Initial information came from our local regional center. Information was poor, services were not appropriate (I learned later), primary physician offered little to no information and never offered any services. Over the course of 6 years and dozens of therapists, doctors, teachers...we had 3 that made the biggest impact.

With little to no knowledge or experience with autism, caregivers fear the progress of their child’s treatment is being significantly impacted. Both high and low SES caregivers shared concern for the lack of help from the child’s school. One caregiver described the school as a “joke” when it came to accessing resources and information for their child. Other participants expressed general dislike for the lack of help from the school system.

Between high and low SES caregivers, 50% (n=9) of the caregivers have found that doing their own independent research has been one of the most helpful ways of gaining helpful information for their child. One participant stated that they simply “called anyone and everyone” to seek information for resources to benefit their child’s treatment. Many parents specifically described using social media to connect with other caregivers who may have information to share. The second most helpful source discussed was support groups. Many of the participants explained that networking with other caregivers of children with ASD is helpful in gaining information and relating to others in a similar situation. A participant discusses their experience with support groups and learning from other caregivers about the good resources and the ones to avoid:

About four years ago I found the organization Autism and Aspergers Connections and joined their private Facebook page and started attending support groups. I found the parents to be extremely helpful when finding services. Even better, they gave me personal recommendations, good and bad.

Some caregivers reported going to in-person support groups or joining online support groups via Facebook.

Caregivers appeared to have a surplus of dissatisfaction with their experiences in gaining information about services and other resources for their child with ASD. They have found some satisfaction with their experiences, but it is typically with an individual experience and knowledgeable service provider who has been helpful in guiding the caregiver and their families through systems to gain access to necessary treatments for the child.

Service Barriers

The second question of the open-ended portion of the survey was stated as follows: Some caregivers have reported experiencing barriers to accessing services for their child with autism such as transportation issues, financial strain, long waiting lists to access services, and not enough providers with knowledge about autism and additional diagnoses the children may have. What barriers have you experienced in accessing services for your child with autism?

Between low and high SES caregivers, there was a total of 15 service barriers reported: 6 were solely reported by high SES caregivers and 9 were shared by both groups. Although most of the reported service barriers were shared by both groups, high SES caregivers reported significantly more service barriers than low SES caregivers. There were no service barriers reported by low SES caregivers that were not reported by high SES caregivers. Existing research has similarly presented findings that suggest high SES caregivers report more barriers, possibly

due to high SES caregivers having more access to services (Durkin et al., 2010). However, it was surprising to find that high and low SES caregivers shared many of the same experiences with service barriers. Previous research has suggested at least some differences in barriers experienced by caregivers; in this study, the difference exists in number of reported barriers rather than types of barriers.

High SES Caregivers

Service barriers reported solely by high SES caregivers included lack of childcare for their other children, lack of consistency among various service providers, inflexible service hours, caregiver's personal thoughts and perceptions of autism, lack of their own knowledge about autism, and long transition processes prior to beginning a treatment. Many of the caregivers feel uneducated about autism and resources because of the lack of communication they have received from service providers.

Low and High SES Caregiver's Shared Service Barriers

Service barriers reported by both low and high SES caregivers included long waiting lists (n=10), financial strain (n=8), lack of service provider knowledge and experience (n=4), time management (n=2), lack of available service providers (n=2), transportation (n=3), issues getting a diagnosis (n=3), insurance coverage and qualifications (n=7), and lack of communication from service providers (n=2). Most of the participants discussed these service barriers in connection to one another. In other words, one barrier has sometimes caused another one for some caregivers. For example, one high SES participant discussed the obstacles they faced in getting a diagnosis for their child, the struggles they endured with insurance, and the long waiting periods that came along with it all:

My child was diagnosed in first grade, although we knew years before. I had been advocating for a diagnosis when he was two years old. We were unable to get a doctor on board to send any referrals to get testing. They sent us to individual therapy at a mental health center instead, which is where he was diagnosed. At the time, he was on Medicaid and there were no providers that took Medicaid in our area. There were also long wait lists for OT, PT, and speech for people with Medicaid. There is still a 4-6 month waiting list, no matter what insurance, to get in for an evaluation with a neuropsychologist.

Other caregivers have also had difficulty accessing services for their child due to the amount of time it can take to access the services needed. Another participant stated, “My son hated therapy because it was no longer appropriate for his needs..I made a decision to remove him from therapy at this point...I contacted our insurance who sent me a large list of providers, the good ones had year long waiting lists.” This suggests that caregivers not only struggle to access services in general, but they also struggle to access services that will be the most beneficial for their child’s needs. Wait lists can especially create barriers to accessing services for families who may have to move. A participant describes their experiences being a part of a military family:

Wait lists can sometimes be a burden. We are a military family who moves every three years. Every time we move, new referrals have to be put in place, and then the service provider has to make appointments. The quickest I have been able to complete the process is three weeks. If there is a wait list on top of that (up to eighteen months), one third of our time is gone before we are starting the process again.

Another participant also discusses their son’s progress in treatment suffering due to these long processes of getting appointments for evaluations and long waiting lists to be accepted into

programs; this person reported observations of her son “falling behind” rather than making progress because he is unable to pick up where he left off in a previous program and has a lack of consistency in his treatment.

Along with long processes and waiting lists, low and high SES caregivers also reported insurance coverage and qualifications as a significant service barrier. One participant reported, “The waiting list for diagnosis was about two years. Finding a psychiatrist to help treat behavioral issues is very difficult. They either aren’t covered under insurance or there’s a shortage of providers with experience in autism.” Many caregivers are finding that it is not only difficult to access a diagnosis and services for their child, but it is also difficult to access resources at all because of insurance restrictions. Sometimes a long waiting period could also be due to unavailable experienced service providers. A participant stated, “The waitlist at most places is absolutely ridiculous! Along with the price, financially our son participating in ABA therapy is putting us in a terrible situation.” Similarly, another participant described their family’s struggles to balance financial strains:

I had to quit my job for a while in order to make time for all of his therapies, and that left us with even less money to pay for them. My husband is a teacher, so his job doesn’t pay enough for me to stay home full time and care for our son. At the same time, we had to pull our son from school and begin homeschooling him because the school staff was not trained to work with him, and so we have to pay a full-time nanny in our home, because he cannot go to daycare (he’s 11)...We make too much for our son to qualify for Medicaid, he is too “high functioning” to qualify for disability, but our private insurance doesn’t cover most things that our doctor recommends.

Some participants reported gaining full insurance coverage for the services their child needed, but for other caregivers it appears to be more difficult financially. Caregivers reported many insurance coverage or qualification restrictions that made it difficult for them to access necessary services their child needed.

For some caregivers, insurance is not a concern, but they still have other financial strains to worry about. One participant explains some of these other concerns:

Financial strain can be an issue because even if insurance covers services fully; there is still driving, purchasing items for therapies (sensory toys, school supplies for aba, laptops for school, replacing items), outings to assimilate child...all of this takes time. Taking care of my child, appointments and care for other Child in the home prevents working, so we are a one income family. We spend approximately 500.00 a month on the aforementioned items, not counting co-pays or non-covered services.

Participants portrayed the various ways in which different service barriers intertwine. The intersection of several barriers creates more difficulty for caregivers to access services and or gain knowledge of services for their child with ASD. Although high SES caregivers provided more elaboration about their experiences and reported more barriers than low SES did, both high and low SES caregivers shared many of the same experiences in accessing services. More than half of the total service barriers reported were shared by both groups.

Solutions to Service Barriers

The third question of the open-ended portion of the survey asked about solutions and was stated as follows: There are ways that service barriers can be resolved to make it easier for caregivers to access services for their children with autism. Services can be made more accessible through the suggestions of caregivers who are directly impacted by barriers. What do

you believe would be possible solutions to the barriers you have experienced when trying to access services?

There was a total of 16 solutions suggested by participants. Three of the suggested solutions came from low SES caregivers, nine of the suggested solutions came from high SES caregivers, and four were suggested by both groups. Some of the participants shared the same ideas of solutions. There were some differences observed among these solutions. High SES caregivers appeared to base their suggestions on specific issues. Low SES caregivers made suggestions that were broader.

Low SES Caregivers' Ideas of Solutions

There was a total of three suggestions solely made by low SES caregivers for service barrier solutions: referrals to resources within close proximity of home (n=1), more services within the school system (n=1), and passionate service providers (n=1). Low SES caregiver responses suggest a need for more convenience to ease some of the barriers they experience. Low SES caregiver suggested that referrals be made for resources that are within close-proximity of the home. Barriers such as transportation and time management make it difficult for caregivers to make it to appointments for their child. There was a common theme among both high and low SES caregivers that the school is particularly unhelpful in accessing services, but the low SES caregivers specifically addressed this issue in their answers and suggested that services be offered within the school system. This would offer more convenience for families to balance the services their child with ASD needs, as well as other aspects of life, such as having time for their other children. Low SES caregivers also suggested that only passionate service providers be hired to work with children with ASD. Caregivers hope this will decrease the immense amount of turnover they experience with providers, which would help bring more

consistency to their child's treatment. Some low SES caregivers shared ideas of solutions related to quality of care, such as trainings for service providers so they can be more knowledgeable about autism. However, most low SES caregivers appeared to be more concerned about convenience of services because without convenience, services would be more difficult to access or not accessible at all.

High SES Caregiver's Ideas of Solutions

There were nine suggested solutions only from high SES caregivers: more collaboration between caregivers and service providers (n=2), travel vouchers (n=1), more available service providers (n=2), more home/community/school visits (n=2), telephone or webcam appointments (n=1), assistance with time management (n=2), shorter waits lists so treatment can begin sooner (n=1), education opportunities for caregivers (n=2), and resources for the child's transition into adulthood (n=1). The high SES caregiver reported more specific solutions to individual issues they have experienced. For example, high SES caregivers suggested there be more collaboration between caregivers and service providers. Caregivers desire an active role as part of the treatment team, and feel more progress will be made and their needs and their child's needs will be heard if service providers and caregivers are consistently and actively working together in the child's treatment. One participant specifically suggested that there be more home/community/school visits from service providers or they have more telephone/webcam appointments with service providers. High SES caregivers also suggested travel vouchers be provided. Like low SES caregivers, high SES caregivers reported struggling with transportation at times. However, high SES caregivers directly addressed this issue and suggested this possible solution. Another suggestion included more available service providers. High SES caregivers reported a lack of available service providers; therefore, their child ends up on a long waiting list.

High SES caregivers suggest that more available service providers will lighten caseloads, which will help service providers make more time for each individual client. Caregivers also specifically addressed the need to shorten wait lists so their children may access services sooner. Another suggestion involved assistance with time management. For example, many caregivers reported their children have multiple appointments in one day, and they find it difficult to have enough time in a day to make it to all appointments on time and balance other aspects of their lives. High SES caregiver also expressed a desire for educational opportunities for caregivers to learn more about autism. Several caregivers found the beginning stages difficult to cope with and felt like they did not know anything about autism. They expressed a need for more support in gaining knowledge about their child's diagnosis, and they reported that more educational trainings for caregivers may remedy the barrier. Last of all, one high SES caregiver, whose child is in adolescence suggested a need for resources regarding a child's transition into adulthood, specifically housing resources. Many caregivers fear what will happen if they are unable to care for their child any longer. More trainings, educational resources, and services for adolescents transitioning into adulthood may help alleviate some of the stress caregivers experience about the unknown.

Improvement to Caregiver Experiences

The fourth and final question of the open-ended portion of the survey asked about improvements in caring for a child with autism and was stated as follows: How will these solutions help improve your ability to care for your child with autism?

Both high and low SES caregivers expressed they would generally feel more supported if the suggested solutions were implemented. The specific ways in which they would feel supported differed. Low SES caregivers proposed their child would have a better quality of life

in general, their child would have a better sense of community and belonging, and the unique and individual needs of each child would get met. High SES caregivers proposed there would be improvements in time spent in treatment rather than research for resources, less anxiety and panic for caregivers, more accessibility in accessing resources and navigating the system, and alleviating fears of the adolescent to adulthood transition. Both groups proposed the children would be able to access the treatment they need (some caregivers cannot afford treatments so the children do not participate at all), and there would be greater success in the child's progress.

CHAPTER V

Discussion

The objective of this study was to examine the difference between low and high SES caregivers' ideas of service barrier solutions. Their experiences with service barriers, their sources of information, and their satisfaction with their sources of information was examined. The results of this study present similar results to previous studies; however, the findings presented a new perspective of solutions to service barriers for caregivers of children with autism.

This chapter will discuss key findings and how they compare to existing literature. The strengths of this study, as well as limitations of this study will also be addressed. Lastly, recommendations for future research regarding ASD and implications for social work practice will be examined.

Key Findings: Comparison with the Previous Literature

This study attempted to answer the question: how does SES of caregivers for children with ASD influence their ideas of service barrier solutions? The purpose of this study was to examine caregivers' perspectives of service barrier solutions and how SES influences their ideas of solutions. It was hypothesized that high SES caregivers would report experiencing less service barriers than low SES caregivers; therefore, there would be a difference in their ideas of solutions. However, the findings of this study concluded that high SES caregivers experience more service barriers than low SES caregivers. Many of the service barriers reported were shared by both low and high SES caregivers, but high SES caregivers reported a higher number. The suggested solutions provided by high SES caregivers were more specific to individual

experiences than the solutions suggested by low SES caregivers. Low SES caregivers reported broader solutions to service barriers.

It was interesting to find that high SES caregivers provided more elaboration about their experiences than low SES caregivers. Many of the answers high SES caregivers provided were elaborated in lengthy answers. However, many of the low SES caregivers provided straightforward answers with little to no explanation. Durkin et al. (2010) concluded that high SES caregivers tend to have more access to services and various sources of information than low SES caregivers. It is possible that the high SES caregivers who participated in this study had more to say because they have the means of accessing more services; therefore, they have more knowledge. Many of the low SES participants reported choosing not to have their children in therapy at all due to lack of insurance coverage and high out-of-pocket costs. It is possible their knowledge is limited due to participating in fewer services.

The findings of this study were like those of the Pickard and Ingersoll (2016) study, which found that high SES families were likely to have more knowledge of services and to make use of those services than low SES families. In the Pickard and Ingersoll (2016) study, researchers concluded that low SES caregivers desired more convenience to alleviate stress such as respite care, in-home services, and parent trainings. Similar requests were made from participants in this study such as recommendations to resources closer to home and educational opportunities for parents. Also, like the Pickard and Ingersoll (2016) study, this study concluded that high and low SES caregivers reported a lot of the same barriers and many of the same service barrier solutions. Even though high SES caregivers reported a higher number of suggested solutions, about half of those were shared by low SES caregivers. High SES

caregivers are more vocal and have more knowledge to share, but both low and high SES caregivers share the many concerns and have similar ideas of how to remedy those concerns.

Sperry et al. (1999) conducted a study that compared caregiver and service provider's ideas of service barrier solutions. They found that they shared many of the same concerns that included issues of finance, training, family support, early identification, parent-provider collaboration, advocacy, equity, and inclusion (Sperry, et al., 1999), which are also concerns reported by caregivers in this study. One of the most significant concerns reported in this study and Sperry et al. (1999) was the lack of parent-provider collaboration. It is important to caregivers that they can actively work with service providers to meet the needs of their child. It is interesting to find that the struggles addressed in Sperry et al.'s 1999 study are still very relevant today for caregivers of children with autism. It appears to be difficult to find an effective way for caregivers and service providers to successfully collaborate.

Issues with insurance coverage was also a similar finding between the two studies. Caregivers report finding it difficult to access insurance coverage for the various therapies their child needs. Therapies are too expensive for caregivers to afford on their own, so without coverage they are unable to access services for their child. Financial strain is a significant barrier for all caregivers, high or low SES.

Dymond et al. (2007) also conducted a study examining service barrier solutions. The four themes they discovered align with the results of this study. Many caregivers want to see more trainings available for everyone involved in the child's treatment. Without caregiver knowledge, understanding ASD and navigating the system can be difficult. Without service provider knowledge, the child may not receive adequate services. It is important to caregivers that everyone involved is provided efficient trainings so everything can help the child effectively.

Also, it can be difficult for anyone to access services without the financial means to do so. Therefore, it is imperative to caregivers that service be made more financially accessible. There are caregivers who qualify for insurance but the child's treatment is limited because insurance only covers certain treatments. Sometimes the child does not qualify for insurance at all because the caregivers make too much money, and since out-of-pocket costs are expensive, the child is limited in what therapies they can participate in. There is a vital need for more affordable costs in ASD treatment.

There are also some differences between this study and previous studies. For example, this study had the advantage of making information about the study more easily accessible than technology has allowed in the past because of social media. With the use of apps or websites such as Facebook and Instagram, information can be dispersed easily and quickly. Social media also makes finding the target population more accessible. Posting a flier on a bulletin board at an office could be helpful, but there is no guarantee that potential participants would see the information. Through social media, the information can be more conveniently sent to multiple potential participants. Participants even discussed the use of the internet as a helpful resource for finding services and other resources for their child. Participants also mentioned Facebook as a helpful way of joining support groups. The use of social media for support groups allows caregivers to access support when needed, rather than waiting for an in-person meeting to discuss their struggles. At one point in time, the internet did not exist and the support systems available to caregivers were not as convenient or accessible. Today, caregivers can access meetings with caregivers via video chat, such as Skype or Google Hangout (free video chat services). It is important to recognize that even though the internet has created more convenience and accessibility for many caregivers, it has also created barriers for other

caregivers. Not all families can afford the technology (e.g., smart phone, computer, laptop, tablet, etc.) necessary for accessing social media, skype, google searching resources, and other conveniences the internet provides for accessing information and support. This is something services providers should consider when working with families of children with ASD.

Strengths of the Study

In this section, the strengths of the study will be addressed. One identified strength is the use of a qualitative approach. There are few studies that use a qualitative approach in the field of ASD and it is important to use this research method to gain information from the participant's perspective. Another identified strength examined is the use of a social justice framework. It is important to examine and dismantle the marginalization of disabled people, and how the loved ones of people with disabilities can help.

Giving Caregiver's a Voice

The qualitative method of this study allowed space for caregivers of children with ASD to voice their experiences and opinions. Sometimes it can be difficult for caregivers to feel heard when collaborating with service providers or accessing services for their child. This study provided them an opportunity to let their stories be known and to be a part of the solution, rather than leaving it in the hands of a service provider to determine what is best for the children. The continuation of qualitative work with caregivers of children with ASD is important because it provides updated information about caregivers' experiences with service barriers and any new ideas they may have about how to remedy or alleviate service barriers.

Social Justice Framework

The various social identities of people are often ignored. It can be useful to examine the intersection of social identities rather than just one at a time. This study focuses on the

intersection of disability and classism by examining the ways SES influences the needs of people with disabilities. It is very uncommon for ASD research to use a social justice approach, but the use of a social justice framework is important to examine to understand the societal standards and judgements that people with disabilities face. This framework would also aid in gaining perspective on how the loved ones of people with a disability are impacted or even unintentionally contributing to the marginalization of people with disabilities.

Limitations of the Study

Small Sample Size

Although there were an adequate number of participants in this study, a larger sample size may have created more information or new ideas of solutions to service barriers and the influence of SES on caregivers' ideas of solutions. Having a small sample size makes it harder to generalize to a larger population; therefore, a bigger sample size may create more generalizability. A larger sample size may also present the opportunity of collecting more elaborated answers, giving the research more information to work with. Some of the participants gave short answers with little to no elaboration. More elaborated answers would provide the research more information to work with.

Measuring SES

This study replicated previous studies by measuring SES using education (Pickard & Ingersoll, 2016). If a caregiver had a four-year college degree or higher, they were considered high SES; anything less was considered low SES. However, there are other ways SES can be measured. One may argue that SES can be measured objectively through the caregiver's financial position. Previous studies have suggested using both objective and subjective measures of SES. The SES of the caregiver would be measured objectively with educational achievement,

and it would be measured subjectively by asking the caregivers how they personally identify their SES. The comparison between how society perceives their SES and how the caregiver perceives their SES would create more reliability and validity for the study. Measuring strictly with education creates assumptions about what caregivers can and cannot afford, as well as whether they are even utilizing their education. Some people go to college but end up in a career unrelated to their education, or some people face difficulties in finding work after graduating. SES is typically associated with current financial status (Rubin et al., 2014). However, a person's education does not necessarily determine financial status. Asking caregivers how they personally identify may create a more accurate portrayal of the caregiver's true SES. If SES was measured this way in this study, it is possible some of the high SES caregivers may have identified themselves as low SES or vice versa.

Generalizability

Unfortunately, this study is not generalizable to the ASD community. There are a lot of people who play a role in the treatment of a person with ASD. Caregivers have an important role in the life of a child with ASD. However, this study does not focus on the experience of the child with ASD. By asking the caregiver to speak for the child, it takes the child's voice away. Therefore, this study cannot be generalized to the stressful experiences a child with ASD may experience from the difficulties of accessing services. Also, there are people with ASD of many ages who experience different type of services and go through different processes to access services. A caregiver of a child with ASD may differ from the experience of a caregiver of an adult with ASD. Therefore, the results of this study could not be generalized to caregivers of adults with ASD.

Recommendations for Future Research

It is recommended that future researchers consider a social justice framework. It is important to recognize the various social identities people hold and how those identities intersect with one another. It is common to find that systems discriminate against marginalized communities, such as people with disabilities. It is suggested that researchers further examine the ways in which marginalization impacts accessibility of services for people with ASD. The examination of ASD and social identities may influence the awareness of social injustices within the community of ASD. It is suggested that future researchers conduct qualitative studies examining the perspective of people with autism. It may not be possible to include someone who is nonverbal, but there are many people with ASD in society who have the verbal capabilities to speak for themselves and form opinions. It could be incredibly beneficial in social justice disability work to also give a voice to the people with a disability.

It is also recommended that research in the ASD field be continued and keep expanding as the needs of the ASD community evolves. There are many factors to consider that cannot be examined in one study. It is important to continue this work so that the community can be better served. ASD research is still very limited and is in need of more expansion. It may be helpful to examine the family system of someone with ASD. It may also be helpful to examine the transition from adolescence to adulthood. People with disabilities are considered a vulnerable population, not just in research, but in society as well. They are often considered fragile and incapable of advocating for themselves.

It may also be good to conduct this study with a larger population to increase the likelihood of generalizability to caregivers of children with autism. As stated previously, a bigger sample size may help the research collect more information than this study was able to collect, and more information may be helpful in gaining a more in-depth understanding of what

the caregivers are trying to communicate. A larger sample size could either help validate the results of this study, or help discover new information this study was not able to discover. It may also be beneficial to conduct this study with a quantitative approach to potentially uncover any data this study did not find.

Implications for Social Work Practice

The findings of this study will help clinicians gain a better understanding of what their clients need from them as service providers. Caregivers reported dissatisfaction with the lack of support they felt from service providers, and it is possible that it is not because service providers do not care, but rather they are over worked and have a lot of responsibilities to worry about. It is common for service providers to have large caseloads, which can make it difficult to remember to check in with clients to make them feel supported during a journey that may feel difficult for them. The findings of this study is a reminder for service providers that caregivers would like to be more involved as members of the treatment team, especially when they first discover their child's diagnosis.

Social justice is a part of the NASW Code of Ethics that all social workers are required to follow in their work with clients. This study highlights the importance of recognizing marginalized identities and remembering to implement social justice frameworks into work with clients. The findings of this study provide clinicians with information regarding how SES and disability intersect. They may use the information gained from this study to determine the best ways to support caregivers of children with ASD. For example, if a caregiver is struggling to access services for their child, a clinician can observe how SES may be impacting accessibility for them. It may be because they cannot afford the ipad and other expensive materials for therapy or it may be because their income is too high to qualify for insurance, and cannot afford

out-of-pocket costs. The clinician can use this information to collaborate with the caregiver and brainstorm solutions. One high SES caregiver admitted that their personal thoughts about disability being a bad thing was a barrier they experienced; the results of this study suggest that high SES caregivers would like educational opportunities for themselves. Clinicians may take this information and seize the opportunity to create educational trainings for caregivers at the agency or create educational/informational support groups caregivers can attend.

The findings of this study may also help clinicians gain insight of accessibility of services. It is possible that SES influences accessibility to knowledge of resources. High SES caregivers tend to have more access to resources than low SES caregiver; therefore, they tend to have more knowledge and experience with navigating the system (Durkin et al., 2010; Pickard & Ingersoll, 2016). With this knowledge, clinicians can ensure that all caregivers are receiving resources and referrals that will benefit their child best. The results of this study suggest that high SES caregivers feel uneducated about autism and services. If low SES caregivers have less access to information than high SES caregivers, then they may have very little to no information at all compared to high SES caregivers. It is important to make sure caregivers are informed about their child's diagnosis and available resources.

The findings of this study may help initiate the creation of trainings for service providers so they are more knowledgeable about autism. Many agencies train service providers enough so they are knowledgeable about how the agency functions, but do not go into depth about the diagnosis of autism. However, the results of this study suggest that caregivers want to see more service providers who are knowledgeable about autism and the autism community. Caregivers often feel like they have to take matters into their own hands, which can be exhausting. Caregivers seek service providers who they can collaborate with. Specialized training is not

typically provided in college. Therefore, it may be beneficial for agencies to provide in-depth trainings about autism to employees. If an agency does not have the resources or financial capability of providing these trainings to employees, they may want to compile a list of resources such as local community centers for people with disabilities or regional centers that may be able to provide trainings, so employees can easily seek out educational opportunities so they can be better informed about autism. The very same local resources may also be good educational resources for caregivers as well. Many caregivers are uneducated about autism as well when they first learn their child's diagnosis and feel lost. More Autism 101 trainings could be beneficial for both service providers and caregivers.

Most of the participants either discussed the need for services in schools, the little bit of help schools provided, or the lack of support they received from their child's school. This is interesting because most schools have some sort of special education program for children with disabilities. Many special education teachers are the only teacher in one classroom full of children with disabilities; they may have one or two teacher aides to assist, but it can be difficult even for three service providers to work with a classroom full of 15 to 20 children with disabilities. There may be a need for more research on how children with ASD are supported within the school system. There could be a lack of resources within the school, or maybe services exist, but there are not enough service providers. More research on this subject may help in gaining information about what the service barriers are within the school system.

This study uncovered that both high and low SES caregivers of children with ASD experience some kind of financial strain as a service barrier. Some caregivers make too much money to qualify their child for Medicaid, and end up having to pay for services out of their own pocket, which can be expensive. As one participant mentioned, therapies can be up to \$130 an

hour. Some caregivers cannot afford the tools necessary for completing treatment, such as an ipad. Other caregivers expressed concern for time management affecting costs; their child has so many mandatory therapies, they have to take time off from work to make sure their child is attending treatments, which means they are not earning income, and then it becomes difficult to pay the bills or even support their other children. Insurance coverage also differs from state to state, which can make accessing services difficult for families who move a lot, such as military families. There is clearly a need to research the financial strains caregivers experience to better understand why it happens and how it can be fixed. Other barriers may be something at a more micro level that service providers may be able to assist with. Financial strain is a barrier at a macro level that may require policy change.

Conclusion

The results of this study aligned with the results of many other existing studies that examined similar factors, such as SES or service barrier solutions. Caregivers share many of the same concerns and have many of the same ideas on how to remedy barriers they experience. However, high SES caregivers have more access to knowledge; therefore, they have more to elaborate on. Low SES caregiver have limited knowledge and sometimes feel very uneducated and unable to help their child. All caregivers need to be adequately educated on their child's diagnosis and the plethora of existing services. There is a need to make services more accessible financially, and there needs to be more communication and collaboration between service providers and caregivers. With improvements in these areas, the children may begin to show a significant amount of progress in their treatment. Researchers should continue to look for gaps in ASD research to discover other ways people with ASD and their families can be better assisted.

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Appendix A:
HSR Approval Letter



School for Social Work
Smith College
Northampton, Massachusetts 01063

March 8, 2017

Rachel Rodriguez

Dear Rachel,

You did a very nice job on your revisions. Your project is now approved by the Human Subjects Review Committee.

Please note the following requirements:

Consent Forms: All subjects should be given a copy of the consent form.

Maintaining Data: You must retain all data and other documents for at least three (3) years past completion of the research activity.

In addition, these requirements may also be applicable:

Amendments: If you wish to change any aspect of the study (such as design, procedures, consent forms or subject population), please submit these changes to the Committee.

Renewal: You are required to apply for renewal of approval every year for as long as the study is active.

Completion: You are required to notify the Chair of the Human Subjects Review Committee when your study is completed (data collection finished). This requirement is met by completion of the thesis project during the Third Summer.

Congratulations and our best wishes on your interesting study.

Sincerely,

Michael Murphy
Human Subjects Review Committee

CC: Tonya Strand, Research Advisor

**Appendix B:
Informed Consent**



Consent to Participate in a Research Study

Smith College School for Social Work • Northampton, MA

.....

Title of Study:

Socioeconomic Status and Autism Spectrum Disorder: Caregivers' Perspectives of Service Barrier Solutions

Investigator(s):

Rachel Rodriguez

rrodriguez@smith.edu

.....

Introduction

- You are being asked to be in a research study examining caregivers' ideas of service barrier solutions and influence of socioeconomic status.
- You were selected as a possible participant because you are at least 18 years of age or older, you are currently the legal guardian caring for a child with autism, and the child you are caring for is between the ages of 2 and 17.
- We ask that you read this form and ask any questions that you may have before agreeing to be in the study.

Purpose of Study

- The purpose of the study is to examine caregivers' perspectives of service barrier solutions, how socioeconomic status (SES) influences caregivers' ideas of solutions, to inform service providers of disparities between high and low SES caregivers' ideas of service barrier solutions, and to provide caregivers the opportunity to voice their perspective on solutions to barriers.
- This study is being conducted as a research requirement for my masters in social work degree.
- Ultimately, this research may be published or presented at professional conferences.

Description of the Study Procedures

- If you agree to be in this study, you will be asked to do the following things:
 - Participate in one online survey that will take up to 30 minutes.
 - Answer demographic questions asking for information such as your age, age of the child, marital status, ethnicity, education level, and socioeconomic status.
 - Answer open-ended questions regarding your experiences with service barriers you have experienced in caring for your child
 - Answer open-ended questions regarding your idea of service barrier solutions.

Risks/Discomforts of Being in this Study

- The study has the following risks:
 - This survey will ask for detailed answers about your personal experiences with the difficulties you have experienced in obtaining services for your child with autism. Some of the questions may result in feeling mild discomfort as the survey material may lead you to remember emotionally challenging memories.

Benefits of Being in the Study

- The benefits of participation are:
 - This study will provide caregivers of children with autism the opportunity to voice their experiences with challenges they have faced in accessing services for their child.
 - This study will provide caregivers the opportunity to voice their perspectives on solutions to the challenges they have faced with service barriers.
- The benefits to social work/society are:
 - Service providers will be able to better understand disparities between high and low SES caregivers' ideas for potential to remedy some of the service barriers caregivers face.
 - This study will assist service providers in finding ways to better accommodate their clients.

Confidentiality

- Your participation will be kept confidential. You will not be asked for your name. Therefore, it will not be possible to connect participants to any particular survey. All research materials, including surveys and consent documents, will be stored in a secure location for three years according to federal regulations. In the event that materials are needed beyond this period, they will be kept secured until no longer needed, and then destroyed. All electronically stored data will be password protected during the storage period. We will not include any information in any report we may publish that would make it possible to identify you.

Payments/gift

- You will not receive any financial payment for your participation.

Right to Refuse or Withdraw

- The decision to participate in this study is entirely up to you. You may refuse to answer any question or withdraw from the study *at any time* (up to the date noted below) without effecting your relationship with the researchers of this study or Smith College. Your decision to refuse will not result in any loss of benefits (including access to services) to which you are otherwise entitled. Since this is an anonymous survey, simply exit at any point by clicking on ‘escape’ at the top of the screen if you wish to do so. Answers to questions prior to exiting will remain in the survey up to that point, but I will have no way to know who you are, and the survey will be discarded as I will not use incomplete surveys in my study.

Right to Ask Questions and Report Concerns

- You have the right to ask questions about this research study and to have those questions answered by me before, during or after the research. If you have any further questions about the study, at any time feel free to contact me, Rachel Rodriguez, at rrodriguez@smith.edu or by telephone at [REDACTED]. If you would like a summary of the study results, one will be sent to you once the study is completed. If you have any other concerns about your rights as a research participant, or if you have any problems as a result of your participation, you may contact the Chair of the Smith College School for Social Work Human Subjects Committee at (413) 585-7974.

Consent

- Your signature below indicates that you have decided to volunteer as a research participant for this study, and that you have read and understood the information provided above. You will be given a signed and dated copy of this form to keep. You will also be given a list of referrals and access information if you experience emotional issues related to your participation in this study.

.....

Name of Participant (print): _____

Signature of Participant: _____ Date: _____

Signature of Researcher(s): _____ Date: _____

Appendix C:

Recruitment Flier Information

Socioeconomic Status and Autism Spectrum Disorder: Caregivers' Perspectives of Service Barrier Solutions

Please consider participating in my research study

Purpose of Study:

1. Examine caregivers' perspectives of service barrier solutions to improve access to services
2. Examine how socioeconomic status influences caregivers' ideas of solutions to assist in meeting the needs of all families
3. To inform service providers of the disparities between high and low SES caregivers' ideas of solutions to service barriers
4. Provide caregivers the opportunity to voice their perspectives of services that would be most beneficial to their families

You qualify to participate if...

- You are 18 years or older
- You currently care for a child with autism
- You are a legal guardian of a child with autism
- The child is 2 to 17-years-old

You DO NOT qualify if...

- You are under the age of 18
- You cared for a child with autism in the past, but no longer do
- You care for a child with autism but are not the legal guardian

If you qualify for participation, access the survey here →
https://qtrial2017q1az1.az1.qualtrics.com/jfe/form/SV_8CWxxT83eA1JdxH

Contact Info:
Rachel Rodriguez
rrodriguez@smith.edu



This study protocol has been reviewed and approved by the Smith College School for Social Work Human Subjects Review Committee (HSRC)

Appendix D:

Social Media Recruitment Message

“Hi there! My name is Rachel Rodriguez and I am conducting a research study for my Master’s level thesis. This study will examine how socioeconomic status (SES) of caregivers for children with Autism Spectrum Disorder influence their ideas of service barrier solutions. The purpose of this study is to examine caregivers’ perspectives of service barrier solutions and how SES influences their ideas of solutions. Existing research has explored caregivers’ experiences with service barriers, as well as the disparities that exist among caregivers from high and low SES. However, research has not focused on solutions to service barriers. My goal is to fill this research gap by examining the influence of SES on caregivers’ ideas of service barrier solutions. This will aid service providers in improving access to services according to the individual needs of the families. My goal is also to provide caregivers with the opportunity to voice their perspective on solutions to service barriers that would be most beneficial for their family.

Participation in this study will consist of completing an anonymous, online survey that will take up to 30 minutes to complete. The survey will consist of demographic questions and open-ended questions asking about personal experiences with service barriers and ideas of solutions to these barriers. At any point prior to submitting the survey, participants may opt out by simply exiting the page.

You qualify to participate if...

- You are 18 years or older
- You currently care for a child with autism
- You are a legal guardian caring for a child with autism
- The child you are caring for is 2 to 17-years-old

You DO NOT qualify if...

- You are under the age of 18
- You cared for a child with autism in the past but no longer do
- You care for a child with autism but are not the legal guardian

Attached to this post is a copy of the recruitment flier for this study. If you meet the qualifications and do not fall under the exclusion criteria listed above, then you may access the survey here → https://qtrial2017q1az1.az1.qualtrics.com/jfe/form/SV_8CWxxT83eA1JdxH

Have questions? I would be happy to answer! You can contact me by email at rrodriguez@smith.edu or by phone at (██████████) to discuss the study. Please feel free to share this information.

This study protocol has been reviewed and approved by the Smith College School for Social Work Human Subjects Review Committee (HSRC).

Thank you for your time!

Best,

Rachel Rodriguez, B.A.

Masters of Social Work Candidate

Smith College School for Social Work”

#autismspectrumdisorder #autism #asd #autismresearch #socioeconomicstatus #ses #solutions
#solutionfocused

NOTE: The hashtags are only effective on Instagram; therefore, they will only appear at the end of the Instagram post (not Facebook) in order to increase probability of potential participants seeing this recruitment post.

Appendix E:
Screening Questionnaire

1. Are you 18 years of age or older?
 - a. Yes
 - b. No

*If NO, sorry, but you are not eligible for this study

2. Are you currently caring for a child with Autism Spectrum Disorder?
 - a. Yes
 - b. No

*If NO, proceed to question 3. If YES, proceed to question 4

3. Are you currently the legal guardian of a child with Autism Spectrum Disorder?
 - a. Yes
 - b. No

*If NO, sorry, but you are not eligible to participate in this study

4. Is the child with Autism 2 to 17-years-old?
 - a. Yes
 - b. No

*If NO, sorry, but you are not eligible to participate in this study

*If YES, please proceed to Informed Consent

Appendix F:

Survey – Demographic and Open-ended Questions

Part I - Demographic Information:

- 1) What is your age?
 - a. 18-30
 - b. 31-49
 - c. 50-69
 - d. 70 or older

- 2) What is the age of the child with autism you are caring for?
 - a. Under 1 year
 - b. 1-4 years
 - c. 5-12
 - d. 13-17

- 3) What is your marital status?
 - a. Single/never married
 - b. Married/domestic partnership
 - c. Widowed
 - d. Divorced
 - e. Separated

- 4) What is your ethnicity?
 - a. White
 - b. Hispanic or Latino
 - c. Black or African American
 - d. Native American or American Indian
 - e. Asian/Pacific Islander
 - f. Other (please describe): _____

- 5) What is the highest level of education you have completed?
 - a. No high school degree
 - b. GED
 - c. High school degree
 - d. Specialized training/trade school
 - e. 4-year college degree
 - f. Graduate degree

Part II - Survey Questions:

- 1) Some caregivers receive information about services for their child with autism from school officials such as a counselor or teacher. Others may receive information from the child's therapist, a friend, family member, an autism support group, or even the internet. Where do you receive the majority of your information about available and the most beneficial services for your child with autism? How would you describe your satisfaction with this/these referral source(s)? Explain.
- 2) Some caregivers have reported experiencing barriers to accessing services for their child with autism such as transportation issues, financial strain, long waiting lists to access services, and not enough providers with knowledge about autism and additional diagnoses the children may have. What barriers have you experienced in accessing services for your child with autism?
- 3) There are ways that service barriers can be resolved to make it easier for caregivers to access services for their children with autism. Services can be made more accessible through the suggestions of caregivers who are directly impacted by barriers. What do you believe would be possible solutions to the barriers you have experienced when trying to access services?
- 4) How will these solutions help improve your ability to care for your child with autism?