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The Impact of Parent Training on Access to Care for Children with Autism Spectrum

Disorder by

Rian Brown-Beasley

A dissertation presented to the Faculty of the School of Education,

Arcadia University,

In partial satisfaction of the requirements for the degree

Doctor of Education

2020

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Thanks to my husband, Rory, for holding down the fort while I worked on my coursework and dissertation. I could not have done any of this without you. We make the best team. I love you.

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ABSTRACT

Autism Spectrum Disorder (ASD) is a developmental disorder that impacts communication and behavior. Parents of children with ASD have the difficult challenge to identify appropriate treatment to address their children's needs. There are unproven treatments that appeal to parents that can cause harm. Parents need targeted educational opportunities in evidence-based interventions such as Applied Behavior Analysis to foster positive outcomes for their children. The purpose of this study was to determine baseline parental knowledge of evidence-based intervention for children with ASD and if specialized parent training increased parental knowledge of ASD interventions, and to determine socioeconomic status was a factor affecting access to treatment for ASD services. It was hypothesized that targeted parent training would increase parental knowledge of ASD interventions, and that families with lower SES experience more barriers to treatment than their higher SES counterparts. This study used a quasi-experimental design using a pre-test and post-test, and a demographic survey. Results indicated that parent training did increase parent knowledge of ASD interventions. This study did not find that SES impacted access to treatment. This study was limited in scope primarily due to the small sample size. However, parent training can improve outcomes for children on the autism spectrum.

Keywords: Parent Training, Autism Spectrum Disorder, Socioeconomic status, Applied Behavior Analysis

Dedication

I dedicate this dissertation to my three children, Rory “Sammy”, Rae, and Riley. This work was arduous, but I did not give up. I hope this accomplishment has demonstrated to you that you can do all things with the help of God. I love you.

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Chapter 1: Introduction

Autism Spectrum Disorder (ASD) is a neuro-developmental disorder that impacts the social functioning and behavior of individuals across all ethnic, racial, and economic groups. There is significant variability in the severity of symptoms people experience as part of this neurological condition. It is characterized by varying degrees of social and communicative deficits including difficulty with social communication and interaction, repetitive behaviors, and patterns of restricted interests (Christ, Kanne, & Reiersen, 2010). ASD is also associated with extensive physical and neurological comorbidities such as epilepsy, inflammatory bowel disease, sleep disorder, and developmental disorders. The prevalence of ASD in the United States is growing each year, with an increase of 15 percent annually (Minjarez et al., 2010). According to the Centers for Disease Control and Prevention (2020), 1 in 54 children nationally have been diagnosed with ASD. Parents play an essential role in identifying evidence-based interventions for their children, and parents need accurate knowledge of the treatments available to support their children. Lizcano (2012) found that children with ASD often receive a more intrusive level of support (e.g., repeated prompting) while learning skills, which can lead to a reliance on prompts and limit independence. Hume et al. (2009) found that difficulty with independent functioning impacts the overall outcomes for individuals with ASD.

Research suggests that socioeconomic status (SES) impacts parents' ability to access services for their children with ASD (Pickard & Ingersoll, 2016). Children with lower SES are more likely to have unmet service needs than their higher SES counterparts, and the lack of parental education is a factor in this disparity (Casagrande & Ingersoll, 2017). The lack of parental knowledge makes families with lower SES less likely to seek out treatment compared to

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their higher SES counterparts (Porterfield & McBride, 2007). Furthermore, individuals with higher SES have more resources to dedicate to improving the health of their children which typically converts to better outcomes for them (King & Bearman, 2011).

Background and Justification

The purpose of this study was to determine whether baseline parental knowledge of evidence-based intervention for children with ASD impacts treatment choice and if specialized parent training increased parental knowledge of ASD interventions. Moreover, this researcher wanted to determine if socioeconomic status is a factor affecting access to quality service delivery for children with ASD. Austin et al. (2016) state there is an overwhelming demand for ASD services, but the services available are limited due to long waitlists. Children who receive an early diagnosis of ASD, early treatment services, and quality ASD care are predominately white and from upper-middle-class backgrounds (Carr, 2011; Carr & Lord, 2016). In contrast, families with lower SES experience considerable hurdles when attempting to access services (e.g., lack of transportation) that limit the availability of meaningful behavior interventions (Fox & Holtz, 2009). It is important parents are knowledgeable enough about the most effective interventions available to select and secure evidence-based treatments for their child. This researcher has worked with children with ASD for over a decade and has observed families select interventions, such as chelation therapy, that are not supported by quality research. There is a long list of unproven treatment options that make broad claims including “curing” ASD that can be understandably very appealing to parents. Moreover, some of these interventions are harmful and can even be fatal—including pseudoscience and antiscience treatments (Davis et al., 2013; Goldfarb et al., 2016). For example, chelation therapy gained popularity as a treatment for children with ASD as it promised to remove mercury and other heavy metals from the child’s

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body, thereby “curing” ASD. However, chelation therapy can have harmful side effects, including kidney damage, subsequent kidney failure, and death (Krenzelok & Baxter, 2010).

Parents who are informed about evidence-based interventions can prevent potentially harmful effects to their children and may see positive outcomes. Burkett et al. (2015) stated that African American parents lacked information about ASD and the resources available to them, which led to a lack of treatment for their children. This is further impacted by the tendency for African American children to be diagnosed later than white children, leading to the need for longer and more intensive intervention (Dababnah et al., 2018; Mandell et al., 2007). Children whose families’ lack resources are more likely to receive services that are not effective and less likely to have access to services overall. These systemic barriers are in part a result of a lack of education related to ASD services, indicating the importance of parental knowledge in gaining access to optimal behavioral interventions (Durkin et al., 2007; Pickard & Ingersoll, 2016).

Parental knowledge is a factor that limits children’s access to services. Additionally, some children do not receive sufficient services because of insurance limitations; parents with low income levels have a tendency to fluctuate jobs, which leads to gaps in health insurance coverage, resulting in inconsistent access to ASD services (Scalli, 2018). Moreover, children with low SES normally have public health insurance (e.g., Medicaid), which is associated with a lack of quality service and coverage (Kemnick et al., 2019; Stockwell et al., 2019).

The Research Problem

Parents of children with ASD should be educated on evidence-based interventions available to their child, as well as be provided with an explanation of the instructional challenges that could develop as a result of teaching practices and core deficits of the disorder that leads to prompt dependence. There is limited research on parents’ knowledge of quality interventions like

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evidence-based strategies for children with ASD, and if the progress of the children who receive evidence-based interventions differ according to their socioeconomic status (SES).

Literature has shown that parents with higher SES access more services geared toward treating symptoms associated with ASD, and this difference has been attributed to their increased knowledge of available ASD services as compared to their lower SES counterparts (Pickard & Ingersoll, 2016). Individuals with ASD of lower SES are more vulnerable to receiving an inadequate number of services, leading to fewer positive outcomes (Shattuck et al., 2012). More research is required to help establish a potential causal relationship between parental knowledge and access to treatment for children with ASD. In an effort to address the gap, provision of targeted educational opportunities for parents was studied. It was hypothesized that parent training would increase parental knowledge in ASD interventions, which would improve access to quality treatment. It was also hypothesized that families of children with ASD with lower SES encounter more barriers to access treatment than do their higher SES counterparts.

Setting and Participants

The project took place in a suburb of Philadelphia, PA. The 16 participants involved in this study came from a range of backgrounds: 37.5% of participants were white (not Hispanic), 50% of participants were black (not Hispanic), and 12.5% were multi-racial. The participants were from a range of SES levels. Participants were recruited from local agencies that provide behavioral and educational services using social media postings and flyers. In order to protect the identity of the participants, they were coded using a numeric system only. All participants completed a demographic survey to gather background information and participated in an educational workshop designed by the author. The workshop was provided using a web-based interactive platform known as Zoom due to the COVID-19 pandemic which impacted face-to-

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face contact given a shelter in place order and related limitations imposed by the Department of Health.

Audience

This research topic has implications for parents of children with ASD, as well as educators and clinicians who work directly with this population of children in urban and suburban settings. Findings from this study could be relevant to researchers interested in inequities in educational and public-health services.

Definition of Terms

Below are terms that are used frequently throughout this dissertation. They are included to orient readers to operational definitions.

Prompt dependence. Clark and Green (2004) define prompt dependency as an individual's ability to respond correctly being dependent on the presence of a controlling prompt, with the inability to respond when the prompting fades.

Prompts. Prompts are antecedent stimuli that seek to get responses to occur (MacDuff et al., 2001).

Functional Behavior Assessment (FBA). An FBA operationally defines behaviors as well as factors thought to increase the likelihood of their occurrence, given environmental stimuli (Cooper et al., 2007).

Applied Behavior Analysis (ABA). ABA is an intervention that uses the science of behavior analysis to alter the behavior of others (Baer et al., 1987; Cooper et al., 2007).

Evidence-based intervention. Evidence-based interventions, also known as evidence-based practices, are strategies proven to be effective through high-quality experimental research (Horner et al., 2005).

Operant conditioning. Operant conditioning is a method of learning governed by the idea that behavior is controlled by its consequences (Skinner, 1938).

Purpose of the Study

The purpose of this study was to evaluate the impact of a specially designed training on evidence-based interventions for children with ASD. The study also sought to determine if there is inequity in access to services for children diagnosed with ASD based on their family's SES.

Conclusion

ASD is a developmental disorder that impacts an individual's behavior and communication skills. Parents of children with ASD have a unique challenge to find effective interventions to improve outcomes for their children. The use of parent training to increase parental knowledge of evidence-based interventions can prevent harm for children with ASD. Applied Behavior Analysis (ABA) is an evidence-based approach that has much empirical evidence to improve the lives of children with ASD (Foxy, 2008). There is limited research on parents' knowledge of quality interventions like evidence-based strategies for children with ASD. Families with lower SES experience more hurdles to autism treatment than families with higher SES making it difficult to effectively support their children's needs.

This study created a 2-hour training workshop to provide information on evidence-based interventions and instructional challenges innate to autism for parents of children with ASD. This study was a quasi-experimental design using a pretest and posttest to determine parents'

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understanding of evidence-based practices for their child with ASD before and after the workshop. Demographic information was collected using a survey to determine if there was a disparity in access to care for children with ASD based on a family's SES. Although there were some limitations and needs for future research, this research moved the field of research in this area by underscoring the importance of parent training and confirming the need to make access to treatment for families easier regardless of SES.

The following chapter will provide a literature review of the current research on evidence-based interventions available for children with ASD, and research available on access to care related to socioeconomic status. The following chapters review the methodology used in this study, results, and an analysis of the findings.

Chapter 2: Literature Review

Many interventions exist for (ASD), yet scientific research has found only some of these interventions to be effective; these interventions are known as evidence-based interventions (e.g., EBPs). Evidence-based interventions are considered high-quality practices because they are based on empirical proof. There is an abundance of empirical support for the use of Applied Behavior Analysis (ABA) interventions with children with ASD (Lovaas, 1987; Koegel et al., 1987; Koegel et al., 1992; McEachin et al., 1993).

This chapter presents the conceptual framework of the science of applied behavior analysis, upon which the training workshop presented to parents in the study was based. It included information related to evidence-based interventions using the principles of (ABA), adherence to the prompt hierarchy, and other strategies such as generalization to increase the independence of children with ASD.

Burrhus Frederic “BF” Skinner is recognized as the founder of the science behind ABA, which is rooted in operant conditioning. Skinner’s theory of operant conditioning was based on the work of Edward Thorndike (1905), who studied basic learning in animals, coining the “Law of Effect.” Skinner used the “Law of Effect” as the foundation for operant conditioning. Operant conditioning is a mode of learning based on the ways behavior of organisms changes as a result of experience (Pierce & Cheney, 2004). Skinner (1938) contended that the science of behavior analysis centered on using environmental contingencies that can be observed to predict, and ultimately control, behavior.

In psychology, the stimulus-response theory has evolved out of classical conditioning in which a stimulus becomes paired with a response through experience. This leads to the concept that one’s environment can be manipulated in an effort to elicit a particular behavior change

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(Skinner, 1938). For example, the smell of an onion (i.e., stimulus) can produce the behavior of crying (i.e., response) through the sensory experience. Therefore, the next time you encounter an onion you may begin to tear prior to cutting it given the past learning. Antecedent, Behavior, Consequence is a contingency to shape behavior: stimulus, response, and reinforcement.

Antecedent is also known as a setting event; behavior is what the child does in response to the setting event, and the consequence is the action that follows it. An underlying principle of ABA is reinforcement: behaviors that are reinforced are more likely to be repeated, and behaviors that are not reinforced are typically extinguished (Cooper et al., 2007).

ABA is the process of applying the science of behavior analysis to improve human behavior. The science of ABA was first described as the current dimensions of ABA and practiced in 1968 (Baer et al., 1987). The formalized therapy of ABA was first developed in the 1970s by psychologists Ivar Lovaas and Robert Koegel at UCLA. It was based on the science of learning and behavior. The goal of ABA is to increase behaviors that are helpful and decrease behaviors that are harmful or affect learning. It originated with a primary focus on Discrete Trial Training (DTT) and has since evolved into a larger umbrella of interventions and related strategies. ABA therapy is now identified as one of the “gold standard” behavioral treatments for ASD, as it is the most widely researched and empirically validated treatment available. In fact, a small subset of children with ASD who have received intensive behavioral interventions have been found to be indistinguishable from their same age, neurotypical peers (Lovaas, 1987).

The Research Problem

Many individuals with ASD lack independent living skills, such as brushing teeth, and need direct instruction to acquire these skills, often using ABA techniques (MacDuff et al.,

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2001). These skills are taught using the prompt hierarchy which refers to the level of instruction one gives the child when instructing them on a particular task. The prompt hierarchy determines the level of prompting based on how intrusive the level of instruction is. Therefore, instruction may use targeted prompts including verbal, gestural, and/or physical aides to teach skills to individuals with ASD. However, this use of such prompts can also lead to prompt dependence in individuals with ASD. Prompt dependence is when an individual needs a prompt to initiate a skill or activity he or she has already mastered. Children with ASD have a greater risk of developing prompt dependence than their neurotypical peers (Clark & Green, 2004). For example, a child who is prompt-dependent might only demonstrate the desired response following a verbal prompt from a guiding parent or teacher, but he will not demonstrate the same response in the absence of that prompt. This may occur as a result of highly repetitive prompting, which children with ASD often receive during one-on-one instruction (Clark & Green, 2004) and a failure to fade or reduce this prompt over time.

“Fading” refers to decreasing the level of assistance needed to complete a task or activity. As a child gains mastery of a skill at a particular prompt level, the prompt is faded to a less intrusive prompt also known as the “least-to-most prompting procedure”. According to Neitzel and Wolery (2009), a hierarchy of prompts has a minimum of three levels: the first level is always the independent level (i.e., no prompts), and the remaining levels are sequenced from the least amount of help to the most amount of help. The last level of the hierarchy should be a controlling prompt—one that results in the learner doing the behavior correctly; this prompt can vary depending on the child. When teaching a skill, the overall goal is for the child to eventually engage in the skill independently. Therefore, a plan to fade the prompt should be part of the treatment plan from the very beginning.

Applied Behavior Analysis Interventions

Three evidenced-based ABA strategies used to teach independent skill acquisition to children with ASD are highly relevant and widely used by practitioners include Functional Communication Training (FCT), Pivotal Response Training (PRT), and Discrete Trial Training (DTT). These evidence-based interventions typically taught while working one-on-one with children, are part of this review because they have been found to improve independent skills and have a strong research foundation (Cividini-Motta & Ahearn, 2013; Gerow et al., 2018; What Works Clearinghouse, 2016). These strategies were incorporated into the training workshop developed as part of this study.

Functional Communication Training

Functional Communication Training (FCT) is an evidence-based intervention that teaches an alternative response that is functionally equivalent to the challenging behavior one is attempting to reduce or eliminate (Carr & Durand, 1985; Durand, 1990; Fisher et al., 1993). Schmidt, Drasgow, Halle, Martin, and Bliss (2014) found that FCT is an effective method for replacing problem behavior, once identified, with a functionally equivalent response. FCT relies on exclusively reinforcing the appropriate response (i.e., the behavior you wish to increase), while applying extinction—the discontinuation of a behavior reinforcement—to all other responses. This dual process, known as differential reinforcement, is frequently utilized within the practice of ABA (Cividini-Motta & Ahearn, 2013). Anderson, Barretto, McLaughlin, and McQuaid (2016) found that FCT was effective in reducing challenging behaviors, and replacing the behaviors concerned with socially acceptable replacement behaviors. A practical example of differential reinforcement would be the responses a teacher gives a child who wants to speak in class but frequently calls out: When the child raises his or her hand without calling out, the

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teacher would call on the child (i.e., reinforcing the appropriate response); when the child calls out, the teacher would not acknowledge the child's contribution (i.e., using extinction), ultimately leading to a decrease in disruptive behavior. Wacker et al. (2013) found that parents were successful in implementing FCT as an effective strategy that reduced problem behaviors by an average of 93%.

In ABA, differential reinforcement can be effectively used to teach communication skills that foster increased independence among children with ASD (Van Haaren, 2017). Some children engage in challenging behaviors due to deficits in communication inherent to the disorder, and some may also have learned that challenging behaviors are a means of accessing the things they want or need, based on their experiences. Therefore, teaching children to use more acceptable communicative behaviors that produce the same results as problematic behaviors can result in decreases in challenging behaviors (Bird et al., 1989; Carr & Durand, 1985; Durant & Kishi, 1987; Wacker et al., 1990). For example, a behavior analyst could determine through a Functional Behavior Assessment (FBA) that a child hits other children to gain access to a preferred object, a toy ball. Physical aggression is a negative behavior that should therefore be extinguished. The behavior analyst can work with the parent to teach the child to say "ball" to request access to the ball, in an effort to replace the physical aggression of hitting other people. FCT is found to be most effective when an FBA has determined the problem behavior is socially mediated (Fisher et al., 1993). FCT is a well-established evidenced-based intervention for problem behavior exhibited by children with ASD (Kurtz et al., 2011; Wilczynski & Pollack, 2009; NRC, 2001; Wong et al., 2015).

Pivotal Response Training

Pivotal Response Treatment (PRT) is a naturalistic behavior intervention that uses ABA techniques to target core impairments associated with ASD (Prelock & McCauley, 2012). The ultimate goal of PRT is to foster intrinsic motivation in children with ASD to respond to cues and social interactions, which can then serve to replace challenging behaviors (Koegel et al., 1999). Parents can use PRT to increase pro-social communication skills (Minjarez et al., 2010). It involves direct, explicit instruction that should be easily understood by the child. The child must then have the opportunity to actively choose the stimulus in which he or she is most interested, or, alternatively, the adult can choose the stimulus he or she knows the child prefers (What Works Clearinghouse, 2016). For example, a parent can present a preferred item such as a ball to the child, prompting, “What’s this?” When the child makes an attempt to verbally respond, the parent verbally confirms the item and gives the child access to the item in response to the request. Initially, the child may make any sound to gain access to the item; over time, the expectation is modified, and the child can only receive the ball when, for instance, making a “B” sound to request the toy. Items used in PRT are deemed to be naturally reinforcing or motivating to the child based upon teacher input, parent input, or reinforcer surveys. PRT opportunities should be incorporated throughout the day by collaborating with parents, teachers, and peers in an effort to increase communication skills and strengthening natural reinforcement (What Works Clearinghouse, 2016). PRT has been found to be effective with children who have difficulty generalizing skills because it uses the natural environment of the child to teach skills (Vismara & Bogin, 2009).

Discrete Trial Training

Discrete Trial Training (DTT) is one of the most commonly used ABA interventions for children with ASD. It is widely used and recognized as an evidenced-based intervention for

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children on the autism spectrum (National Autism Center, 2010). Its use relies on personalizing and simplifying instruction, systematically using prompts to promote accurate and independent responses. Discrete trial teaching is a systematic form of instruction that has been demonstrated to be an effective teaching procedure for children with autism (Lovaas, 1987; McEachin, Smith & Lovaas, 1993). Further analyses of the DTT have been conducted with children with ASD, and the results have found tremendous gains in cognitive abilities, language skills, and adaptive behavior (Bogin, Sullivan, Rogers & Stabel (2010; Wilczynski & Pollack, 2009; NRC, 2001; Wong et. al., 2015). For children with ASD it is mainly used to teach behaviors such as fine motor skills or speech (Smith, 2001). DTT uses discriminative stimulus, known as an “SD,” and targeted consequences following the elicitation of a correct response (Brand et al., 2018).

Whereas FCT and PRT are employed in a variety of settings, DTT is most often implemented in school settings, by a single clinician—which can limit the generalization of skills acquired. DTT’s generalizability can be improved, however, when other individuals implement it with fidelity, as well as when peers participate in instructional delivery (Steege et al., 2007).

Some children with ASD have also been found to respond to only parts of relevant cues used in DTT, without attending to all relevant portions of the targeted stimuli (Rieth et al., 2015). This phenomenon is known as stimulus over selectivity (Lovaas et al., 1971). One study by Wilhelm and Lovaas (1976) found that DTT is especially effective for individuals with ASD who have significant cognitive deficits. Despite its challenges, when implemented with fidelity and appropriate augmentation, DTT remains one of the most effective behavioral interventions for children with ASD.

One such strategy used to augment DTT is errorless teaching, a highly customizable strategy used to teach a variety of skills. Errorless teaching is designed to reduce incorrect

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responses by preventing errors (Mueller et al., 2007). An instructor completes multiple trials for a given question, maintaining an expectation for the correct response. When a child responds incorrectly or does not respond, the instructor elicits a correction, following a prompt hierarchy to reinforce the desired response. For example, an instructor would present a child with a red ball and a blue ball and say, "Touch the red ball." If the child does not respond or selects the blue ball, the instructor would point to the red ball and correct the error. After multiple trials, with the instructor using a prompt hierarchy, the child would be expected to respond appropriately going forward. This process of errorless teaching relies on immediate feedback and prompt fading to promote accuracy with the fewest number of errors and least amount of frustration.

Prompt Dependence

Stimulus control is a phenomenon that occurs when an organism behaves one way in the presence of a given stimulus and another way in its absence. For example, the presence of a stop sign at a traffic intersection alerts the driver to stop driving and increases the likelihood that the behavior of braking will occur. Individuals with ASD often lack stimulus control, as compared to neurotypical individuals. ABA, which relies on a variety of intervention techniques, has been an effective tool to teach stimulus control to children with ASD (MacDuff et al., 2001). Being quiet in a library is an example of stimulus control, with the simple presence of the library being a stimulus that indicates a response of no talking. Individuals with ASD typically do not have stimulus control unless they are systematically taught a given response, using prompts. Stimulus control is an essential life skill for independent skill development.

ABA therapy primarily uses prompts to teach skills related to stimulus control, which have been found effective for children with ASD. However, as a result, children with ASD are more likely to develop prompt dependence, which adversely affects their ability to independently

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demonstrate acquired skills. Prompt dependence is when a mastered skill is only demonstrated when a prompt is given (Clark & Green, 2004). For example, a learner may only perform a skill in the presence of the instructor who taught the skill, relying on the instructor himself as a prompt. Cividini-Motta and Ahearn (2013) suggest that prompt dependence might also be a result of the way instructors apply reinforcement in teaching skills, because in many settings they may give both incorrect and correct responses similar levels of reinforcement.

In general, children with ASD are likely to receive frequent prompts, which may also lead to prompt dependence (Milley & Machalicek, 2012). For individuals with ASD, prompt dependence is a significant barrier to acquiring independent stimulus-control skills. Therefore, systematically fading prompts and providing targeted reinforcement for accurate and independent responses using evidence-based ABA strategies help to increase the independent-skill acquisition of children with ASD (MacDuff et al., 2001).

Access to Care

Results from several qualitative studies focused upon African Americans who had one or more chronic illnesses found that low-income respondents expressed greater dissatisfaction with health care than did middle-income respondents (Lindly, Zuckerman & Kuhlthau., 2019; Magana et al., 2013; Lin & Yu, 2015). Low SES is an important determinant of access to health care as evidenced by the breath of literature and surveys. Person with low income are more likely to be Medicaid recipients or uninsured, have poor-quality health care, and seek health care less often compared to their higher SES peers. Children with lower SES typically have public insurance, which is also linked to other barriers to treatment such as excessive wait times to receive care. However, individuals with higher SES, who normally have private insurance, do not experience the same obstacles (Lindly, Zuckerman & Kuhlthau., 2019; Magana et al., 2013; Lin & Yu,

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2015; Rowan et al., 2013). Children with higher SES were found to receive more services than children with lower SES (McIntyre & Zemantic, 2017). The type of insurance that children with ASD have dictates the sector of the health care system in which they are seen. Middle-income persons usually seek care with private physicians or have health plans that provide comprehensive care through a health maintenance organization (HMO). Persons who had Medicaid coverage were seen primarily in hospital low-income clinics which are limited by funding and resources which have a direct impact on quantity and quality of care. The lack of access to care has been connected to poor outcomes for children with ASD (Kuhlthau et al., 2017; Zablotzky et al., 2015; Adler & Newman 2002). Therefore, the health care bureaucracy is a true obstacle when seeking both diagnosis and treatment for those showing signs of an Autism Spectrum Disorder. To reduce health disparities, it is necessary not only to overcome the present policy and develop universal health insurance that is equitable but also to undermine racist and class biases in the healthcare system that impact quality of care for those with lower SES.

Conclusion

Evidence-based treatment for ASD provides parents the scientific research to make well-founded decisions to meet their children's needs. Applied Behavior Analysis is an effective treatment for ASD and has an abundance of empirical support. The evidenced-based treatments that were highlighted in this chapter was because of their widespread usage, and the overwhelming evidence of their effectiveness to improve the lives of children with autism. FCT, PRT, and DTT are evidenced-based treatments when done well can lead to increased prosocial behaviors, independence and communication skills. Prompt dependence is learned helplessness that can hinder a child's ability to be independent by the child becoming reliant on a prompt. It's important for practitioners to implement plans to fade prompts to prevent prompt dependence.

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Children with lower SES experience hurdles to care due to lack of resources that their higher SES counterparts rarely experience. Many parents with lower SES receive less services for their children with autism which lead to poor outcomes for their children. Notable barriers that families with lower SES experience more often include delays in ASD services, and limited access to service providers to treat their children's needs.

The next chapter includes the methodology used in this study to include the structure of the parent training workshop that focused on evidence-based interventions for children with ASD. The parent training workshop took place on a website platform that was designed to help parents increase their knowledge in evidenced-based interventions for ASD. Teaching parents evidence-based intervention for autism can increase their children's independence and lead to beneficial outcomes for their children.

Chapter 3: Methodology

This chapter is a description of the methodology that was used to answer the research questions in this study. This chapter includes who was involved in the research and how this study was conducted.

Participants

The participants in this study included parents and caregivers of children with ASD who voluntarily elected to participate in the study. Participants for this study were solicited through social media posts and flyers shared with families whose children receive behavioral or educational services in the Greater Philadelphia area. A \$25 gift card was offered for participation in the study, awarded to one participant at random. To attempt to ensure a diverse group of participants, the researcher asked for information regarding participants' socioeconomic status (SES) beforehand. Individuals not selected for the study were provided with ASD resources (i.e., parent support group, free workshops, and special education guides). A power analysis was conducted using G*Power (Faul et al., 2007) to determine the difference between two dependent means (matched pairs) using a t-test, a moderate effect size ($d = .40$), an alpha of .05. Results of the power analysis showed that 40 participants achieved a power of .80.

Research Setting

This study took place during a worldwide pandemic (COVID-19), leading to the widespread closures of schools and universities throughout the United States. Many schools and universities in the greater Northeast Region moved to an online instruction to prevent the further spread of COVID-19. The governor of the state of Pennsylvania where the researcher resides had

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mandated shelter in place orders, and many states and countries around the globe had similar orders in place. Families had been confined to their homes for several months with most private, public and government buildings closed leading to record setting unemployment rates that has led to rampant financial despair. Many families have had difficulty coping under these extreme circumstances leading to depression and an increase in domestic violence disputes.

This study also took place during civil unrest due to race, and a polarized political landscape. The United States was more divided than ever, gridlock over issues involving race, the economy, and the presidential election had led to social protests across every state. The presidential election had led to further attacks on healthcare reform, and protections for pre-existing conditions. Treatment for ASD services have been limited or have been moved to telehealth, placing families with lower SES at a disadvantage because they are more likely to lack access to the internet which would limit their ability to secure services for their children with ASD.

Given the pandemic, this researcher made sure families had access to the needed technology (e.g. internet and devices) to access the workshop. The study utilized a two-hour online workshop via a web-based interactive program (i.e., Zoom). When participants entered the training session, they received a web-based survey tool (i.e., Qualtrics) to complete a pretest that gauged parents' understanding of evidence-based practices for their child ASD, family demographic information, and their child's service needs. The pretest was used to establish participants' baseline knowledge of the instructional content, details regarding demographic information, and current treatment services received related to their child's diagnosis of ASD. The researcher presented the training manual to participants using visuals, exemplars, and reference guides as part of the zoom training. After the workshop, participants were asked to

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complete a post-test, composed of the same statements as the pre-test, to determine if there was a difference in their level of understanding after the training.

Procedures

The purpose of this quasi-experimental design was to investigate the effects of training parents of children with ASD on available, effective ASD interventions, and to determine if SES is a factor in service access for children with ASD. The researcher conducted an initial screening of participants by requesting their demographic information to determine SES in order to select a balanced group of participants. Participants were asked to contact the researcher by phone to conduct the initial screening. The researcher collected basic demographic information to classify participants' SES based on income, education level, and occupation, factors that have been shown to more accurately capture SES than do other measurements (White, 1982). Higher SES was defined as parents whose children are not eligible for free or reduced-price lunch based on income and who have completed a bachelor's degree or higher, as well as by their current occupation. Lower SES was defined as parents whose children are eligible for free or reduced-price lunch based on income and who do not possess a bachelor's degree, as well as by their current occupation. Participants were given a pseudonym to use during the workshop to maintain their anonymity. Materials did not ask participants for any identifiable information; the data was anonymous. Attrition was not problematic because the interviews were conducted over a short period of time and the use of a virtual workshop helped to reduce any burden related to travel or childcare costs.

Recruitment Procedures and Study Timeline

Participants were recruited for this study via a research flyer posted on social media websites that provide treatment and support to families of children with ASD (see Appendix E). This flyer included a brief description of the study as well as a phone number to contact the researcher for the initial screening. Participants contacted the researcher by phone. The researcher did not ask participants any identifying information. The researcher read a verbal consent form (see Appendix C) prior to the screening process. Once verbal consent was given, the researcher conducted a verbal demographic prescreen to determine SES (see Appendix C). Using a pseudonym name generator, participants were given a pseudonym that was used for data collection and during the workshop. The workshop took place on the web platform, Zoom. At the start of the workshop, participants were given a pre-test (see Appendix A) that included demographic information and information regarding their child with ASD via the web platform, Qualtrics via a URL link placed in the chat. There was an informed consent landing page at the start of the pre-test (see Appendix F). The workshop presentation (see Appendix G) was presented that explained evidence-based interventions, instructional challenges related to ASD, and parent support information. Prior to the end of the workshop, participants were given a post-test (see Appendix B) using the web platform, Qualtrics via a URL link placed in the chat. There was an informed consent landing page at the start of the post-test (see Appendix F). At the end of the workshop a \$25 gift card was given away at random using a number generator.

Participants' Protections

All the participants in this study gave their informed consent through the pre-screening process, and prior to completing the pre-test and post-test. At no time were participants asked to provide any identifying information. The data collected for the prescreening used pseudonyms,

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was kept on a password protected computer, and destroyed at the end of the study. All other responses from the pre-test and post-test were collected through the third-party server, Qualtrics, and did not include any identifying information. Participation in the study was completely voluntary and no coercion was used to recruit participants. Participants could terminate their participation at any time without penalty.

Measures

Parents were asked to provide basic demographic information about themselves including their gender, race/ethnicity, employment status and job, level of education, marital status, and household income. Parents were asked to provide information about their child's age, age of diagnosis, and symptom severity. Symptom severity of ASD was measured using the Aberrant Behavior Checklist (ABC). According to the literature ABC is a good measure of severity of characteristics of ASD (Brinkley et al., 2007; Kaat et al., 2014). Parents were also asked to provide a list of barriers to service and indicate service needs. The researcher compared the ratings given on the pre-test and post-test measures and performed an analysis of the data using repeated measures. The Treatment Evaluation Inventory – Short Form (TEI-SF) was used as the pre-test and post-test to get parental understanding of evidence-based interventions for their child; this form was modified from the Treatment Evaluation Inventory for simpler application (Kelley et al., 1989). Cronbach's alpha, a measure associated with instrument reliability in research (Cronbach, 1951; Taber, 2016), was indicated. A reliability analysis employing Cronbach's alpha examined whether the series of questions were designed to measure the underlying themes in the survey and were internally consistent. Cronbach's alpha (1951) indicated acceptable internal consistency ($\alpha = 0.81$), which is consistent with reliability approximations (Rellini, et al., 2004; Volkmar et al., 1988). The pre-test and post-test (TEI-SF)

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was a 9-item measure composed of statements paired with a Likert-scale rating configuration which had good internal consistency (Choi & Kovshoff, 2013). The researcher analyzed the data collected for this study to answer the following research questions:

1. What knowledge do parents have regarding evidence-based interventions for children with ASD?
2. What is the effect of the training workshop on parents' knowledge of evidence-based interventions for children with ASD?
3. Is there a difference in service access of children with ASD based on their family's SES?

Conclusion

This study sought to determine if baseline parental knowledge of evidence-based intervention for children with ASD impacts treatment choice and if specialized parent training increased parental knowledge of ASD interventions. Moreover, this research sought to determine if socioeconomic status was a factor affecting access to quality service delivery for children with ASD. A specialized parent training was provided as part of this study to determine if parental knowledge was acquired as a result of this training. Demographic information was collected to obtain details regarding demographic information, and current treatment services received related to their child's diagnosis of ASD

The next chapter details the results in this study which determined if parental knowledge increased as a result of the parent workshop, and if SES impacted access to care. The literature has shown access to ASD treatment is impacted by SES resulting in families with lower SES receiving less services. This study also explored current treatment access for children with ASD,

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and if there were barriers to treatment experienced by the families in this study based on their SES.

Chapter 4: Results

The research method used was a quasi-experimental design. Possible benefits of participation in the parent training workshop were evaluated by analyzing data between a pre-test and post-test, to assess whether parents' knowledge of ASD services increased. A demographic survey form was used to obtain SES and service needs of children with ASD. Participants in this study were parents of children with ASD, all of whom volunteered to participate in the study. The pre-test and post-test were compared to investigate the treatment options parents of children with ASD had knowledge of. The independent variable was participation in the workshop, and the dependent variable was the parents' knowledge of ASD interventions. Data was analyzed using SPSS for Windows.

Data Collection

The 16 research participants were all parents or caregivers of a child diagnosed with ASD; their responses on the pre- and post-tests served as the primary source of research data. Demographic questionnaires served as supporting research data. Participant data was coded by pseudonyms to maintain anonymity. Pre-test and post-test data were collected on a single instrument known as the Treatment Evaluation Inventory – Short Form (TEI-SF) (Keller et al., 1989). The TEI-SF is a nine-item measure that consists of statements paired with a Likert-type rating scale; it has good internal consistency (Choi & Kovshoff, 2013). The two sets of data were matched for comparison data analysis. Following initial data set reviews, four subjects could not be included in the comparison data analysis due to failure to complete the pre-test and post-test.

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However, the demographic data analysis accounted for the entire sample of 16 research participants.

Sample Demographics

Parent Characteristics

Parents who have higher socio-economic and education levels may find it easier to access information and programs to address the symptoms of ASD in their children. Since eligibility for a free or reduced lunch at school is based solely upon income of the parents, the participation in the free or reduced lunch program was used to separate parents into low and high SES levels. Of the 16 initial participants in the study, 44% ($n=7$) reported that their children participated in a free or reduced lunch program while 56% ($n=9$) had an income level above the requirements of the program. The education level of the parents showed correlation with the SES levels.

According to the US Census (2018), in the Greater Philadelphia region, 83% of the population's highest level of education is a high school diploma. The participants in this study indicated an overall higher level of education. Over 75% had an education above that of a high school diploma. In the table below (Table 1) parent education was classified into five categories: high school (level 1), technical school (level 2), associate's degree (level 3), bachelor's degree (level 4), and master's degree or higher (level 5). Thus, parents in this study may have had fewer obstacles to obtaining information and help for their children.

Table 1. Educational Attainment

Education	<i>N</i>	%
High school (Level 1)	4	25.0
Technical School (Level 2)	2	12.5
Associate degree (Level 3)	2	12.5
Bachelor's degree (Level 4)	3	18.8

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Master's degree or higher (Level 5)	5	31.3
Total	16	100.0

Parents with higher socio-economic status are more likely to have reliable transportation to get their children to their service providers for treatment. Families with lower SES experience considerable hurdles when attempting to access services (e.g., lack of transportation; lack of available service hours) that limit the availability of meaningful behavior interventions (Fox & Holtz, 2009). In the Greater Philadelphia region, a household of three is considered to be living in poverty if the household income totals \$19,700 a year or less; the median household income is about \$44,000 a year (Pew, 2018). In this study, 31.3% ($n = 5$) of participants had household incomes greater than \$100,000. 43.8% ($n = 7$) had household incomes of \$60,000 or less. Thus, the parents in this study with high SES are less likely to experience barrier accessing services for their children with ASD.

Household income is presented in Table 2.

Table 2. Household Income

Income	<i>N</i>	%	Cumulative %
\$20,000–\$30,000	2	12.5	12.5
\$30,000–\$40,000	2	12.5	25.0
\$40,000–\$60,000	3	18.8	43.8
\$60,000–\$75,000	1	6.3	50.0
\$75,000–\$100,000	3	18.8	68.8
Greater than \$100,000	5	31.3	100.0
Total	16	100.0	

Parental age was separated into categorical groups. Only one parent (6.3%) was between 25 and 30, 25% ($n = 4$) were 31–40, 43.8% ($n = 7$) were 41–50, and 25% ($n = 4$) were older than 50. Participant relationship to the child was also ascertained: Most participants (62.5%, $n = 10$)

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were mothers; 25% ($n = 4$) were fathers, and the remaining 12.6% ($n = 2$) were grandparents or other caregivers. The majority of respondents (81.3%, $n = 13$) were married; 12.5% ($n = 2$) were divorced or separated. This sample was exceptional because most of the participants in this study were married. About 50% of married couples in the United States divorce, and the divorce rate for subsequent marriages is even higher (American Psychological Association, 2020). Parents of children with ASD have a higher divorce rate than families without a child with a disability (Hartley et al., 2010).

Participants were asked their race and ethnicity. Race and culture play a critical role in how we see ourselves and others (Swartz, Balocchi & Hartmann, 2017). Culture, race, and ethnicity are complexities that can impact people's lives and identities in many different ways. Regarding race, 50% ($n = 8$) of parents self-identified as Black, 37.5% ($n = 6$) as White, and 12.5% ($n = 2$) as "other". For ethnicity, two individuals did not respond; of the 14 participants who did respond, one individual (7.1%) self-identified as Hispanic, and the remaining 92.9% ($n = 13$) self-identified as non-Hispanic. In the Greater Philadelphia region, 45% of the population is White, 44% is Black, and 15% is Hispanic (U.S. Census, 2018). The majority of participants in this study were black which is not reflective of the population. The findings in this study could have been drastically different if the sample in study was more reflective of the Greater Philadelphia region.

A cross-tabulation was generated for race by marital status. All of the Black parents, who represented 50% ($n = 8$) of the sample, reported being married; 31.3% ($n = 5$) of the sample were White and married, and one participant (6.3%) was White and divorced or separated. Of the remaining two individuals who listed their race as "other," one (6.3%) was divorced or separated

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and one (6.3%) was single. A cross-tabulation was also generated for race by SES. Twenty-five percent of the sample ($n = 4$) were Black and of low SES and 25% ($n = 4$) were Black and of high SES; one participant (6.3%) was White and of low SES and 31.3% ($n = 5$) were White and of high SES; and both individuals who listed their race as “other” were of low SES (12.5%).

Parent age, relationship to child, marital status, race, and ethnicity are summarized in Table 3

Table 3. Parent Age, Relationship to Child, Marital Status, Race, & Ethnicity

Parent Age, Relationship to Child, Marital Status, Race, & Ethnicity

Variable	Description	<i>N</i>	%
Parent Age	18–24	0	0.0
	25–30	1	6.3
	31–40	4	25.0
	41–50	7	43.8
	50+	4	25.0
Relationship to Child	Mother	10	62.5
	Father	4	25.0
	Grandparent	1	6.3
	Caregiver	1	6.3
Marital Status	Married	13	81.3
	Widowed	0	0.0
	Divorced/Separated	2	12.5
	Separated	0	0.0
	Single	1	6.3
Race	Black	8	50.0
	White	6	37.5
	Asian	0	0.0
	Other	2	12.5

Ethnicity	Hispanic	1	7.1
	Non-Hispanic	13	92.9

**Note. n = 16 for each group except for ethnicity, which had two missing values*

Parent occupations varied. Families who are employed are more likely to have private health insurance. The literature shows families with private health insurance experience less barriers to services than families with public insurance (Pew Trusts, 2018). Public insurance typically has less providers for ASD services, and longer waitlists. All of the families in this study were employed, and likely to have private health insurance, resulting in a shorter wait list and more reliable access to ASD services for their child. Three parents (18.8%) were social workers and two (12.5%) were teachers; otherwise, every parent had a different occupation. Parent occupations are presented in Table 4.

Table 4. Parent Occupations

Occupation/Field	<i>N</i>	%
Accounting	1	6.3
Finance	1	6.3
Home health aid	1	6.3
Information systems security manager	1	6.3
Licensed health insurance agent	1	6.3
Nail technician	1	6.3
Paraprofessional	1	6.3
Realtor	1	6.3
Shop man at family plumbing business	1	6.3
Social worker	3	18.8
Steamfitter	1	6.3
Teacher	2	12.5
Trucking	1	6.3
Total	16	100.0

Child Characteristics

The ages of the children diagnosed with ASD ranged from 3 years to 19 years ($M = 9.84$, $SD = 4.26$) with a median age of 11 years. The age of diagnosis ranged from 16 months to 8 years; 50% of the children ($n = 8$) were diagnosed at 3 years of age. According to the CDC (2016), 1 in 54 children in the U.S. is diagnosed with ASD. The average age at diagnosis is more than 4 years old (American Psychiatric Association, 2016). Age of diagnosis is presented in Table 5.

Table 5. Age at Diagnosis

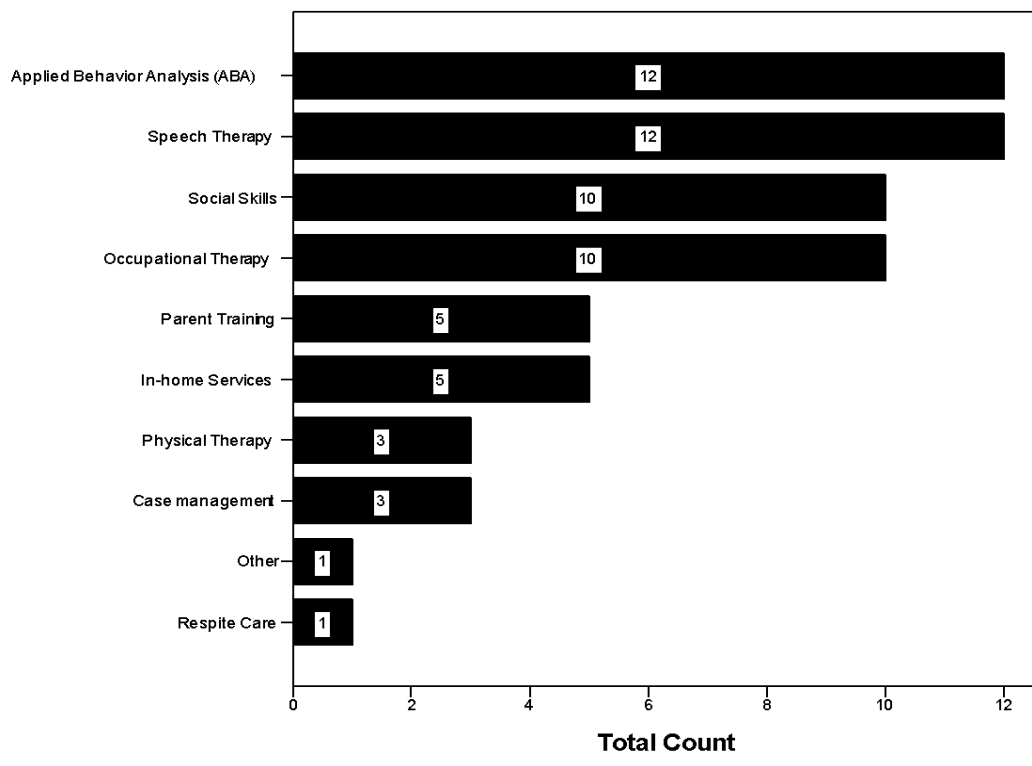
Age	<i>N</i>	%
16 months	1	6.3
20 months	2	12.5
2	1	6.3
2.5	1	6.3
3	8	50.0
3.11	1	6.3
6	1	6.3
8	1	6.3
Total	16	100.0

Fifty-six percent of parents ($n = 9$) had other children living in the home; 44% of parents ($n = 7$) did not. ASD severity was measured by the Aberrant Behavior Checklist (ABC). The scale ranges from 1 (not an issue) to 4 (high severity). Severity scores ranged from 1.14 to 2.51 ($M = 1.84$, $SD = 0.46$). With a mean score of 1.84, which can be rounded to 2.00, all of the parents rated the severity of their children's ASD as mild. Mild symptoms of ASD typically result in less service needs. Children with moderate and severe symptoms of ASD were not included in this study which limited generalizability of the findings.

Service Needs

Parents were asked on the report form about their child’s service needs and could select all needs that applied. The most common service needs identified by parents were applied behavior analysis (ABA) (75%, $n = 12$), speech therapy (75%, $n = 12$), social skills (62.5%, $n = 10$), and occupational therapy (62.5%, $n = 10$). About one-third of parents selected parent training (31.3%, $n = 5$) and in-home services (31.3%, $n = 5$) as among their child’s service needs. Less cited service needs were case management (18.8%, $n = 3$), physical therapy (18.8%, $n = 3$), and respite care (6.3%, $n = 1$); one person selected “other” (6.3%). Service needs are provided in Figure 1.

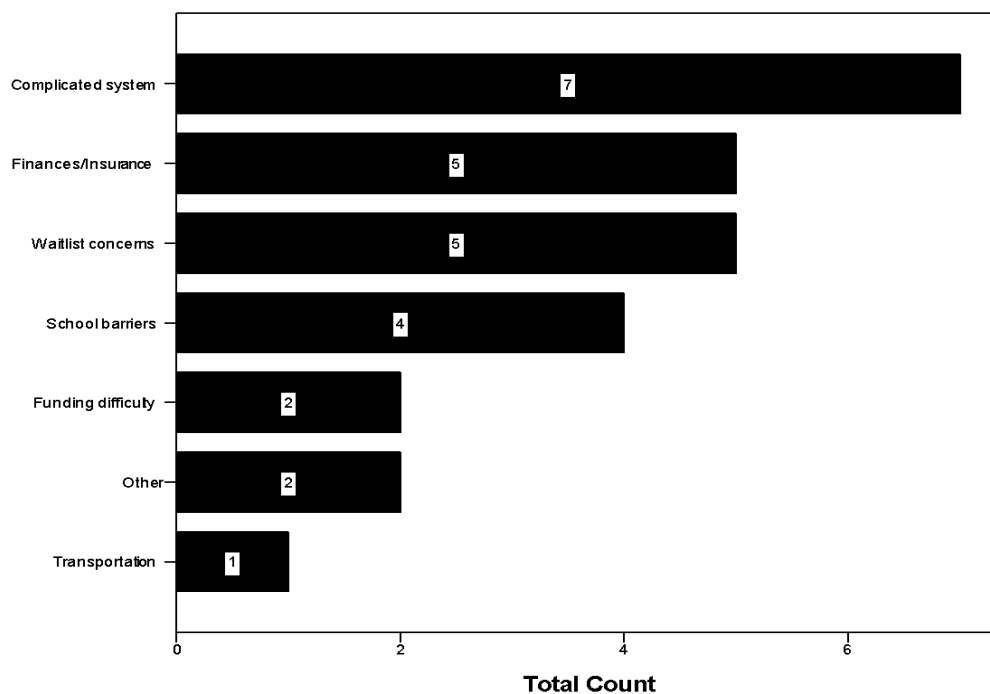
Figure 1. Service Needs



Barriers to Services

Parents were asked on the report form to provide information about potential barriers to services and could select all factors that applied. The most commonly cited barrier was a complicated system (43.8%, $n = 7$), followed by finances/insurance (31.3%, $n = 5$) and waitlist concerns (31.3%, $n = 5$). School barriers (25%, $n = 4$) were cited less frequently, as was funding difficulty (12.5%, $n = 2$). Two parents selected “other” (12.5%) for this question: one specified service disruption related to COVID-19 as an additional barrier, and one parent noted being unsure. Transportation was the least frequent barrier to services (6.3%, $n = 1$). It is important to note that 43.8% ($n = 7$) of parents reported no barriers to service. The data for this domain is provided in Figure 2.

Figure 2. Barriers to Services



Instrument Reliability for Sample

A reliability analysis employing Cronbach's alpha (Cronbach, 1951) examined whether the series of questions on the survey accurately measured the underlying themes and were internally consistent. Cronbach's alpha indicated acceptable internal consistency ($\alpha = 0.81$), which is consistent with reliability approximations (Rellini et al., 2004; Volkmar et al., 1988). The reliability for the sample of parents was tested with Cronbach's alpha. The reliability of the ABC was excellent ($\alpha = .92$). The reliability for the TEI at pre-test ($\alpha = .97$) and post-test ($\alpha = .91$) was also excellent.

Research Questions

Research Question 1

What knowledge do parents have regarding evidence-based interventions for children with ASD? This question was answered with descriptive statistics using the answers to the TEI report form administered as a pre-test. The TEI is composed of Likert-type items with choices ranging from 1 (strongly disagree) to 5 (strongly agree). Scores were computed by adding up the responses and dividing them by the total number of test items ($n = 9$). Scores ranged from 1.00 to 4.56 ($M = 3.11$, $SD = 1.10$). With a mean value of 3.11, the parental knowledge of this group can be described as neutral. Table 6 provides a frequency distribution of the pattern of responses on the pre-test.

Table 6. Knowledge of Evidence-Based Interventions at Pre-Test

Item	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
I find this treatment to be an acceptable way of dealing with this child's problem behavior.	3(20.0)	0(0)	5(33.3)	4(26.7)	3(20.0)
I would be willing to use this procedure/strategy if I had to change the child's problem behavior.	2(14.3)	0(0)	3(21.4)	5(35.7)	4(28.6)
I believe that it would be acceptable to use this treatment without children's consent.	2(14.3)	1(7.1)	8(57.1)	1(7.1)	2(14.3)
I like the procedures used in this treatment.	2(15.4)	0(0)	6(46.2)	3(23.1)	2(15.4)
I believe this treatment is likely to be effective.	2(15.4)	0(0)	5(38.5)	3(23.1)	3(23.1)
I believe the child will experience discomfort during treatment.	3(23.1)	0(0)	8(61.5)	1(7.7)	1(7.7)
I believe this treatment is likely to result in permanent improvement.	2(15.4)	0(0)	6(46.2)	2(15.4)	3(23.1)
I believe it would be acceptable to use this treatment with individuals who cannot choose treatments for themselves.	2(15.4)	0(0)	7(53.8)	2(15.4)	2(15.4)
Overall, I have a positive reaction to this treatment.	2(15.4)	0(0)	3(23.1)	4(30.8)	4(30.8)

Research Question 2

What is the effect of the training workshop on parents' knowledge of evidence-based interventions for children with ASD? This question was answered with a paired samples t-test. The repeated measures t-test assesses whether the mean scores change within subject experimental designs. The independent variable was the training workshop. The dependent variable was knowledge of evidence-based interventions for children with ASD, as measured by

the TEI given as a post-test. Means for knowledge of evidence-based intervention before and after the training workshop are presented in Table 7 and t-test results are presented in Table 8.

Table 7. Paired Samples t-Test Results

		<i>M</i>	<i>N</i>	<i>SD</i>	Std. Error Mean
Pair 1	TEI_Pre	3.11	12	1.10	0.32
	TEI_Post	4.18	12	0.57	0.16

Table 8. Paired Samples t-Test Results

		<i>M</i>	<i>SD</i>	<i>SEM</i>	<i>T</i>	<i>Df</i>	<i>P</i>
Pair 1	TEI_Pre–TEI_Post	-1.06	1.28	0.37	-2.89	11	.015

There was a significant difference in parents' knowledge of evidence-based interventions for children with ASD before and after the training workshop, $t(11) = -2.89$, $p = .015$, two-tailed. Specifically, scores were significantly higher at post-test ($M = 4.18$, $SD = 0.57$) than they were at pre-test ($M = 3.11$, $SD = 1.10$).

Research Question 3

Is there a difference in service access of children with ASD based on their family's SES? This question was answered with a chi-square test of independence. As previously noted, 43.8% ($n = 7$) of parents reported they had no barriers; the remaining 56.2% ($n = 9$) reported at least one barrier. Among parents of low SES, 57.1% ($n = 4$)—which represented 25% of the total sample—experienced barriers to services, compared to 55.6% ($n = 5$) of those of high SES who experienced barriers, which represented 31.3% of the total sample. This difference was not statistically significant: $X^2(1, n = 16) = .004$, $p = .949$. A cross-tabulation of SES by barriers to services is presented in Table 9 and chi-square results are presented in Table 10.

Table 9. Socioeconomic Status by Barriers to Services

		Barriers to Services			
		No Barriers	Barriers	Total	
Socioeconomic Status	Low SES	Count	3	4	7
		% within SES	42.9	57.1	100.0
		% of Total	18.8	25.0	43.8
	High SES	Count	4	5	9
		% within SES	44.4	55.6	100.0
		% of Total	25.0	31.3	56.3
Total	Count	7	9	16	
	% within SES	43.8	56.3	100.0	
	% of Total	43.8	56.3	100.0	

Table 10. Chi-Square Results

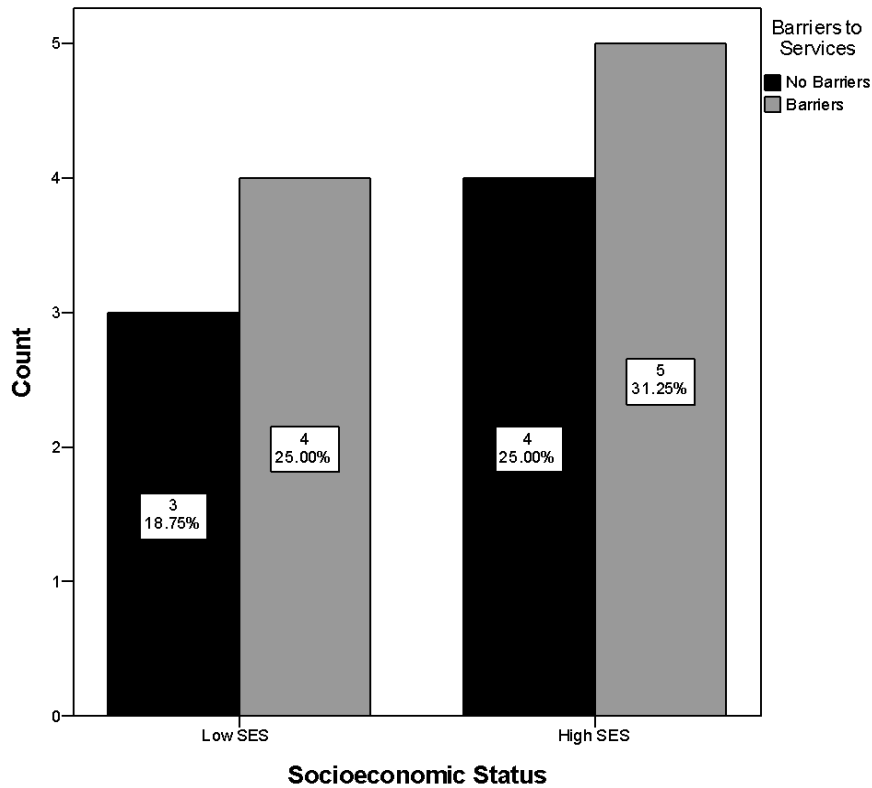
	Value	df	Asymptotic Significance (2-sided)	Exact Sig. [1] (2-sided)	Exact Sig. [2] (1-sided)
Pearson Chi-Square	.004 ^a	1	.949		
Continuity Correction	.000	1	1.00		
Likelihood Ratio	.004	1	.949		
Fisher's Exact Test				1.00	.671
Linear-by-Linear Association	.004	1	.951		
<i>n</i> of Valid Cases	16				

^a3 cells (75%) have an expected count less than 5. The minimum expected count is 3.06.

^bComputed only for a 2x2 table

A clustered bar graph of the non-significant results is illustrated in Figure 3.

Figure 3. Status by Barriers to Service



Conclusion

Three research questions were formulated for investigation. One question was answered with descriptive statistics; the others were answered with inferential statistics. Parental knowledge of evidence-based interventions for children with ASD can be described as neutral or fair prior to the delivery of the training workshop. There was a significant increase in parents' knowledge of evidence-based interventions for children with ASD after the training workshop. There was no significant difference in service access of children with ASD based on their

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family's SES. The most commonly cited service needs identified by parents were applied behavior analysis (ABA), speech therapy, social skills and occupational therapy. The commonly cited barrier to services was a complicated system, followed by finances/insurance and waitlist concerns. All the children represented in the data set all had mild symptoms of ASD, and their ages ranged from 3 years to 19 years with a median age of 11 years. The discussion of results, limitations, and recommendations for future research are discussed in Chapter 5.

Chapter 5: Discussion

Introduction

The purpose of this study was to determine whether baseline parental knowledge of evidence-based intervention for children with ASD impacts treatment choice and if specialized parent training increased parental knowledge of ASD interventions. Moreover, this researcher wanted to determine if socioeconomic status is a factor affecting access to quality service delivery for children with ASD. Austin et al. (2016) concluded there is an overwhelming demand for ASD services, but the services available are limited due to long waitlists. Children who receive an early diagnosis of ASD, early treatment services, and quality ASD care are overwhelmingly white and from upper-middle-class backgrounds (Carr, 2011; Carr & Lord, 2016). In contrast, families with lower SES experience considerable hurdles when attempting to access services (e.g., lack of transportation; lack of available service hours) that limit the availability of meaningful behavior interventions (Fox & Holtz, 2009). This is important as the literature has shown that early diagnosis and treatment of ASD leads to the best long-term outcomes for individuals with ASD. It was hypothesized that families of children with ASD of lower SES encounter more barriers to access treatment than their higher SES counterparts.

Research suggests that socioeconomic status (SES) impacts parents' ability to access services for their children with ASD (Pickard & Ingersoll, 2016). Children of parents with lower SES are more likely to have unmet service needs than their higher SES counterparts, and the lack of parental education is identified as a factor in this disparity (Casagrande & Ingersoll, 2017). The lack of parental knowledge makes families with lower SES less likely to seek out treatment

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compared to their higher SES counterparts (Porterfield & McBride, 2007). Furthermore, individuals with higher SES have greater resources to devote to their children's related needs which typically converts to better outcomes for the children (King & Bearman, 2011).

Summary of Findings

Three research questions were formulated for investigation. The first question was answered with descriptive statistics to determine the baseline knowledge participants had regarding evidence-based interventions for children with ASD. The TEI is composed of Likert-type items with choices ranging from 1 (strongly disagree) to 5 (strongly agree). Scores were computed by adding up the responses and dividing them by the total number of test items. Scores ranged from 1.00 to 4.56. With a mean value of 3.11, the parental knowledge of this group was described as neutral or fair prior to the delivery of the training workshop.

The second question was answered with inferential statistics to determine the effect of the training workshop on parents' knowledge of evidence-based interventions for children with ASD. The independent variable was the training workshop. The dependent variable was parental knowledge of evidence-based interventions for children with ASD, as measured by the TEI given as a pre-test and post-test measure. There was a significant increase in parents' knowledge of evidence-based interventions for children with ASD after the training workshop evidenced by a significant difference in parents' knowledge of evidence-based interventions for children with ASD before and after the training workshop, $t(11) = -2.89, p = .015$, two-tailed. Specifically, scores were significantly higher at post-test ($M = 4.18, SD = 0.57$) than they were at pre-test ($M = 3.11, SD = 1.10$).

The third question was also addressed using inferential statistics to determine if there was significant difference in service access of children with ASD based on their family's SES. Results demonstrated that 43.8% ($n = 7$) of parents reported they had no barriers regarding access to service; the remaining 56.2% ($n = 9$) reported at least one barrier in access to care. Among parents of those defined as low SES, approximately 57.1% ($n = 4$)—which represented 25% of the total sample—experienced barriers to services, compared to 55.6% ($n = 5$) of those in the High SES group who experienced barriers, which represented 31.3% of the total sample. This difference was not statistically significant and was interesting given the previous literature that identified SES as a factor when evaluating barriers to fair and appropriate treatment. The most commonly cited barrier in both groups was a complicated system (43.8%, $n = 7$), followed by finances/insurance (31.3%, $n = 5$) and waitlist concerns (31.3%, $n = 5$). School barriers (25%, $n = 4$) were cited less frequently, as was funding difficulty (12.5%, $n = 2$). Two parents selected “other” (12.5%) for this question: one specified service disruption related to COVID-19 as an additional barrier, and one parent noted being unsure. Transportation was the least frequent barrier to services (6.3%, $n = 1$), identified by both groups.

Interpretation of Findings

These research results did not support the hypothesis that SES was a factor affecting access to service delivery for children with ASD which is in sharp contrast to previous research (Lindly, Zuckerman & Kuhlthau., 2019; Magana et al., 2013; Lin & Yu, 2015; Rowan et al., 2013; McIntyre & Zemantic, 2017). This sample was limited and drastically different from the low SES families represented in the literature which could account for the discrepancy in

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results. . Specifically, the majority of my research participants were from intact marriages, actively employed, and from one geographic area which is not typical among families with ASD and very limited when evaluating generalizability. In this study, 81% of the parents were married which is rare for parents of a child with a disability. This is in sharp contrast to the literature as several studies have examined parental divorce in heterogeneous samples of children with a variety of disabilities other than ASD (Hartley et al., 2010; Witt, Riley & Coiro, 2003; Barker, Seltzer, Greenberg, Floyd, Orsmond, 2010). They have found that divorce rates seem to be higher in families with a child diagnosed with ASD. Furthermore, few disabilities appear to be more taxing on parents than ASD (Seltzer et al., 2001) given the behavioral needs, comorbid conditions, communication delays, and related symptoms. There have also been reports that parents of children with ASD have poorer wellbeing due to factors related to the severity of ASD, the stressful nature of symptoms associated with ASD (Ingersoll & Hambrick, 2011).

As noted above all participants in my sample were gainfully employed. The state of Pennsylvania has a 13% unemployment rate (Pennsylvania Department of Labor and Industry, 2020) so again my sample may not be fully representative of the population at large. Furthermore, there is a great deal of literature on employment in parents of those with Autism. Results have shown that these parents earn less money and work less hours than their parental counterparts of “typical” children. Families of children with ASD face significant economic burden. Given the substantial health care expenses associated with ASD, the economic impact of having lower income in addition to these expenses is substantial and warrants further evaluation. It again suggests the need to better design a universal health care system and workplace policies that recognize the full impact of Autism.

Every person with Autism receives the same diagnosis, ASD, but Autism is a spectrum with varying levels of functioning. The acuity of ASD ranges from mild to severe (Kandola & Gill, 2019), as many with ASD have certain core symptoms, while others have additional symptoms including intellectual or language impairments. Levels of ASD severity are associated with greater needs or assistance in their daily lives. Individuals with severe symptoms of ASD require a higher level of support to function safely. Severe symptoms of ASD interfere with the child's ability to communicate which often lead to dangerous behaviors that are difficult for parents and caregivers to manage. Severe symptoms of ASD interfere with the individual's ability to complete everyday tasks like visits to the grocery store or doctor's office, which adds additional strain on parents and caregivers.

While all children diagnosed with ASD must have the core symptoms to meet diagnosis, those with severe symptoms of ASD are more often unable to communicate, have significant sensory dysfunction, and uncontrollable and extreme repetitive behaviors. Severity of ASD for the children in the study was measured using the Aberrant Behavior Checklist (ABC). All of the parents in this study rated the severity of their children's ASD as "mild", suggesting reduced service needs compared to their "severe" counterparts. Mild ASD would also lead to less parental stress which could also have been the reason the majority of parents in this study had intact marriages and careers. Parental stress of with a child diagnosed as ASD is significantly higher than parents without a child with ASD, and the severity of ASD symptoms was a predictor of parental stress (Pastor-Crezuela, Fernandez-Andres, & Tarraga-Minguez, 2015; Valicenti-McDermott, Lawson, Hottinger, 2015; Padden & James (2015). While parental stress was not examined as part of this study, research has shown a causal relationship to service needs.

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Therefore, one can conclude that reduced parental stress and reduced service needs may have been an important factor when considering these results.

Parents in this study did identify select barriers to services, and the most commonly cited barrier was a complicated system, finances/insurance, and waitlist concerns which is consistent with the literature discussed in previous chapters. Transportation was the least cited barrier to services which is in sharp contrast to previous research which cited that transportation is a primary barrier to services for families with low SES (Fox & Holtz, 2009). The participants in this study were all employed which is suggestive of their ability to access services more readily because they are more likely to have health insurance.

Implications of Findings

The results of this study have implications for parents of children with ASD, as well as educators and clinicians who work directly with this population, who can ensure parent training is made a priority for families of children with ASD. Parents in this study indicated they have experienced barriers to services including complicated systems, finances/insurance complications, and waitlist concerns as noted above. These findings suggest the need to remove such barriers to allow for easier access to services. This also reinforced the importance of parent training to increase parental knowledge on empirically validated ASD interventions, which will hopefully lead them to advocate and seek out quality treatment programs. As discussed in previous chapters, it is essential that parents of children with ASD are knowledgeable in identifying evidence-based interventions for their children, and parents need accurate knowledge of the available treatments accessible for ASD.

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Parent training in the areas of service delivery including prompting can reduce the likelihood that children will receive an intrusive level of support (e.g., repeated prompting) while learning skills which can lead to the concern of prompt dependence.

It is also important parents are knowledgeable about evidence-based treatments to ensure they are focused on accessing appropriate interventions for their child. Given the abundance of research focused on the use of Applied Behavior Analysis (ABA) interventions with children with ASD, families should receive psychoeducation on ABA and include an explanation of the instructional challenges such as prompt dependence. There is limited research on parents' knowledge of quality interventions like evidence-based strategies for children with ASD, and this research is a significant addition.

Limitations of the Study

There were several notable limitations to this study that will be addressed. First and foremost, this study is limited in scope as it focused on participants from one small area of the Northeast Region. It is presumed that the participants in this study are from Montgomery County, Pennsylvania. Although participant recruitment for this study was completed using an online platform, the location of participants was not verified. Second, inherent in the quasi-experimental design methodology used, participants were not randomly assigned, and the pre-test/post-test was conducted without a control or comparison group. As a result, it is possible other factors outside of the workshop contributed to the results of the study. The majority of the parents in this study indicated that their child received ABA, speech therapy, social skills, and occupational therapy. Participants previous exposure to the treatments (e.g. ABA) indicated

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could have contributed to the results found of this study. If the children represented in the data set received ABA therapy in the past their parents would be more familiar with the terms presented in the workshop which could have contributed to the results.

Related to the study's execution, the small number of participants involved may not be an adequate representation of the population, and therefore limits the ability to generalize these findings.

Other study limitations were due to the manner in which this study was conducted. Given the global COVID-19 pandemic which led to shelter in place executive orders and school closures to promote social distancing, this study was conducted online through a virtual platform known as Zoom. However, this may have limited participation as the online nature may only be available to those who have access to the internet, and who have time to commit to completing the surveys and workshops outside of their existing responsibilities. Internal generalizability may also be limited by the participant sample, even though online methods aim to promote diversity of participants. Lastly, in-person and semi-structured interviews may have allowed for clarification of questions, follow-up questions, and a more personalized experience for the participants.

This study did not verify diagnosis of ASD of the children represented in the data set. The children represented in this study could have been misdiagnosed with ASD, and/or the parent who elected to participate in this study could have felt their child met the criteria for ASD. However, participants in this study were asked to indicate the age of diagnosis for their child. Validation of ASD is important to prevent misdiagnosis of ASD. Instruments that rely on parent reports can lead to false positives. In addition, the gold standard for ASD diagnosis includes the

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tools the Autism Diagnostic Observation Schedule (ADOS) and Autism Diagnostic Interview-Revised (ADI-R) because they are most reliable in identifying ASD (Mazefsky & Oswald, 2006; Kamp-Becker et al, 2018). Therefore, it is possible that diagnoses were made based on brief observations, checklists, or parent reports and that diagnosis was made by someone other than an expert in the field. Therefore, it is possible that participants did not in fact have ASD but another developmental delay or diagnosis.

Although demographic variables were collected regarding factors contributing to SES, it may have been helpful to collect information regarding family make-up and financial access to care, one's cultural experience as it relates to the diagnosis of ASD, and a more thorough analysis of the broader context of participants' cultural experience. For example, it is important to consider that some cultural groups may react differently to certain life events and stressors based on their previous experiences or beliefs which may have contributed to the unique features of this sample. Research has also shown that different cultures have different views of ASD and thus different preferences for treatment, and previous research has also revealed that different cultures hold stigmatizing views of an ASD which may also pose as a barrier to treatment.

Directions for Future Research and Recommendations

The ongoing study of ASD, reinforcing parent advocacy, and access to care is critical given the growing rates of ASD in the United States. This study could be replicated using a larger sample of participants whose children have varying degrees of ASD severity which could better clarify the possibilities of disparity in access to treatment, quality of treatment, and quantity of treatment in hours of service per month. As part of the screening process for children

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to be eligible for services a psychologist typically evaluates children, and children suspected of ASD could be given the ADOS screening tool. Future researchers could also consider having a comparison group or control group for this study would lead to further understanding of how to best support children with ASD. A comparison group would help control for any factors that may have influenced the results. Researchers should consider a follow up with parents to determine if their children did in fact access more services, and if there were positive treatment outcomes. Use of a longitudinal experimental design including expanded data collection is also suggested. This model could determine if the growth in knowledge obtained by parents was retained over time, and if access to services change based on this knowledge in future service delivery.

It is also suggested that future researchers should validate ASD diagnosis as part of the criteria for inclusion in the study. It is suggested that this validation include the use of gold standard diagnostic tools (e.g. ADOS) to verify diagnosis of ASD. The ADOS is a widely used measure to screen and diagnose ASD (Kroncke, Willard, & Huckabee 2016; Chlebowski, Green, Barton & Fein 2010) published by Western Psychological Services (WPS) in 2000 and now available in 15 different languages. The ADOS-2 provides a systematic and standardized method for identifying kids with ASD. The process involves making direct observations under controlled circumstances that other clinicians are able to replicate. Only trained professionals can administer the ADOS diagnostic screening, but it eliminates some of the differences of opinion otherwise possible when two different experts provide a diagnosis without following common guidelines considered the gold standard in the field of child development. Researchers could also characterize the individuals with ASD as to whether or not they have comorbid intellectual

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disability, using a variety of sources of information. This could include administration of the Wide Range Intelligence Test (WRIT; Glutting, Adam & Sheslow, 2000) to the individual with ASD. In addition, the caregiver could report adaptive behavior via the Vineland Screener (Sparrow, Carter & Cicchetti, 1987) as well. Researchers should also determine the severity of ASD symptoms and the associated impact on parental stress and siblings. This could be done using additional measures such as the Parenting Stress Index form (PSI; Abidin, 2012) and the Positive Affect Index (PAI; Bengtson & Black, 1973a), which includes 10 items measuring positive affect in the relationship.

The results of this study would have been strengthened if replication could have been conducted on a larger scale through additional participants. This study could be replicated by changing the location for recruitment to an early intervention agency. Early intervention provides services and support to babies and young children with developmental delays and disabilities and their families. The workshop would be most beneficial to families with young children diagnosed with ASD (e.g. toddler to preschool age). Research suggests that early detection of ASD and early implementation of evidence-based interventions for ASD can help minimize the symptoms associated with the disorder, and improve outcomes (Elder, Kreider, Brasher. & Ansell, 2017). The workshop in this study can help parents make informed decisions regarding treatment which can result in better outcomes for their children. As part of the screening process for children to be eligible for early intervention services, an evaluation team typically assesses children. Children suspected of an ASD diagnosis could be given the ADOS diagnostic screening to verify diagnosis. Once an ASD diagnosis is confirmed parents could be invited to participate in a future study. Future Researchers could use a control group who do not participate in the workshop (e.g.

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independent variable) and an experimental group who do participate in the workshop. Future researchers could compare the control group's knowledge (e.g. dependent variable) with the experimental group's knowledge using the pre-test (TEI-SF). Future researchers could also compare service levels of the control group to the experimental group to see if there was a difference in services children represented in the experimental group received after parental participation in the workshop.

Future researchers could also have participants complete the ABC instrument as part of the screening process to ensure variability of severity of ASD symptoms represented in a future study. The pre-test (TEI-SF) could be given with a stress index measurement to determine how stress impacts families of children with ASD along with demographic information. The in-person workshop at the early intervention agency would allow for follow-up questions and give parents a meaningful in person experience. Future researchers could teach parents coping strategies to help alleviate stress as part of the training. The post-test (TEI-SF) could be provided at the end of the workshop as detailed in this study. After the workshop, the researcher could follow-up with parents in the experimental group using Qualtrics to determine if parents were able to secure additional services for their children and compare service levels before and after the workshop.

Despite advances in treatment, people of color tend to be more likely to receive a lower quality of care and unmet service needs than their white counterparts (Egede, 2006). African Americans have a unique experience in the United States because they are the only group of citizens that are involuntary immigrants. African Americans have a long-standing history of brutality and oppression which has resulted in a mistrust within the healthcare system. Conner et al. (2010) state that African Americans are less likely to seek mental health treatment than their

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white counterparts for fear of being further stigmatized. This mistrust can result in more African American families of children with ASD delaying treatment, and/or using unproven treatments with their children leading to damaging outcomes. There can also be cultural differences within the same ethnic group, due to the number of years in the United States. The impact of culture on the variables being researched should also be further evaluated. Culture can determine what is considered a disability vs. a social condition which could lead to marginalization (Sheridan & Scior, 2013). There is perception within the Asian American culture that one's deficiencies can devalue their worth within the community, leading to the subjugation of individuals with a disability which can result in families seeking antiscience treatments or no treatment at all. ASD affects people of all backgrounds, cultures and heritages. Different cultural factors can change how individuals experience autism in everyday life, influencing their interactions with family, community, schools and health services. Cultural factors can also impact how autism is understood, interpreted, and accepted in different communities. Cultural myths about autism and other disabilities can deter people from seeking help and can also shape what types of interventions they seek out. Therefore, this should be further evaluated and considered when evaluating access treatment and related barriers to care. Furthermore, research has shown that in urban communities or large cities, non-white families or recent immigrant families can have a more difficult time getting developmental services, which often delays a proper diagnosis and can serve as a further barrier to care. Bias can impact how service providers treat their clients based on unfounded negative stereotypes leading to prejudgments or discriminatory practices that can lead to a further disparity within the treatment or evaluation process for children with

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ASD. The role of the service provider's race and training in multicultural competent service provision should also be considered and evaluated if possible.

Finally, while my study did not evaluate health care policy and the concept of health care disparities for those of low SES and historically marginalized groups, there is a clear discrepancy based upon the literature. In light of the COVID-19 Pandemic these disparities have become an important topic when evaluating health care services in the United States. A recent study showed that nearly half of all Black, Hispanics and Indigenous people had discontinuous insurance coverage. Racial and ethnic disparities in maternal and child health outcomes have recently been labeled a national public health crisis. So while the Affordable Care Act (ACA) helped make health insurance access more equal, racial and ethnic gaps remain and this is a significant concern for those with a child on the Autism Spectrum. The findings of this review suggest a number implication of and directions for future research on health disparities in ASD. First, the presence of racial health disparities in ASD related to decreased access to and quality of healthcare earlier in life warrants further evaluation. Future research should focus on identifying both policies and a universal healthcare system that addresses the needs of those with ASD from initial diagnosis, treatment, and addressing the health and behavioral needs of those with Autism as they age.

Recommendations for Clinicians

- Integrate parents in daily sessions with their child to help them learn the interventions being implemented with their child. Clinicians could use procedure fidelity checks with parents to ensure accuracy of interventions used during sessions.

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- Dissemination of resources to parents to increase their knowledge of their child's instructional plans, as well as to assist them to stay abreast of new evidence-based interventions available for their child.
- Provide parent training to help parents learn how to implement evidence-based interventions to promote generalization of skills across settings and people to reduce the likelihood prompt dependence will occur.
- Teach parents coping strategies to manage their stress.
- Facilitate support groups for families to help reduce parental stress.

Recommendations for Educators

- Ensure that only evidence-based interventions are being offered to parents as an option for service selection.
- Facilitation of collaboration amongst parents, clinicians, and educators to prompt generalization of skills.
- Train staff to implement prompt fading procedures and provide targeted reinforcement for accurate and independent responses using ABA strategies which helps to increase independent-skill acquisition of children with ASD.
- Offer parent training that teaches parents how to identify evidence-based interventions, so they are better equipped to make appropriate treatment choices for their child.

Recommendations for Public Health Officials

- Create policy that makes treatment available to families equitably regardless of public vs. private insurance to reduce barriers to treatment.

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- Work with insurance providers to provide transportation to families who need it to allow for easier access to treatment facilities.
- Mandate that assessments (e.g. ADOS) be made available to children as early as possible to promote early identification of ASD to improve outcomes.
- Dissemination of resources to families that explains evidence-based interventions for children with ASD.
- Assist families with completing documentation essential for service access and treatment to help make the system less complicated.

Recommendations for Policy

- Create policy that promotes culturally sensitive programs that recognize racial, ethnic, and cultural diversity
- Create a bias training initiative for ASD service providers
- Eliminate waitlist to make access to services shorter and/or provide more service providers
- Create long-term care programs that are available to families who have children with severe symptoms of ASD that supports the family as a whole.
- Create a national organization that oversees access to ASD services to ensure services are being provided equitably.

Conclusion

In summary, this research used a quasi-experimental design to investigate the effects of training parents of children with ASD on available, effective ASD interventions, and to determine if SES is a factor in service access for children with ASD. This researcher's experience as a parent of a child with ASD, and a behavior analyst gave me the desire to explore this study. Through my work as a behavior analyst, I have found that some parents rely heavily on clinicians and educators to decide treatment options for their child, despite many professional staff having to balance the child's needs with competing factors (e.g. budget, staffing).

Parents being knowledgeable in evidence-based interventions for children with ASD will help them to be better equipped to advocate for evidence-based services for their child. This research supports the importance of educators, clinicians, and public health officials collaborating with families to make access to treatment easier. Parents need support to manage stressors related to their child's diagnosis especially parents who have a child with severe symptoms of ASD. It is vital that educators and healthcare professionals provide care and resources to families that are culturally competent since culture can impact when and if a family will seek treatment for their child.

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Appendix A. Pre-test

Pseudonym _____ (Please do not include any identifiable information)

Parent and Child Information Form

BACKGROUND/DEMOGRAPHICS

1. My child is eligible for free/reduced lunch based solely on income criteria. Yes No
2. Highest degree or level of school completed. High School Technical School Associate's degree Bachelor's degree Master's degree/professional degree/doctorate
3. Household income. Less than \$20,000 \$20,000-\$30,000 \$30,000-\$40,000 \$40,000-\$60,000 \$60,000-\$75,000 \$75,000-\$100,000 Greater than \$100,000
4. Parent Age. 18- 24 25-30 31-40 41-50 50+
5. Relationship to child. Mother Father
6. Marital status. Single Married Divorced/Separated Widowed
7. Race & Ethnicity. Black White Asian Other Hispanic Non-Hispanic
8. Occupation: _____

CHILD CHARACTERISTICS

1. Current age of Child with ASD: _____
2. Age of Diagnosis: _____
3. Other Children in the home: _____
4. Autism Behavior Checklist (ABC)

*Indicate a score of 1-4 with 4 being the highest severity

1	Whirls self for long periods of time				
2	Learns a simple task but “forgets” quickly				
3	Frequently does not attend to social/environmental cues				
4	Does not follow simple commands (sit down, come here, stand up) given once				
5	Does not use toys appropriately (spins wheels, etc.)				
6	Poor use of visual discrimination when learning (fixates on parts of objects such as size, color, position...)				
7	Lacks a social smile (may smile out-of-context)				
8	Exhibits pronoun reversal (you for I...)				
9	Insists on keeping certain objects with him/herself				
10	Seems not to hear (despite normal hearing tests)				
11	Speech is atonal and arrhythmic				
12	Rocks self for long periods of time				
13	Does not (or did not as a baby) reach out when reached for				
14	Strong reactions to minor changes in routine/environment				

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15	Does not respond to own name when called out among two or more other names				
16	Lunges and darts about, interrupted by spinning, toe walking, hand flapping...				
17	Not responsive to other people's facial expressions or feelings				
18	Seldom uses "yes" or "I"				
19	Has special abilities in one area – seems to rule out mental retardation				
20	Does not follow simple prepositional commands (e.g., "put the ball in the box")				
21	Sometimes shows no "startle response" to a loud noise				
22	Flaps hands (or other self-stimulating behavior)				
23	Severe temper tantrums and/or frequent minor tantrums				
24	Actively avoids eye contact				
25	Resists being touched or held				
26	Sometimes, painful stimuli (cuts, injections, bruises) evoke no reaction				
27	Is (or was as a baby) stiff and hard to hold				
28	Is flaccid (doesn't cling) when held in arms				
29	Gets desired objects by gesturing				
30	Walks on toes				
31	Hurts others by biting, hitting, kicking...				
32	Repeats phrases over and over again				
33	Does not imitate other children at play				
34	Often will not blink when a bright light is directed toward eyes				
35	Hurts self by biting hand, banging head...				
36	Does not wait for needs to be met (wants things immediately)				
37	Cannot point to more than five named objects				

SERVICES

1. Service needs for your child. Applied Behavior Analysis (ABA) In-home services Speech Therapy Occupational Therapy Respite care Parent Training Social skills Case management Physical Therapy Other: _____
2. Barriers to services. Transportation School barriers Waitlist concerns Complicated system No barriers Finances/insurance Funding difficulty Other: _____

The Treatment Evaluation Inventory – Short Form (TEI-SF)

1. I find this treatment to be an acceptable way of dealing with this child's problem behavior.

Strongly Disagree Disagree Neutral Agree Strongly Agree

2. I would be willing to use this procedure if I had to change the child's problem behavior.

Strongly Disagree Disagree Neutral Agree Strongly Agree

3. I believe that it would be acceptable to use this treatment without children's consent.

Strongly Disagree Disagree Neutral Agree Strongly Agree

4. I like the procedures used in this treatment.

Strongly Disagree Disagree Neutral Agree Strongly Agree

5. I believe this treatment is likely to be effective.

Strongly Disagree Disagree Neutral Agree Strongly Agree

6. I believe the child will experience discomfort during the treatment.

Strongly Disagree Disagree Neutral Agree Strongly Agree

7. I believe this treatment is likely to result in permanent improvement.

Strongly Disagree Disagree Neutral Agree Strongly Agree

8. I believe it would be acceptable to use this treatment with individuals who cannot choose treatments for themselves.

Strongly Disagree Disagree Neutral Agree Strongly Agree

9. Overall, I have a positive reaction to this treatment.

Strongly Disagree Disagree Neutral Agree Strongly Agree

Appendix B. Post-Test

Pseudonym _____

The Treatment Evaluation Inventory – Short Form (TEI-SF)

1. I find this treatment to be an acceptable way of dealing with this child's problem behavior.

Strongly Disagree Disagree Neutral Agree Strongly Agree

2. I would be willing to use this procedure if I had to change the child's problem behavior.

Strongly Disagree Disagree Neutral Agree Strongly Agree

3. I believe that it would be acceptable to use this treatment without children's consent.

Strongly Disagree Disagree Neutral Agree Strongly Agree

4. I like the procedures used in this treatment.

Strongly Disagree Disagree Neutral Agree Strongly Agree

5. I believe this treatment is likely to be effective.

Strongly Disagree Disagree Neutral Agree Strongly Agree

6. I believe the child will experience discomfort during the treatment.

Strongly Disagree Disagree Neutral Agree Strongly Agree

7. I believe this treatment is likely to result in permanent improvement.

Strongly Disagree Disagree Neutral Agree Strongly Agree

8. I believe it would be acceptable to use this treatment with individuals who cannot choose treatments for themselves.

Strongly Disagree Disagree Neutral Agree Strongly Agree

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9. Overall, I have a positive reaction to this treatment.

Strongly Disagree Disagree Neutral Agree Strongly Agree

Appendix C. Verbal Script for Obtaining Informed Consent

Hello, my name is Rian Brown-Beasley. I am a graduate student at Arcadia University in the Department of Education, and I am undertaking research that will be used in my dissertation.

The purpose of this study is to evaluate the impact of specially designed training on parents' knowledge of evidence-based interventions for children with ASD. The study also seeks to determine if there is inequity in access to services for children diagnosed with ASD based on their family's socioeconomic status.

The information you share with me will help participants make informed decisions regarding interventions for their child, and determine if socioeconomic status is a factor in service delivery.

The study will require about 2 hours of your time. The pre-test will take approximately 20 minutes, and the post-test will take approximately 10 minutes. The training will be approximately 1.5 hours.

There is no risk to participants, and the data collected will be anonymous. The information you will share with us if you participate in this study will be kept anonymous to the full extent possible. Participants will be asked not to use any names during the workshop discussion, and please do not use any identifiable information during any part of the study. Please be advised that although the researcher will take every precaution to maintain anonymity of the data, the nature of the workshop prevents the researchers from guaranteeing anonymity. The researchers would like to remind participants to respect the privacy of your fellow participants and not repeat what is said in the workshop to others. A \$25-dollar gift card will be given to one participant at random at the end of the study.

Participation is voluntary, and you can skip any question. If you decide not to participate, there will be no penalty or loss of benefits to which you are otherwise entitled. You can, of course, decline to participate, as well as to stop participating at any time, without any penalty or loss of benefits to which you are otherwise entitled.

If you have any additional questions concerning this research or your participation in it, please feel free to contact me, committee chair, or our research office at any time."

(The respondent will be verbally provided with the contact information to the committee chair and Arcadia 's research board.)

“Do you have any questions about this research? Do you agree to participate?”

If so, let's begin....

Verbal Demographic Prescreen

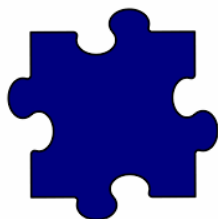
1. Is your child eligible based on the PA income requirement to receive free or reduced lunch?
The researcher will read the income criteria based on household income for free or reduced lunch
2. What is your highest level of education?
3. What is your occupation?

Appendix D. Training Overview

- I. Introductions (researcher and participants)
- II. Pre-test
- III. Review of key terms and concepts
- IV. Explanation of evidence-based interventions
 - Applied Behavior Analysis
 - Functional Communication Training
 - Discrete Trial Training
 - Pivotal Response Training
 - Prompts
 - Prompt dependence
- V. Review of case examples (e.g., a student tantrum when he wants a preferred book—what intervention is appropriate?)
- VI. Communication Training
- VII. Adaptive Skills
- VIII. Special Education
- IX. Questions
- X. Post-Test

Appendix E. Research Flyer

Families of Children with Autism Spectrum Disorder (ASD) – Research workshop



A research workshop for parents and caregivers of children with ASD who want to learn evidence-based practices, parent's rights, and resources available for children with ASD. **The workshop includes a demographic screening, pre-test, and post-test. Parents and caregivers are being recruited as research participants for a dissertation.**

When: Spring 2020

Time: 10:00-12:00PM

Where: Online format via Zoom

A \$25 Gift card will be given to one participant at random at the end of the study.

For information on the workshop please contact:

Rian Brown-Beasley, M. Ed, LBS, BCBA

Board Certified Behavior Analyst and Licensed Behavior Specialist

Please contact the researcher by phone at 856-xxx-xxxx for the initial screening.

Educational Leadership Doctoral Student

Arcadia University

450 S. Easton Road

Glenside, PA 19038

Appendix F. Informed Consent for Pre-test and Post-test Landing Page

The pre-test will take approximately 20 minutes, and the post-test will take approximately 10 minutes.

There is no risk to participants, and the data collected will be anonymous. The information you will share with us in this study will be kept anonymous. Participants will be asked not to use any names during the workshop discussion, and do not use any identifiable information during any part of the study. Please be advised that although the researcher will take every precaution to maintain anonymity of the data, the nature of the workshop prevents the researchers from guaranteeing anonymity. The researchers would like to remind participants to respect the privacy of your fellow participants and not repeat what is said in the workshop to others.

Participation is voluntary, and you can skip any question. If you decide not to participate, there will be no penalty or loss of benefits to which you are otherwise entitled. You can, of course, decline to participate, as well as to stop participating at any time, without any penalty or loss of benefits to which you are otherwise entitled. Thank you.

Appendix G. Parent Workshop – Presentation

A WORKSHOP FOR PARENTS OF CHILDREN WITH AUTISM
BY BRIAN BROWN-BEASLEY, LBS, BCBA
BOARD CERTIFIED BEHAVIOR ANALYST, LICENSED BEHAVIOR SPECIALIST, DOCTORAL CANDIDATE

OVERVIEW

- Welcome
- Introduction
- Review of Agenda & Housekeeping (e.g. send questions to chat, sound, privacy, etc.)

PRE-TEST

- Procedure for Pre-test: [https://arcadiau.co1.qualtrics.com/jfe/form/SV_d5A\(GrNaHnNd5u5](https://arcadiau.co1.qualtrics.com/jfe/form/SV_d5A(GrNaHnNd5u5)
 - Use pseudonym (e.g. fake name) – if you don't remember your fake name please send me a message in the chat)
 - Please do not share identifiable information
 - When completing the pre-test portion of study refer to your current knowledge of evidence-based strategies

POLL

Populated by Zoom regarding age range of Children represented in the study

EVIDENCED-BASED INTERVENTIONS (EBI)

- Evidence-based interventions, also known as evidence-based practices, are strategies proven to be effective through high-quality experimental research (Homer et al., 2005).

Well-designed scientific evidence to support its effectiveness.....

APPLIED BEHAVIOR ANALYSIS (ABA)

ABA is identified as one of the "gold standard" behavioral treatments for autism, having been found to teach new skills, replace challenging behaviors with more socially acceptable behaviors, and improve long-term outcomes for children.

ABA can be used to assess problem behaviors, and teach replacement behaviors

- Functional Behavior Assessment (FBA) – identifies a behavior(s) of concern, the purpose of the behavior(s), and factors maintaining the behavior(s).
- ABA can be used to teach new replacement behaviors based on function of the behavior of concern (e.g. escape, attention, access, sensory)

Running head: IMPACT OF PARENT TRAINING

APPLIED BEHAVIOR ANALYSIS

- **ABA Interventions to teach independent skills:**
 - Discrete Trial Training is an evidence-based intervention that relies on personalizing and simplifying instruction using prompts to promote accurate and independent responses (Smith, 2001).
 - Functional Communication Training is an evidence-based intervention that teaches an alternative response that is functionally equivalent to the challenging behavior one is attempting to reduce or eliminate (Carr & Durand, 1985; Durand, 1990; Fisher et al., 1993).

Pivotal Response Training (PRT) is an evidence-based intervention that uses ABA

PROMPTS

Prompts are cues to promote a desired behavior, and prompts are typically used to teach a variety of skills to children with autism

- Types of Prompts
 - Visual prompts – picture or written cue provided to obtain desired task
 - Verbal prompts – statement or questions promoting the desired response
 - Gestural prompts – non-verbal motion to the desired response (e.g. pointing)
 - Physical guidance – physical contact to aid in the demonstration of the desired response

PROMPT DEPENDENCE

- Children with autism are more likely to become reliant on prompts known as prompt dependence which can lead to learned helplessness
- Systematic fading of prompting procedures is essential and should be in place to reduce the likelihood that prompt dependence will occur which hinders children with ASD's ability to be independent:
 - Prompt fading procedures (e.g. least to most prompting)
 - Targeted reinforcement (e.g. praise, access to tangibles)
 - More reinforcement for independent and accurate responses

COMMUNICATION TRAINING

- Promotes social interaction – opportunities to socialize, opportunities to practice communication
- Visual supports – tools presented visually to support a person to move about their daily life regardless of age – many individuals with autism are visual learners, and benefit from visual tools:
 - Visual schedules
 - Social stories or scripts to teach social interactions
 - Picture or written prompts
- Assistive Technology - high-technology (e.g. iPad, text to speech) & low-technology - doesn't require much training (e.g. large print text, magnifier)

ADAPTIVE SKILLS

- Adaptive skills (also known as functional skills) are daily living skills used in one's daily life. Adaptive skills should be taught as much as possible to increase independence:
 - Task Analysis (breaking larger tasks into smaller steps) – shoe tying, tooth brushing, making a meal, setting the table
 - Strengthen communication skills (e.g. functional communication training, socially appropriate language, etc.)
 - Teach safety skills – implementation of a safety plan (e.g. if child wanders are your neighbors aware, child's picture on file with the police station, ID bracelet?), teach safety through goals, etc.

SPECIAL EDUCATION

Individuals with Disabilities Act (IDEA) – Ensures students with a disability are guaranteed educational rights :

- Individual Education Program (IEP) & Individualized Family Service Plan (IFSP) – a legal document that details supports, instruction, and services a child will receive
- Notice of Recommended Placement (NOREP) – formalizes the school's plan to address your child's needs in the IEP. It is a means to reject or accept services recommended
- Free Appropriate Public Education (FAPE) – a free APPROPRIATE education must be available to ALL children ages 3-21. A FAPE violation is when the school fails to implement a student's IEP (e.g. School only gives students 2 hours a month of speech instead of the 2 hours weekly the IEP states).

SPECIAL EDUCATION

- Parents are essential members of the IEP team – (e.g. parent concerns section)
- Special considerations section – IEP team must consider special considerations before developing an IEP - behavior, limited English, visual impairment, hearing impairment, assistive technology
- Transition planning/goals – it's never too early to start think about you child's future – special education laws mandate transition goals be represented in the IEP by 16 years old or sooner (in PA age 14). Contact your local office of vocational rehabilitation for support.

RESOURCES

https://docs.google.com/document/d/1U7WPIWwehT3vix_BZhsmP-CFyt52ZEasQnc0wotg/edit?usp=sharing

References available upon request

POST-TEST

- Procedure for post-test https://arcadiau.soi.qualtrics.com/jfe/form/SV_0rsoMjGNzb0QR
- Use pseudonym (e.g. fake name) – It's important to use the same fake name as you used in the pretest
 - Please do not share identifiable information
 - When completing the post-test portion of study refer to your current knowledge of evidenced-based interventions
 - Once the post-test is complete feel free to Zoom for the gift card giveaway & questions

QUESTIONS & DRAWING

- Questions – your turn
- \$25 Gift card giveaway to one lucky participant.... <https://numbergenerator.org/randomnumbergenerator/1-20>