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PARENT-FOCUSED INTERVENTIONS, FAMILY NEED, AND FAMILY ADJUSTMENT FOR PARENTS OF CHILDREN WITH AUTISM

by

Sara Carse

A Dissertation Submitted in
Partial Fulfillment of the
Requirement for the Degree of

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ABSTRACT

PARENT-FOCUSED INTERVENTIONS, FAMILY NEED, AND FAMILY ADJUSTMENT FOR PARENTS OF CHILDREN WITH AUTISM

by

Sara Carse

The University of Wisconsin-Milwaukee, 2023

Under the Supervision of Professor Karen C. Stoiber

Children with autism often have disability-specific deficits such as delays in communication and social interaction, restricted interests, rigid thinking patterns, repetitive behaviors, atypical responses to sensory experiences, and challenging behaviors (Balbouni et al., 2016; Bishop et al., 2012; Chistol et al., 2017; Anixt et al., 2018). As a result, parents of children with autism face unique challenges compared to parents of neurotypical children and report high levels of stress, especially towards their child's challenging behaviors (Stadnick et al., 2017). Parent stress has been shown to cause dysfunction in family adjustment (Keen et al., 2010). Families may seek child-focused or parent-focused interventions to improve their child's communication, social skills, and behavior. Parents of children with autism also report unmet needs related to information about their child's disability, behavior management, and treatment avenues (Brown et al., 2012). Due to unique deficits and their impact on parent stress, children with autism are typically the main focus of research with parent stress also being a lead interest of parent-focused research. However, the association between parent-focused interventions and factors like family adjustment and family need is currently understudied. This quantitative survey study explored the relation between family adjustment and family need as well as the relation between specific parent-focused interventions with family adjustment and family need for a sample of 62 caregivers of school-aged children with autism. Analyses included conducting descriptives and a series of multiple regression analyses. The results suggested family adjustment was a significant predictor of family need. Specifically, increased ratings of family maladjustment were consistent with more unmet needs reported by a family. The specific type of parent-focused intervention received by a family was not significant in predicting family needs or family adjustment. Limitations, implications, and future directions are discussed.

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This work is dedicated to all the people in my life who saw me through the difficult and tenuous journey that is graduate school. Thank you to my cohort who became more like family. Abby, Amber, Rachael, and Sam- there is just no way I would have finished without all of you. You taught me so many things and were the people I could rely on every step of the way. Thank you to my chosen family- for understanding my absence from time to time and supporting me anyway. Thank you to my family, especially my parents. Dad- you have encouraged me since day one to never let anything hold me back from achieving my goals and supported me to make the right decisions for me. Mom- you always believed I could do anything and loved me unconditionally; it is hard to believe you are not here to see me cross the finish line, but I know you would be proud if you could. A special thanks to Joe- this quite literally would not have been possible without you. You took on more so I could focus on this and along the way I think you have become just as invested as me. Your support throughout this journey will always be something I appreciate and one of the many reasons I love you. Thank you to the participants who contributed to my research and the field of autism research. Finally, thank you to my dissertation committee members and my advisor, Dr. Karen Stoiber, for their guidance, feedback, and support along the way.

TABLE OF CONTENTS

Introduction

Children with autism may have various unique characteristics including social interaction and language delays (Flippin & Watson, 2018), adaptive skill deficits (i.e., functional communication, daily living skills, and socialization) (Balbouni et al., 2016), unusual repetitive behaviors and rigid thinking patterns (Bishop et al., 2012), atypical sensory processing (Chistol et al., 2017), and major challenging behaviors (Anixt et al., 2018). Most children with a diagnosis of autism receive interventions to improve symptoms associated with the disorder. Interventions most commonly include behavioral interventions (Reichow, 2012), social skills training (Guivarch et al., 2017), and occupational and speech-language therapy (Cummings et al., 2016). Given the difficult symptoms exhibited by children with autism, children have typically been the primary focus of the intervention and have monopolized the spotlight for research outcomes. Research has also focused on certain parent outcomes including parent stress and parent competence. However, a gap still exists in the research focused on if family need is associated with family adjustment as well as if parental involvement in specific types of parent-focused interventions is related to family need and family adjustment.

Parents of children with autism are in particular confronted with an abundance of challenges different from those faced by parents of neurotypically developing children. These challenges are due to deficits and discrepancies observed in their child’s behavior, communication, and development. Parents of children with autism may experience a variety of obstacles that are associated with autism including unique developmental characteristics, deficits in communication, impaired quality of relationships, difficult behaviors, and external difficulties such as social stigma or financial burdens; these obstacles are responsible for contributing to a disruption in the social feedback loop between parents and child as well as higher levels of parent stress, which have been found to impede family adjustment. Family adjustment can also be affected by the type of parenting practices used by parents. For example, coercive practices (e.g., yelling, hitting, threatening, etc.) are shown to limit developmental progress for children with developmental disabilities. In contrast, Biglan et al. (2012) reported nurturing parenting practices reduce children's challenging behaviors and improve self-regulation and flexibility. According to Day and colleagues (2021), coercive parenting practices used by parents of children with disabilities can be improved when parents participate in evidence-based parenting interventions. Parents of children on the autism spectrum may also experience difficulties in understanding, absorbing, and responding to atypical communicative and repetitive or difficult behaviors. According to Brown and colleagues (2012), parents of children with autism generally report unmet needs in the areas of information, specifically about autism and options for treatment, skill development for managing challenging behaviors, care coordination services for treatment, and respite care for their children. These aspects are consistently reported as unmet needs for parents of children with autism given the particular characteristics associated with autism. Due to the challenges that parents of children with autism experience, research suggests parents can benefit from support that reflects educational, behavioral, and psychological parent needs (Derguy et al., 2015).

For the purpose of this study, parent and family needs are defined as the needs reported by parents of children with autism in the areas of information, family and social support, financial, explaining the disability to others, childcare, professional support, and community services. It should be beneficial to examine parent needs with attention to contextual aspects, such as family adjustment and parent intervention, to further the field of autism research and create practical implications for practitioners working with families of children with autism.

Family adjustment refers to the tendency for families to function positively during difficult situations by utilizing their own strengths (Rosenbrock et al., 2021). Parent intervention in the form of parent support or parent implementation can be very beneficial for parents of children on the autism spectrum to learn valuable information about autism, child development, and skill acquisition (Bears et al., 2015). Parental involvement in parent-focused interventions has been shown to lead to positive outcomes for both the child with autism and the child's family (McConachie & Diggle, 2007).

According to Titelman (1998), Bowen's family systems theory understands the family as a complex unit in which each member assumes responsibilities and complies with rules developed within the family system. Each member in the unit influences the system in a unique way to maintain stability within the family. Family members experience stress or anxiety when conflict exists among members, excessive fusion and lack of individuality, or an instability within the unit. Reducing anxiety and triangulation are two of the chief principles in Bowen's family systems theory. Family systems theory offers insight into the complicated nature of diverse family systems while maintaining consideration of aspects that vary among families such as parent perspective, parent and family need, and familial adjustment.

The Family Needs Survey (Bailey & Simeonsson, 1988) has been a commonly used tool that measures family needs in terms of information about disabilities and development, social support, financial support, explaining the disability to others, childcare, professional support, and community services. According to Derguy and colleagues (2015), studies using the Family Needs Survey revealed that families need additional support in understanding the aspects of the child's disability; many parents report being dissatisfied with the information they received about their child's disability. Further, the inadequate information received about their child's disability limited their child’s progress as a result of limited access to services. Parents are able to make more appropriate decisions for their child's therapeutic path after they become more knowledgeable about their child’s disability, however, parents may initially require more guidance and support for choosing disability-related therapeutic options (Edwards et al., 2018). The survey also revealed parents need to feel more supported in implementing specific strategies with their child in order to foster development and manage behaviors. Additionally, the survey showed that parents indicated a need for social support and effective communication. Parents of children with autism have been identified as being motivated to seek social support due to complications with their child’s communication skills and being able to understand ways to communicate effectively with their child (Papgeogiou & Kalyva, 2010).

Deficits in communication and nonverbal language can baffle parents of children with autism. According to Lucas and colleagues (2008), communication may be an area of particular confusion or frustration for parents of children with autism because of the various deficits that their child may be experiencing such as an expressive or receptive language disorder, or difficulties in structural or pragmatic language (Park et al., 2012). Expressive language deficits have serious consequences for the parent-child relationship as they can interfere with the child’s ability to engage in reciprocal conversations and use language to express needs. Further, receptive language deficits can inhibit the child’s ability to process language. Thus, parents of children with autism may experience low confidence regarding their ability to parent and interact with their child. Boonen and colleagues (2014) found pragmatic language difficulties (e.g., use of language for social interaction) were positively associated with behavior problems. When children are not able to effectively communicate their desires, thoughts, and needs with verbal or nonverbal language, they are more likely to engage in externalizing or challenging behaviors as a means to produce a desired outcome. Parents may not interpret their child's challenging behaviors as a form of communication leading to further stress on the parent-child relationship, missed opportunities for learning, and strain on the family unit and overall adjustment.

Stadnick and colleagues (2017) reported a number of challenging behaviors (e.g., aggression, noncompliance, and self-injury) children with autism may exhibit that can be especially difficult for parents to manage or eliminate. Challenging behaviors and the ability to manage difficult behaviors have been shown to be an area of major stress for parents of children with autism, which can also serve as a risk factor for families and become an area that may cause dysfunction in family adjustment (Keen et al., 2010). Parents of children with autism reported having feelings of helplessness surrounding management of their child's difficult behaviors as well as seeking the necessary resources to service their child therapeutically and medically (Strunk et al., 2014). Derguy and colleagues (2015) found that parents needed informational support in managing aspects of their child's disability such as challenging behaviors. Information support for parents in the area of behavior management can help reduce stress and improve feelings of self-efficacy for parents, thus strengthening family adjustment.

Raising a child with autism has been associated with serious financial burden due to a number of potential circumstances, including costlier childcare, services that are not covered by insurance, and one parent having to leave the workforce or cut hours to stay home with their child (Hoefman et al., 2014) as well as higher routine and out-of-pocket expenses (Bachman & Comeau, 2010). Parents raising children with autism on average surrendered approximately 14% of their annual salary to such costs (Montes & Halternman, 2008). According to Bachman and Comeau (2010), health care insurance and service delivery differ between states making services decisions and policies difficult to navigate for parents. Consequently, parents may lack knowledge not only on the best type of services for their child but the correct pathways to follow to receive services for their child that may be covered by insurance. Care coordination, or the practice of helping families reduce their unmet needs, financial burdens, and barriers to services (Culnane et al., 2020), could be especially helpful for parents of children with autism navigating the difficult avenue of autism treatment.

The purpose of this research was to better understand whether parents who reported a higher number of needs endorsed lower family adjustment when controlling for child age, child gender, and number of interventions received by parents. Additionally, this research aimed to understand the association between specific types of parent-focused interventions and family needs and family adjustment. Specifically, the study examined how parent needs and family adjustment differed based on parental involvement in a parent skill behavior-focused intervention compared to parental involvement in a parent-focused intervention without a behavioral component when controlling for child age, child gender, and number of interventions received by parents. Findings are expected to be helpful for practitioners in supporting families of children with autism through the understandings that the study offers regarding more individualized and streamlined approaches for families with unique needs, experiences, and adjustment.

Literature Review

Children with autism often face substantial behavioral difficulties (McConachie & Diggle 2007), significant language barriers (Lucas et al., 2008), and various verbal and nonverbal communicative and social interaction deficits (DSM-V, 2013). As a result, parents of children with autism have encountered unique challenges unlike parents of neurotypically developing children. This literature review has provided an overview of autism, parent-focused research outcomes, treatment and level of support, care coordination, important components of interventions, parent need, family systems theory, and family adjustment.

First, the background of autism is discussed at length including information on the diagnostic criteria, the nature of spectrum disorders and autism severity, social interaction and communication deficits, and repetitive restricted behaviors. Second, I provide an overview of parent-focused research outcomes including previous parent interventions, external difficulties specific to parenting a child with autism, and heavily researched parent outcomes (e.g., parent stress and parent competence). Third, I reviewed treatment and level of support for children with autism and their families. Fourth, care coordination was reviewed as currently received by parents of children with autism. Fifth, important intervention components are explained through the lens of the development of autism treatment, parental involvement, early intervention, evidence-based rationale, psychoeducation, and skill development. Sixth, parent needs were examined with previous research, assessment of parent needs for families of children with autism, and the Family Needs Survey. Seventh, family systems theory is explained including the family unit, the interlocking concepts, and the application of those concepts to families of children with autism. Finally, family adjustment research is explained in detail.

Overall, readers will learn the basis for which the proposed research aimed to understand the relation between parent needs for parents of children with autism and family adjustment. Additionally, readers will gain an understanding of the ways in which parent needs for parents of children with autism differ based on parental involvement in specific types of parent-focused interventions. These research findings may be helpful in future analysis of parent needs, family adjustment, and the importance of parent-focused interventions for parents of children with autism.

Background of Autism

Autism is a neurodevelopmental disorder that is characterized by social deficits, communication difficulties, and repetitive and restricted interests or behaviors (DSM-V, 2013). According to the Centers for Disease Control and Prevention (2018), boys are four times more likely than girls to be diagnosed with autism and the overall average diagnostic rate of children with autism is 1 in 44. As prevalence for autism diagnoses increase, so does the need for adequate intervention options for children and parents of children with autism as well as a foundational knowledge (e.g., deficits, changes in criteria, severity, and evolution of treatment) of the disorder.

Diagnostic Criterion Changes

The American Psychological Association (APA, 2013) highlighted the changes made in the diagnostic criteria for autism between the fourth and fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM). First, the DSM-V presented autism as a spectrum disorder including four previously separate disorders known as autism, Asperger's disorder, childhood disintegrative disorder, and pervasive developmental disorder not otherwise specified. Spectrum disorders encompass a range of impairments related to the disability; the range can be extremely low functioning with limited verbal and adaptive skills to high functioning with mild social impairments (Russell & McCloskey, 2016). The range of potential impairments associated with autism and related disorders is an important consideration for evaluation, diagnostic procedures, and treatment avenues as every individual with autism will have a combination of unique skills and deficits. Second, the DSM-V combined social communication and social interaction into one domain instead of emphasizing the two separately. Grouping social communication and social interaction in a single domain rather than independent domains is advantageous because of the overlap in deficits observed between social communication and interaction. Social communicative deficits contribute to strained communication and limited interaction ability for children with autism. According to Hudry and colleagues (2013), parents may be overly direct while interacting with their child with autism in an attempt to atone for communication deficits which may further perpetuate a lack of, or weak interaction attempts made by the child. Additionally, researchers found that parent-child dyads for children with autism with limited capacity for social interaction displayed lower parent synchrony (e.g., parent responsiveness and effective communication), less child-initiated communication attempts, and less shared attention by both parents and children. Alternatively, children with better social communication and interaction skills resulted in stronger parent-child dyads implicating a strong relevance for grouping communication and interaction into a single domain (Hudry et al., 2013).

Autism Spectrum Disorder and Severity

The nature of autism as a spectrum disorder implies varying levels of severity from low to high functioning (Russell & McCloskey, 2016). As previously mentioned, autism also includes disorders previously known as Asperger's disorder, childhood disintegrative disorder, and pervasive developmental disorder not otherwise specified. According to the DSM-V (2013), autism can range in severity levels for individuals on the spectrum from level one to level three. Severity levels for autism spectrum disorder are dependent on variables related to social communication and restricted, repetitive behaviors, all requiring varied levels of support. Individuals with a level one impairment exhibit noticeable deficits in communication such as a lack of conversational initiation or fluidity in conversation. They may also seem to lack interest in social interactions. Additionally, individuals with a level one impairment may lack the ability to adapt to their environment and are often rigid when changing activities. Individuals with a level two impairment require substantial support. Their communication deficits include verbal and nonverbal communication skills, reduced conversational abilities, and abnormal responses to social interaction. Level two impairments are also marked by major behavioral rigidity, lack of adaptability, restricted interests, repetitive behaviors, and distress may be present when changing focus. Finally, a level three impairment is characterized by severe communication deficits causing significant limits to social interaction. Further, level three impairments are marked by severe inflexibility of behavior, lack of ability to adapt to change, and major restricted and repetitive behaviors. Individuals with a level three impairment require substantial support.

Social Interaction and Communication Deficits

The DSM-V (2013) classifies autism as a spectrum disorder that produces deficits in social communication and interaction both verbally and nonverbally. Verbal communication refers to using language to communicate needs, wants, and conversation, as well as components of vocal expression like tone, volume, and cadence (Oller et al., 2013). Language is one of the single strongest predictors of parent-child interaction styles in that parents are more responsive to child communication attempts, the child is independently initiating communication, and meaningful shared attention is occurring between the parent and child with autism (Hudry et al., 2013). Nonverbal communication can include hand gestures, body language, emotional expression, and embracing (Van Der Meulen et al., 2010). A combination of verbal and nonverbal communication deficits contributes to further social strains for children with autism. According to the DSM-V (2013), a child with autism is likely to be unable to recognize, identify, and reciprocate emotions and typically lacks the ability to establish, understand, and maintain relationships. Examples of social and communication problems include a lack of shared enjoyment, joint attention, knowledge of personal space or other social norms, eye contact, and unresponsiveness to their own name (Kirchner et al., 2010). Joint attention refers to shared attending behaviors between two parties involved in an interaction (e.g., eye contact, following gaze and point, and responsiveness to affect, expression, and vocal tone) (Howard et al., 2018). According to Gorlin and colleagues (2016), communication deficits perplexed parents of children with autism, contributed to extreme parent stress, lead to feelings of isolation within the household between the parents and the child with autism, and lead to parent feelings of inadequacy. Communication is an area in which parents of children with autism can benefit from explicit instruction to increase skills for their own interactions with their child. Kashinath and colleagues (2006) conducted a study in which parents of children with autism were enrolled in a parent-focused training program designed to improve parenting strategies including environmental arrangement, natural reinforcement, time delay, contingent imitation, modeling, and gestures across daily routines. The intervention strategies were utilized within the families' daily routines, creating a naturalistic opportunity to improve the parent's ability to elicit both verbal and nonverbal communication from their child. Results indicated significant improvements in generalized parenting practices and child communication.

Repetitive Restricted Behaviors

The DSM-V (2013) diagnostic criteria for autism also includes a set of restricted, repetitive patterns of behavior, interests, or activities (e.g., hand flapping, repetitive body movement, and repetitive vocal expressions). Restricted interests may be focused on a hobby, an item, or specific people. Repetitive behaviors and restricted interests can contribute to difficulties in the child's social interactions, establishing friendships, and forming bonds with peers or family members. Children with autism who engaged more frequently in repetitive behaviors have been shown to have limited responses from parents, initiate parent-child interactions less, and display lower shared attention with parents compared to children with autism who have fewer repetitive behaviors (Hudry et al., 2013).

Challenging Behaviors

Although challenging behaviors are not a diagnostic criterion for autism spectrum disorder, children with autism are often reported to engage in behaviors characterized as "challenging" (Boonen et al., 2014). The term challenging behaviors broadly describes behaviors considered to be aggressive, destructive, and self-injurious (Emerson, 2001). According to Murphy and colleagues (2009), challenging behaviors can pose serious threats to the safety of the individual with autism and others and are shown to significantly reduce quality of life as well as physical and mental health. Behavior problems can negatively impact the child's daily functioning, overall development, ability to develop relationships, ability to learn new skills, and access to services. Additionally, individuals with autism who engaged in challenging behaviors typically engage in more than one form. Challenging behaviors are often the result of a combination of social deficits (e.g., language, communication, and interaction) as well as the child's environment (Kabashima et al., 2020).

Behavior problems often contributed to negative outcomes for parents such as increased stress and the emergence of mental health problems (e.g., depression and anxiety) (Boonen et al., 2014). Stress is more prominent for parents of children with autism when their child engages in challenging or problematic behaviors (Rao & Beidel, 2009). Parents often reported not knowing how to manage their child's challenging behavior (DePage & Lindsay, 2015), signaling a need for parents to receive focused interventions in order to learn skills for behavior management related to autism. Milgramm and colleagues (2022) found that parenting stress was reduced after participating in a parent education program specifically in the area of stress towards the parent-child relationship, however, results did not indicate that parenting stress was reduced in the areas of personal factors (e.g., mental health) or child characteristics such as challenging behaviors. Researchers inferred that parenting stress did not significantly decrease in the latter areas because parents were not taught specific skills to manage their child's challenging behaviors, rather they were presented information about autism spectrum disorders and treatment. According to DePape and Lindsay (2015), challenging behaviors have the potential to interfere with family functioning in a myriad of ways. For example, parents of children with autism reported higher stress than parents of typically developing children when taking their child out in public. Parent stress is accelerated by the possibility of their child engaging in challenging behaviors, criticism from strangers regarding their child's behavior, and being labeled as "bad parents" by others because of their child's behavior. Additionally, because challenging behaviors may consume primary focus from one or both caregivers, other members of the family (e.g., siblings) may not feel as though they are a valued member of the family unit. In some cases, siblings of children with autism had a diagnosed anxiety disorder, reported markedly different treatment from their parents compared to their sibling with autism, and at times served as a caretaker for their sibling with autism.

Age of Diagnosis

The age a child is diagnosed with autism is a crucial factor in the context of autism treatment and support. According to the Center for Disease Control (2022), an early diagnosis is imperative to providing children with autism with the necessary services. Developmental monitoring is considered to be the first step in acquiring an autism diagnosis and important for all children regardless of suspected disability. Typically, primary care physicians ask parents questions about their child's playing, learning, speaking, behaving, and motor skills; these questions help the physician understand whether a child is meeting developmental milestones. When a physician encountered information about the child that is atypical, a more formal developmental screening can be completed. The American Academy of Pediatrics (AAP) recommended developmental screening for autism as early as 18 months old. There are several developmental milestones toddlers should be accomplishing at 18 months in the areas of social/emotional skills, language and communication, cognition, and motor skills. Social/emotional skills can include pointing to show interest, putting their hands out for washing, or looking for their parent. Language and communication skills should be developing on pace for a child to have three or more words outside of “mom” or “dad” and the ability to follow one-step directions. Cognitive skills can be related to copying chores or playing with toys as intended (e.g., pushing a toy car). Motor skills include walking independently, scribbling, drinking from a cup, self-feeding without utensils, and climbing.

If the developmental screening tool identifies areas of concern, a formal evaluation is conducted by a specialist to procure a diagnosis. While children can be diagnosed with autism between the ages of 18 and 24 months, it is common for children to be diagnosed with autism after the age of three years old. Following a diagnosis, a multidisciplinary team works together to form a comprehensive treatment plan for the child. Due to the unique needs of each child, treatment plans often vary and may include services in the areas of behavior, development, education, social-relations, pharmacology, psychological, and adaptive behaviors. According to Gabbay-Dizdar and colleagues (2022), children diagnosed with autism prior to 30 months observed greater improvements in the area of social interaction and communication compared to children diagnosed after 30 months. On average, approximately 65% of children diagnosed with autism prior to 30 months experienced improvements on a standardized diagnostic assessment for autism whereas only 23% of children diagnosed after 30 months performed more favorable on the same autism assessment. Researchers suggested these improvements are exhibited due to heighted brain plasticity at a younger age allowing for greater benefits to be absorbed from early interventions. According to Mandell and colleagues (2005), early diagnosis for autism was crucial to more observable improvements over the course of a lifetime. There are a variety of factors that have been shown to be influential when a child received a diagnosis including location (e.g., rural, suburban, urban), number, type (e.g., repetitive behaviors, over sensitivity to stimulation, etc.), and severity of symptoms associated with autism, household income, number of pediatricians seen, etc.

Parent-Focused Research Outcomes

This section overviews previous parent interventions, external difficulties observed by families of children with autism, and heavily researched parent outcomes. These elements are pertinent to future parent-focused research for parents of children with autism by examining existing knowledge and exposing gaps in literature.

Previous Parent Interventions

Research on parent interventions has shown the importance of parental involvement in psychoeducation, skill training, and directly working with their child to improve skills like communication, joint attention, and challenging behaviors. The research below overviews the positive outcomes for parents and children with autism when parents have a role in learning and implementing evidence-based strategies. While the literature has done a great job of highlighting benefits for child outcomes and specific parent outcomes like parent stress and parent competence, there is a lack of focus on parent and family needs. Understanding family adjustment and parent needs prior to implementing interventions could allow for more individualized support.

Project ImPACT. Ingersoll and Wainer (2013) discuss Project ImPACT as a social communication intervention for very young children with autism with a parent-mediated component. The goal of Project ImPACT was to teach parents interventions for working with their child, explain the rationale for techniques, and fit the techniques to specific goals for the child. The intervention was conducted once or twice a week for approximately one hour in a laboratory setting with the parent, child, and one interventionist. Parents were given homework and reflections at the end of each session. Project ImPACT yielded positive outcomes for almost all participants and parents showed significantly higher fidelity of implementation strategies after skills were introduced (Ingersoll & Wainer, 2013). While this intervention was effective in serving parent and child outcomes, it did require a heavy time commitment and focused on dyadic learning opportunities. Further, a clinical setting can limit generalizability for both parents and children. Ingersoll and colleagues (2017) modified Project ImPACT to be implemented with low intensity (i.e., approximately one to two hours per week) by an interventionist. Results showed a majority of children's social engagement language abilities improved and generalized to multiple settings. However, play skills were only minimally better for some of the children involved in the study. Parents reported gains in their child's capacity for reciprocity in social situations. Research suggested Project ImPACT can be successful in improving intervention targeted outcomes for children (i.e., language, social engagement, and play skills) regardless of whether the intervention is implemented by parents or an interventionist (Ingersoll & Wainer, 2013; Ingersoll et al., 2017). However, it appeared results were consistently better when parents are involved in treatment, reiterating the importance of parent involvement in implementation and parent support of skill knowledge.

Stadnick and colleagues (2015) conducted additional research on Project ImPACT in a community setting in which researchers evaluated child outcomes including communication skills, adaptive functioning and severity of autistic symptoms as well as parent outcomes such as intervention adherence, parent depression, and parenting stress compared to a control group. Results indicated overall child communication skills significantly increased over a 12-week intervention period compared to communication skills of children in the control group. Parent adherence to intervention also significantly increased for parents in the intervention group as compared to parents in the control group. An additional notable finding is the significantly inverse relationship between baseline parenting stress and progress in child social skills for participants in the intervention group; higher initial parenting stress led to less progress made by children in developing social skills.

PLAY Home Consultation Program. Mahoney and Solomon (2016) analyzed data on research for the Play and Language for Autistic Youngsters (PLAY) home consultation program. PLAY is a program geared towards teaching parents to engage with their children to improve development and language by interacting in social and communicative play. Participants assigned to the PLAY group, rather than community standard treatment, received monthly parent-child intervention sessions for one year. A preliminary analysis revealed significant improvements for social affect in children with autism but no changes in restricted and repetitive behaviors. A secondary analysis found that neither severity scores or restricted and repetitive behaviors were significantly reduced after the intervention. However, results showed social engagement and the severity of social affect in children with autism mediated by an increase in parent responsiveness and affect. Additionally, parent responsiveness and affect were mediated by the impact the intervention had on social engagement. Overall severity scores for children with autism in the secondary analyses were hypothesized to show an insignificant change due to the intervention's lack of progress on restricted repetitive behaviors. While this intervention had many promising components such as the emphasis on high responsiveness and engagement from parents, there were also limitations that should be addressed. Monthly sessions may be ideal for parents with busy schedules, however, one session a month may not be a sufficient dosage for learning skills focused on frequent interactions. Researchers expressed concern for adequate parent participation in the intervention program in areas such as parent buy-in, presentation of materials to parents, and parent difficulty following the intervention's recommendations.

Pivotal Response Training for Parents. Hardan and colleagues (2015) extended pivotal response training for children with autism into a parent focused intervention and examined group differences in child functional communication skills between parents of children with autism in a pivotal response parent training group and parents of children with autism in a psychoeducation group. According to the Center for Disease Control and Prevention (2014), pivotal response training is a type of applied behavior analysis (ABA) that targets child motivation in areas of learning, self-monitoring, and initiation of communication. The parents in the pivotal response training group were explicitly taught how to implement skills to their children with autism whereas the parents in the psychoeducation only group were educated (i.e., did not receive explicit training) in pivotal response training. Pivotal response training has been used as an effective behavioral treatment for children with autism that uses tenants of applied behavior analysis during play to progress pivotal areas of a child's development such as motivation. Results indicated parents in the pivotal response training group were more successful at implementing pivotal response training and improving their child’s functional communication and adaptive skills as compared to the psychoeducation only group. While the parent psychoeducation group did not experience significant gains in improving their child’s functional communication skills, more research is needed to understand the benefits of interventions aimed at both educating parents through explicit behavioral training and psychoeducation.

Functional Communication Training (FCT). Deb and colleagues (2020) found that functional communication training with parents of children with autism was effective in reducing challenging behaviors in children across studies. Functional communication training is an evidence-based behavioral intervention that can be used by practitioners with parents of children with autism (Gerow et al., 2018) that closely resembles a functional behavioral analysis. The first step is to identify the function of a challenging behavior. Second, an alternative or replacement behavior is taught to the child. Third, the child is reinforced for their altered response. Last, reinforcement is withheld from the child after a challenging behavior, which can reinforce the child to engage in a replacement behavior or use communication to elicit the desired outcome. According to Gerow and colleagues (2018), the effects of reducing challenging behavior through functional communication training generalized to novel situations and people and demonstrated relevance over time. Additionally, parents had positive impressions about the effectiveness of using functional communication training, reporting it was a feasible approach to managing their child’s challenging behaviors. Parents also reported they would continue to use functional communication training as a method for managing behavior in the future.

External Difficulties

External difficulties (i.e., stressors indirectly related to child symptoms) such as social stigma, impaired family relationships, financial burdens, and time constraints have contributed to increased parent stress and decreased parental competence for parents of children on the autism spectrum as well as increased parent and family needs for support (Elder et al., 2017; Kinnear et al., 2008). Parents of children with autism have often experienced a combination of external difficulties or stressors that are common among families with children with autism but also unique to their family and warrant targeted expertise in order to organize support for the family with the overall goal of reducing stressors, barriers to progress, and better overall familial adjustment.

Family Relationships. Although no significant differences in divorce rates are reported for parents of typically developing children compared to parents of children with autism, parents of children with autism reported significantly less marital satisfaction and higher stress than their peers (Freedman et al., 2012). Diminished couple (i.e., marital) satisfaction has been associated with lower quantity and quality of interactions between parents of children with autism (Hartley et al., 2017). Lower marital satisfaction has been associated with inadequate developmental progress for children (Kwok et al., 2014). Married parents of children with autism may choose to stay together for financial stability, support, or the overall developmental wellness of their child. Harper and colleagues (2013) found families with access to respite care for their child experienced reduced stress and improved martial quality, however, respite care can be difficult to access for families of autism that display markedly challenging behaviors.

Parents of children with autism may also have other children with or without autism. Siblings of children with autism have reported feeling they do not receive the same treatment from their parents as their sibling with autism (DePape & Lindsay, 2015). According to Rao and Beidel (2009), siblings of children with autism often reported feelings of loneliness and depression and may also display their own behavioral difficulties. Although negative outcomes have been observed for siblings of children with autism, positive outcomes have also been reported. Siblings of children with autism reported a more positive self-concept (Macks & Reeve, 2007), as well as increased patience and maturity (Markoulakis et al., 2012).

Number of Children with Disabilities. Parents of children with autism may have more than one child with a disability in their household. Research within the scope of parenting multiple children with disabilities is limited. Although the percentage of children in the United States with a disability rose to 4.3% in 2019 (Young, 2021), there is a lack of data to suggest the current number of families living with multiple children with disabilities. Gronborg and colleagues (2013) concluded a recurrence risk of 7% when analyzing population data in Denmark for families with multiple children with autism. However, recurrence risks as high as 19% were observed when younger siblings of children with autism were monitored since infancy (Ozonoff et al., 2011). Based on group averages from existing studies, Myers (2013) suggested the estimate for having a subsequent child with autism is 10%. While understanding the recurrence risk for having multiple children with autism is important given the unique challenges parents encounter raising a child with autism, there is not sufficient data to determine the frequency of having multiple children with varying disabilities.

Orsmond and colleagues (2007) found parenting more than one child with autism can lead to impaired family adjustment and heightened frequency of depressive symptoms in mothers as well as stress. According to Ghosh and Parish (2013), families with multiple children with disabilities were significantly more likely to experience poverty and were unable to meet basic material needs compared to families without multiple children with disabilities.

Hansen and colleagues (2019) compared families with an older sibling with an autism diagnosis to families without any diagnosed children to determine the likelihood of another child in the family receiving a diagnosis. Results indicated an 8.4-fold increase in the occurrence of a younger sibling also receiving an autism diagnosis at some point if an older sibling also has an autism diagnosis, however, the rate of risk appears to vary throughout research as previously indicated. Additionally, while a sibling of a child with autism sits at a higher likelihood of receiving an autism diagnosis, they may also be born with other disabilities or mental health disorders. According to Orsmond and colleagues (2007), the most frequent types of disabilities observed in sibling of children with autism included attention deficit and hyperactivity disorder, autism, cognitive and psychiatric disorders, and learning disabilities. Mothers parenting a child with autism and a child with another disability were found to experience more depression and anxiety compared to mothers of a child with autism without any additional children with disabilities. Additionally, lower levels of family adjustment (i.e., family adaptability and cohesion) were found in families with both a child with autism and a child with another disability compared to the autism only group. Consistent with previous research, Orsmond and colleagues (2007) also reported mother well-being and family adjustment was impacted by the severity and number of challenging behaviors exhibited by the child with autism.

Financial Burdens. Parents of children with autism have experienced significantly higher financial burdens raising their child compared to parents of typically developing children (Parish et al., 2015). Financial hardship can also be elevated if one parent leaves the workforce to care for their child with autism full time (Elder et al., 2017). Further, more time and resources are spent choosing appropriate health care plans best suited for their child and family needs, which may add to stress and confusion for parents of children with autism (Thomas et al., 2016).

Time Constraints. Parents are responsible for navigating various intervention options for their child with autism, which can be difficult due to a variety of conditions, including busy schedules, financial burdens, insurance misinformation, and complex service options. Adding to the stress, children with autism may have intervention commitments of 40 hours a week or more depending on intensity, type, or specific need in which their parents are expected to be present (Green, 2007). A typical intervention routine may include 27 to 40 hours a week of intensive intervention (e.g., behavior, speech and language, occupational, and social skills groups) (Reichow et al., 2018). Additionally, parents may or may not have the opportunity through their child's treatment options to engage or receive psychoeducation about their child's diagnosis and therapeutic path. Correctly selected interventions for parents of children with autism facilitated positive outcomes including better parent-child interactions, stronger communication between parents and their children, and parent skill development; these positive outcomes have been shown to decrease parent stress and increase parent competence (Ji et al., 2014).

Social Stigma. Parents of children with autism have reported feeling hesitant to take their children on public outings due to their child's unpredictable, undesired behaviors (Elder et al., 2017). Parents of children with autism have experienced higher social stigma than parents of children with other disabilities due to the lack of outwardly visible characteristics associated with autism (Kinnear et al., 2016). Social stigma and feelings of discrimination for parents of children with autism have impacted not only parent well-being but child well-being and development (Worcester et al., 2008). Parents of children with autism often experienced stigma in the form of shame, exclusion, and judgement as a result of their child's atypical or challenging behaviors which can leave parents feeling worthless and inadequate (Farrguia, 2009).

Heavily Researched Parent Outcomes

Next, I highlight previously researched parent outcomes that have captured a majority of the research spotlight including parent stress and parent competence. Additionally, this section reviews the impact these parent outcomes have on child outcomes for parents of children with autism. While parent stress and parent competence are not the focus of this research study, they are important aspects of family functioning that warrant review.

Parent Stress. According to Burrell and Borrego (2012), parent stress is defined as tension exhibited by the parents of children with autism that affect the family and child with autism. Further, parent stress is known to have a major impact on a child's development and functioning for both children with autism and children in general. Parents of children with autism are reported to have higher levels of stress regarding their view of themselves as parents, less satisfaction with their bonding abilities with their child, and stress related to difficult behaviors exhibited by their child (Lai et al., 2015). Deliberately targeting certain areas of parent need related to specific deficits associated with autism and common stressors reported by parents of children with autism may be helpful in tailoring an intervention that best serves parents as intervention recipients.

Previous Research on Parenting Stress. Estes and colleagues (2014) examined research on parent stress levels as an outcome of the intervention. Their review presented mixed results across the spectrum including decreased stress, no change, and even an escalation in reported stress. Previous research showed parents receiving too many direct (i.e., in-person) treatments reported higher stress levels than parents receiving fewer treatments (Schwichtenberg & Poehlmann, 2007). Higher stress levels associated with excessive intervention hours indicated a need for families to receive support that not only focuses on child outcomes but also considers feasible and realistic operations for the family. Estes and colleagues (2014) found stress levels for parents receiving a tailored intervention as compared to a community-based intervention differ on the basis of whether their child has received a recent diagnosis. Parents of children with autism who recently received a diagnosis reported higher stress than parents of children with autism who received a diagnosis in the past. Additionally, parents often reported more stress when their child with autism engaged in challenging behaviors (e.g., aggressive, destructive, and self-injurious) (Boonen et al., 2014; Rao & Beidel, 2009). Parent stress had many implications for overall family adjustment. According to Rao and Bidel (2009), parent stress often restricted family functioning in the areas of sustaining supportive relationships within the family unit, personal growth for individual family members, and family organization and structure.

Parent Stress on Child Outcomes. Communication deficits, behavioral symptoms, social stigma, decreased marital satisfaction, time, financial burdens, complicated insurance choices have contributed to an increase in parent stress for parents of children with autism. Due to these variables, parents of children with autism are reported to experience higher stress than parents of typically developing children or children with other types of disabilities (e.g., intellectual disabilities) (Rivard et al., 2014). According to Strauss and colleagues (2012), parent stress has affected child outcomes and response to treatment as well as their own capacity to engage in consistent practices with their children. Parents of children with autism interacting with their children, responding to behaviors, and sticking to routines with consistency is necessary for children with autism to understand clear expectations and generalize appropriate behaviors (Kashinath et al., 2006). Due to the inverse relationship between parent stress and positive child outcomes, research has suggested that it is important to find evidence-based solutions to decrease parental stress for the betterment of child outcomes as well as the quality of family life (Hsiao, 2018).

Parent Competence. Parental self-efficacy and parental competence are terms regarding the perception of parenting skills which differ by the individual responsible for skill perception

(Glaveanu, 2015). Skills are either perceived by the parent themselves or an external source such as an intervention coach. According to de Montigny and Lacharité (2015), parental self-efficacy is the perception a parent holds of their own parenting competencies. Parenting competencies are the responsibilities associated with effective parenting such as preventing or dealing with crisis situations or taking care of the child's basic needs (Glaveanu, 2015). Parental competence is a more lenient definition; there has been debate amongst researchers whether parental competence refers to parent skill perception or external source perception of parent competencies (i.e., skills). The view of parent competence encompassed parent responsibilities that contributed to adaptive and positive developmental outcomes for children (de Montigny & Lacharité, 2005; Jones & Prinz, 2005).

Social Feedback Loop. Parents of children with autism reported feeling lower levels of parent competence than parents of typically developing children due to barriers in parent-child communication, their child's overall ability to communicate, difficulty managing behaviors, and lower quality of relationships with their children (Hudry et al., 2013; Keen et al., 2010). According to Vernon (2014), the nature of the deficits associated with autism disrupt a feedback system that occurs between parent and child naturally in development that supports parental competence and improves parenting behaviors. The failure of the natural feedback loop led to lower feelings of parent competency and contributes to higher levels of parent stress for parents of children with autism. Additionally, a disruption of the natural feedback loop led to further deficits in child speech development and the child's ability to verbally learn from interaction with parents (Warlaumont et al., 2014).

Child Deficits and Parent Competence. As previously discussed, child communication deficits have emerged as an area of difficulty for parents of children with autism. Because communication difficulties in children make it more challenging to understand their child and the child's needs, this in turn, contributed to lower levels of parent competence. A child's engagement in extreme behaviors such as self-injurious episodes, tantrums, hitting, kicking, biting, screaming or unsafe behaviors (e.g., running into the street) and high levels of stress have been found to contribute to low levels of parent competence (Rezendes & Scarpa, 2011). Extreme challenging behaviors exhibited by children with autism are difficult for parents to manage and pose threats to safety. Bearss and colleagues (2015) described essential skills for parents to learn including effectively managing the child's behavior, fostering typical nonverbal behaviors (e.g., following gaze or awareness of personal space), and encouraging reciprocal play and sharing. The skills necessary to respond effectively to a child with autism are not always innate or intuitive for parents, therefore parent-focused interventions aimed at teaching skills deliberately (e.g., managing behavior or fostering communication) with opportunities for feedback are supported as essential for child progress and overall family adjustment.

Treatment and Level of Support

There are many different treatment options for children with autism ranging from mild to intensive; these also may vary based on intervention recipient (i.e., child, parent, or both). While there is not a gold standard for a single specific intervention, effective treatment methods for individuals with autism have often incorporated tenants of applied behavior analysis; applied behavior analysis adheres to empirically supported principles of human behavior and behavior modification (Foxx, 2008). As treatment has developed with avenues in applied behavioral analysis and developmental therapy, results have shown a tremendous amount of progress is attainable for children with autism on both ends of the spectrum of severity (Thompson, 2013). Importantly, researchers have demonstrated that children with autism yield greater results when parents are involved compared to children who engage in treatment without parental involvement (Smith & Eikeseth, 2010). Parental involvement in intervention for children with autism has also been shown to lead to positive parent outcomes such as increased self-efficacy as a parent and decreased stress (Brockman et al., 2016). When both parents and child are receiving effective treatment that leads to positive outcomes, better overall family adjustment can be observed.

Due to the incredibly variable nature in selecting different types of treatment options for individuals with autism, the level of treatment and support for children with autism and their families is quite diverse. Additionally, service delivery type can differ by setting (e.g., in-home, school-based, or clinic). Children with autism may receive services through a community organization that provides intensive in-home therapy, treatment provided in a clinical-based setting, or services through special education at school (Barry et al., 2003; Lushin et al., 2020). The individualized needs of a family and child with autism are not one size fits all, therefore, care coordination services and working to support family needs can be especially helpful.

Care Coordination

The goals of care coordination for parents of children with disabilities have included reducing unmet needs, financial burdens, barriers to service reception and improving overall well-being of the child and family functioning and satisfaction of care (Culnane et al., 2020). According to Nolan and colleagues (2007), access to services, amplifying parent voice in the decision-making process, and open communication and collaboration between the family and various health care providers (e.g., mental health and primary care physician) were reported by families of children with developmental disabilities and chronic conditions as the most important aspects of care coordination services. Parents of children with autism were 24% less likely to receive adequate care coordination services for their child's disability compared to children with emotional behavior disorders (Kogan et al., 2018). According to Sobotka and colleagues (2015) families of children with autism reported less satisfaction and consistency with medical care and home care for their children with autism than parents of children with other disabilities. Further, families of children with autism with public insurance or no insurance reported being even less satisfied in the consistency with medical and home care than their peers with privatized insurance. Overall, many parents of children with autism reported having adequate access to their child's primary care physicians, however, care coordination services, especially between schools and early intervention services were lacking. Care coordination for children on the spectrum is also positively correlated with receiving adequate special education services as delineated by their individualized education plan (Harstad et al., 2013). Additionally, even when parents are receiving services for their children, a care coordinator has been shown to be helpful in promoting parent voices in conversations and decision making with their children's doctors (Iadarola et al., 2019).

According to Vohra and colleagues (2014), parents of children with autism have faced barriers to services for their children because of long waitlists for diagnostic evaluations and services and an overall lack of information about possible services for their child. Additional common barriers to services for parents of children with autism included variation in transition planning and management for services, disconnection between health and disability, lack of services and expertise, caregiver anxiety regarding transition, dissatisfaction and unmet needs during transition to adult care, and building capacity, collaboration, and shared care (Culnane et al., 2020). Including a care coordinator in a family's toolbox, specifically for parents of children with autism, could help to eliminate certain barriers for the family and child's access to services and satisfaction with service delivery. Overall, care coordination services offer many benefits to families of children with autism in navigating service options, financial barriers, satisfaction in care, and advocacy for individual family and child needs.

Important Components of Interventions

Thompson (2013) explained the constantly changing nature of the evaluation and treatment of autism with development of training and treatment models, views on progress, and varying additional components such as intensiveness of therapy or parental involvement. Advances in treatment allow for considerable progress for children with autism regardless of severity or required level of support. Progress for children with autism of varying severity levels means a notable number of children, regardless of severity on the spectrum, have shown significantly better outcomes when receiving treatment as compared to children with autism not receiving treatment. Incorporation of parental involvement and early intervention also are areas in which treatment has evolved that have been shown to lead to positive outcomes such as increased social-communicative skills and reduced challenging behaviors for children with autism and their families (Burrell & Borrego, 2012; Estes et al., 2014; Lovaas, 1987). Importantly, researchers have demonstrated that children with autism yielded greater results when parents were involved compared to children who engage in treatment without parental involvement (Smith & Eikeseth, 2010). Additionally, parental involvement in intervention for children with autism has been shown to lead to positive parent outcomes such as increased self-efficacy as a parent and decreased stress (Brockman et al., 2016).

Parental Involvement

According to Bearss and colleagues (2015) parent involvement (i.e., parent training) in interventions for children with autism can be divided into two categories which include parent support and parent implementation. Parent support is a knowledge-based treatment that involves psychoeducation and care coordination. Parent support treatments regard the child as the indirect beneficiary. On the other hand, parent implementation is a skill-focused treatment that involves parent-mediated interventions for autistic symptoms and parent training for maladaptive behaviors. Parent implementation treatments regard the child as the direct beneficiary of services. McConachie and Diggle (2007) conducted a study of parental involvement (i.e., parents implementing intervention components) during interventions for children with autism. Results showed child success and positive outcomes for children receiving an intervention that explicitly incorporated a focus on parental involvement compared to children receiving intervention without parental involvement. Additionally, while some studies show mixed results, a majority of research strongly supported including parents in the intervention and treatment of children with autism leads to more positive outcomes for children and families. Interventions focusing on parent support with care coordination components have been shown to reduce the burden of care by educating parents on strategies to integrate services for their child with autism (Bears et al., 2015). Further, there is evidence to support that parental involvement in interventions for children with autism not only improved outcomes for parents and children but allowed a more tailored intervention. Interventions tailored to meet the unique needs of the child and family utilizing a naturalistic setting for treatment have been shown to increase the child’s success and decrease parent stress (Koegel, 2000).

Acquired Skills. Educating parents to use natural, daily occurrences as opportunities for learning experiences lead to increases in generalizability for their child with autism, consistency of behavior management, and the quality of social experiences for their child (McConachie & Diggle 2007). Engaging in naturalistic strategies with children with autism can be difficult initially for parents and interventionists due to the semi-unstructured disposition of the method.

A lack of structure contributed to difficulty capturing and maintaining attention, setting demands for shared engagement such as turn taking, and changing the child's narrative for play (i.e., rigid and repetitive play) (Rogers et al., 2012). Parent knowledge and skill acquisition were shown to require time, opportunities for practice, and corrective feedback. According to Shire and colleagues (2016), parent-mediated interventions often aim to teach parents to exhibit a more responsive parenting interaction style in order to better influence the child's engagement, communication, attention, and behavior. For example, parents of children with autism enrolled in a parent-mediated intervention for young children with autism called Joint Attention, Symbolic Play, Engagement, And Regulation (JASPER) were compared to a group of parents of children with autism enrolled in a parent education intervention (i.e., psychoeducation). Parents receiving the JASPER intervention yielded higher levels of responsive parenting behavior compared to the parents in the parent education intervention. While psychoeducation is essential for understanding autism, a focus on developing parental skills with practice and live feedback demonstrated the most success for parents of children with autism.

Consistency. Kashinath and colleagues (2006) have provided evidence suggesting children with autism thrive in consistent and routine environments. Consistency is highly essential for progress in treatment for children with autism as it allows them to learn expectations, safety, understand important limits, and develop language. Parents involved in treatment had more knowledge of current best practices and therapies used for children with autism compared to parents uninvolved in therapy or interventions. Parental involvement during intervention fostered a natural consistency between the language used for requests and setting limits, practicing joint activity routines, and the use of gestures. Thus, researchers showed children with autism with more involved parents have more positive outcomes as compared to children with autism with a lack of parental involvement in therapy (Burrell & Borrego, 2012). Anecdotally, parents involved in therapy also learned consistent responses from their children, which allowed them to observe when limits are being pushed in a healthy way or when demands are exceeding the current instructional level or skill set of their child with autism. Parents' knowledge of their child's ability, skill sets, and escape mechanisms was shown to be important for pursuing goal attainment, preventing burnout, and maintaining implementation fidelity.

Early Intervention

The American Academy of Pediatrics, an organization dedicated to healthcare for children, suggests screening children for autism beginning at the early age of 18 months. Dawson and colleagues (2012) explained that with an early diagnosis, there is opportunity to begin intervention at an early age. Early intervention is crucial and necessary for children with autism to have significantly improved outcomes. Early intervention, pursued with fidelity, has led to improved social and communicative functioning, intellectual abilities, (Vismara & Rogers, 2008), adaptive behaviors (Dawson et al., 2012), and a reduction in challenging behaviors (Koegel et al., 2014). Koegel and colleagues (2014) further suggested that with effective, early interventions, up to 25% of children with an autism diagnosis will lose or "grow out" of the diagnosis at some point in their lives. Losardo and colleagues (2016) explained developmental research demonstrating peak neuroplasticity for the first five years of a child's life. Neuroplasticity refers to the plasticity or malleability of the brain; thus, the ability of the brain to change its wired pathways. Neuroplasticity is the brain's ability to functionally reorganize itself by learning and having new experiences (Losardo et al., 2016). According to LeBlanc and Fagiolini (2011), a child's brain had the highest rates of restructuring synaptic connections as a result of new experiences and environmental stimuli. High rates of restructuring synaptic connections are connected to the rapid rate of learning and acquired new experiences taking place at this time in a child's life and the ability at the time for the cortical circuits in the brain to be reconstructed by environmental input. Taking advantage of peak brain plasticity in early intervention appeared to lead to improved social skills, communication, language, and less challenging behaviors for children with autism. Further, researchers have shown that early intervention, using developmental and behavioral components, implemented before the age of four can significantly improve communication skills.

Evidence-Based Rationale

The implementation of evidence-based interventions (EBI) is essential for the child's developmental progress, monitoring of the child’s progress, and the development of effective future practices (Horner et al., 2005). Horner and colleagues (2005) discussed five components of evidence-based practices that eliminate risks of practitioners using interventions that are ineffective and not in the child’s best interest. These components included the following criteria: first, the practice/intervention should be operationally defined. An operational definition allows future practitioners and researchers to be able to replicate the practice with fidelity. An operational definition also refers to the language used in the practice goals, steps, and objectives. The language must be clear and measurable. Second, the context, goals, and outcomes are clearly stated and operationally defined. Context includes setting, persons responsible for all procedures, targeted individuals, and materials. Goals and outcomes are the desired progress and long-term outcomes for the individuals receiving the intervention. Third, the intervention should be implemented with fidelity. Fidelity refers to the integrity of the interventionist or adherence to procedure. Fidelity should be monitored through a checklist or by a treatment integrity interventionist to promote maximum accuracy. Fourth, interventions should be directly related to a change in desired outcomes. For example, if increased social interactions for a child with autism is the desired outcome, the selected intervention should have a theoretical basis for being implemented. Further, dependent on the need of the individual, the intervention could be geared towards increasing independent social interactions with peers, functional social interactions as related to life-skills, and likelihood to ask an adult for help. Fifth, the practice should have multiple research studies to prove the effective basis of the intervention. For interventions to obtain an "evidence-based" and well-established classification they must have effective and replicable results in at least three between-group design studies with 30 participants or single-participant design studies, publication in peer-reviewed journals, and effective use in multiple locations (Hoagwood & Johnson, 2003; Horner et al., 2005; Kratochwill et al., 2010). Current literature for single-case experimental designs suggested three replications incorporating three different points in time as recommended as a conceptual norm (Kratochwill et al., 2010).

According to Kratochwill (2012), evidence-based practices in the context of school psychology promote the practice of empirically supported interventions compared to pseudoscientific practices or interventions that lack an adequate research base. Additionally, evidence-based practices (EBPs) aim to limit implementation bias and error. EBPs require practitioners to follow a set of guidelines specific to target population, treatment goals, and theoretical orientation (Lilienfeld et al., 2012). Lubas and colleagues (2016) discussed the complexity of implementing EBPs for children with autism due to extreme uniqueness of autistic symptomology (e.g., severity, language ability, adaptive skills, and challenging behaviors) on a highly individualized basis. Generalizability in practice has been controversial among researchers due to the exceptionally dynamic nature of autism. Practitioners should evaluate individual characteristics (e.g., severity, strengths, weaknesses, and comorbidities) when implementing interventions to promote positive outcomes for children with autism while implementing EBPs (Lubas et al., 2016).

Psychoeducation

Psychoeducation is a process by which the targets of the intervention are educated on the research basis, background, treatment, and major concerns of a specific area (e.g., autism, mental health, and aggression) (Martinez et al., 2017). Parent psychoeducation for parents of children with autism has been shown to significantly improve symptoms associated with autism, the generalizability of parent skills to various settings, and parent emotional functioning (Hardan et al., 2015). Additionally, psychoeducation has been shown to increase parental involvement in proactive intervention strategies for children with behavior disorders (Martinez et al., 2017). Kilicarslan and Atici (2017) conducted research on the effects of psychoeducation programs for aggressive behaviors to improve coping skills for children and parents. Results showed psychoeducation targeting family structure and research on correcting aggressive behaviors led to both positive emotions and significantly improved awareness on interactions for parents and children. Psychoeducation has also been reported to decrease parent stress by teaching strategies to parents of children with autism aimed at improving their child's difficult behavior (Argumedes et al., 2018). Patra and colleagues (2015) found psychoeducation to be effective in decreasing parent stress for parents of children with autism as well as empowering parents and increasing knowledge. Additionally, psychoeducation was reported to be inexpensive and subjectively helpful.

Skill Development

Moore and Symons (2011) conducted research on parent adherence to six specific skills learned during in-home behavioral therapy with their child with autism. The skills taught directly by interventionists included establishing reinforcers, offering activity choices, delivering instructions, honoring requests, redirecting minor challenging behavior, and responding to major challenging behavior. Parent skill adherence was explicitly taught to help parents manage minor and major challenging behaviors exhibited by their child with autism. Although parents had mastered all six skills during the in-home therapy sessions with the interventionist and child present, parents did not report a significant increase in their consistent skill use during daily life with their child. Interventions targeted to improve parent skills to work with their children with autism have been shown to be effective at improving child imitation skills (Zaghlawan & Ostrosky, 2016), increasing child initiation in communication, progressing child development, decreasing children non-speech verbalizations (Elder et al., 2017), and managing challenging behaviors (Moes & Frea, 2002). Skill development is an essential component of interventions geared towards parents of children with autism because it allows parents to master important skills (e.g., responding to behaviors, teaching replacement behaviors, and encouraging communication motivation) to work with their children. Additionally, parent skill development during intervention provided parents with instructional guidance, feedback, and opportunities for practice to master important skills. Parent skill development for parents of children with autism has been shown to be associated with an improvement in cognitive ability, language and social communication, and adaptive skills (Patra et al., 2015).

Many parent-mediated interventions have focused on teaching parents to work and play with their children in ways that promote essential elements of life and communication such as language, joint attention, social interaction, and adaptive behaviors. As discussed above, challenging behaviors are extremely common amongst children with autism and can be a major struggle for parents to manage in the home or out in public. Therefore, parent-mediated interventions aimed to equip parents with the skills to manage their child’s minor and major challenging behaviors have been increasingly in demand. A meta-analysis conducted by Postorino and colleagues (2017) concluded parent skill behavior-focused interventions for challenging behavior demonstrated significant effects in reducing challenging behavior in children with autism and successfully preparing parents to manage those behaviors. However, parent skill behavior-focused interventions for challenging behavior are yet not accessible to all in price or location. As more evidence supports the use of parent skill behavior-focused intervention to better parent and child outcomes, it is expected more options will become available for families of children with autism.

Parent and Family Needs

The research on parent and family needs specifically for parents of children with autism has mainly focused on the number of met and unmet needs of parents and families as well as the type of needs that are met and unmet. However, it would be of interest to see which aspects of treatment may be associated with fulfilling met needs such as parent intervention and family therapy to improve familial adjustment. This study aimed to further understand parent and family needs for parents of children with autism.

Assessment of Parent Need for Families of Children with Autism

Brown and colleagues (2012) evaluated the needs of parents of children with autism using the Family Needs Questionnaire. Overall, parents of children with autism reported needing support regarding information about autism and service programs for their child, social inclusion for their child, management of challenging behaviors, care coordination, respite care, and cohesion among services. Researchers also found prompting parents to answer open-ended questions or provide explanations for their ratings on the Family Needs Questionnaire was helpful in understanding the rationale behind unmet needs.

Needs assessments have been used for parents with autism to examine parent needs specifically towards genetic testing and information, assessments evaluated knowledge, awareness, sources of information, interest in health education, preferred topics in health education and preferred delivery (Zhao et al., 2019). Zhao and colleagues (2019) found parents often did not receive information about genetic testing from their physicians but expressed an interest in the needs assessment in engaging in health education about genetic testing. The needs assessment was able to determine and quantify the areas of need for parent education in a specific area of autism knowledge.

Family Needs Survey

The Family Needs Survey (Bailey & Simeonsson, 1998) is a tool used to measure family needs in regard to information about disabilities and child development, social and financial support, family care services, and community options. Parents often reported being dissatisfied with the information and psychoeducation they receive about their child’s development and disability as well as a lack of support for implementing strategies learned with their child during typical daily life (Derguy et al., 2015).

The Family Needs Survey has been utilized in research to evaluate the needs of parents and families with children with cerebral palsy (Almasri et al., 2011; Almasri et al., 2012). Cerebral palsy is a developmental disorder that is extremely costly, similar to the financial burdens of parenting a child with autism (Almasri et al., 2012). According to Almasri and colleagues (2011), treatment and intervention planning for families of children with cerebral palsy needs to be individualized due to the different abilities in communication, behavior, motor function, and cognitive functioning. While the impairments between autism and cerebral palsy are markedly different, both disorders require effective intervention planning including considerations of family context. Almasri and colleagues (2012) found that using the Family Needs Survey was effective in determining family needs as high or low need and pinpointing specific areas in which the family needed additional support.

Aaron and colleagues (2014) conducted a study using the Family Needs Survey for parents of children with disabilities needing early intervention services. Researchers observed parents reported a variety of needs, had diverse needs for support services, and required specific informational support about their child’s disability. Overall, administering the Family Needs Survey prior to intervention planning allowed for important considerations for family context and unique family needs.

Family Systems Theory

This section provides information about family systems theory and the key role this theory played as a theoretical framework for parents of children with autism, parent outcomes, and incorporating family context in addressing important parent and family needs. Family systems theory provided a conceptual framework to understand a family as a unit that functions together and strives for homeostasis or consistent stability with deviations (Sutphin et al., 2013).

Family Unit

According to Sutphin and colleagues (2013), when a family unit or system becomes maladjusted due to an individual or individuals within the family unit, modifications are necessary in order to help the family return to homeostasis. According to Factor and colleagues (2019), most individuals with autism required support throughout their lifetime, often from their family members. Therefore, when considering supports for a child with autism, it is essential to consider the whole family unit when planning and executing interventions. Modifications may include adjusting communication, boundaries, roles and responsibilities of family members, and consideration of influences outside of the direct family system such as community or government. Family systems theory applied to include a child with autism in the family unit implicates critical changes in communication patterns and interactions among family members as well as essential places to define routines, boundaries, and specific roles and responsibilities for different family members including the child with autism. Redefining the family system to operate successfully including a child with autism is the first step in understanding the family as a unit. Not only is family life altered after a diagnosis in that the family has to center their household and life around supporting the needs of their child with autism, they also are forced to shift their own family norms, routines, and expectations (Farrugia, 2009). Therapeutically, family systems theory has been utilized broadly in order to intervene with the family unit in a variety of different capacities such as family therapy, couples' therapy, crisis models, and assessment. Family systems theory is a practical framework to examine children with autism and parents of children with autism due to the impact that parents and family have on child development and family functioning in general (Johnson, 2003).

Interlocking Concepts

According to Haefner (2014), Bowen's family systems theory includes a set of eight concepts that connect in order to explain levels of dysfunction, stress, and anxiety present in a family system. The eight interlocking concepts include differentiation of self, triangles, nuclear family emotional system, family projection process, emotional cut-off, multi-generational transmission process, sibling position, and societal regression.

The differentiation of self refers to the ability of an individual to simultaneously pursue an independent mindset while acknowledging the significance of societal and familial ideals. Individuals more able to differentiate themselves appropriately are more likely to be flexible in thinking patterns and behavior as well as more emotionally autonomous. As individuals with autism are prone to display rigidity in their thinking patterns, routines, and behaviors (DSM-V, 2013), one can speculate the effect their rigidity on their own differentiation of self as well as their parents' ability to differentiate themselves. Triangles refer to the relationship which includes three persons within the family that is able to preserve a dyad between two family members. The three-person relationship incites a fluidity within the dynamic of those three family members that can either alleviate tension and anxiety between two family members by invoking a third person or create tension by alienating one person's feelings within the dyad. An example of this triangular relationship is a mother, father, and child. Nuclear family emotional systems are the manner in which fusion (i.e., dysfunction within the family relationship) can lead to a series of issues within the family such as spousal conflict, impairment of one spouse, impairments of at least one child, or emotional distance between family members. The family projection process is the passing of strengths and weaknesses from parent to child. Projection follows a three-step process that begins with the parent having anxiety about their child's development. Next, parents may endorse their own anxiety within the child's behavior whether or not their initial fear is actually present. Finally, the parent will behave in a manner that is consistent with their child having an issue. Emotional cut-off occurs when individuals within the family cannot resolve affective obstacles and choose to manage the difficulty by removing themselves from a certain situation geographically or periodically. Multi-generational transmission process refers to the mechanism by which families facilitate the development of the children within their family and the emotional processes by which a family operates. Sibling position can be informative of how siblings will interact with their own differentiation of self by performing within the family as a leader (i.e., typically the oldest sibling) or a follower (i.e., generally the younger sibling). Finally, societal regression or societal emotional process is a function of the family systems theory that applies to the correlation between the anxiety or stress within society and family systems. As societal stressors increase, it is probable that anxiety will also increase on a familial level.

Applications of Concepts to Autism

Family systems theory offered a practical conceptualization of families with a child on the autism spectrum by viewing the family as a unit which may need modifications to communication, responsibilities of family members, boundaries within the family unit, and routines and rituals in which the family engages. Many families raising a child with autism also have multiple children, which may or may not be neurotypical or neurodivergent, therefore, it is important to understand the relationship between siblings and parents in the family unit using the family systems theory approach. Wood-Rivers and Stoneman (2003) found siblings of children with autism rated their experience with their sibling more negatively when parents reported higher rates of marital dissatisfaction and parental conflict. Marital dissatisfaction and parental conflict were also responsible for influencing challenging behavior and poor adjustment. Determining areas of need to target during intervention, which boost individual parent or martial stress, may be helpful in fostering positive family relationships, adequate adjustment, desired behaviors, and reduced parent stress.

In addition to attention towards sibling-parent dynamics, family systems theory also offered a space to recognize additional relationships that can be included in a family unit.

According to Prendeville and Kinsella (2019), family units can be increasingly complex as intergenerational relationships among other unique family factors are introduced; intergenerational relationships, such as support from grandparents, can serve as a pillar of support or a major stressor on different family units. Additionally, due to the complexity of family systems, interventions should plan to target the child, parent, and family. Researchers also found benefits to assessing the family unit in order to determine the variable needs, struggles, and existing support exclusive from family to family. Further, Prendeville and Kinsella (2019) established a demand for assessments and interventions to engage in a family systems approach in order to plan around complex relationships and individual needs which occur in diverse families. Similar to school psychologists using an eco-behavioral consultation approach evaluating all elements of a classroom environment to provide feedback to the teacher for a better functioning classroom (Lee & Niileksela, 2009), there are advantages in practitioners using a family systems theoretical approach to evaluate family units for families of children with autism in order to provide feedback supporting a better functioning unit.

Family Adjustment

According to Rosenbrock and colleagues (2021), family adjustment refers to the tendency for families to function positively during demanding situations by utilizing their own strengths. Positively adjusted families engaged in preventative strategies that are beneficial to them when experiencing a crisis while negatively adjusted families are not shown to be as proactive in the managing of challenging situations. Family functioning for families of children with autism can be impacted by having limited time for enjoyable family activities (e.g., outings or vacations) and an overall lack of flexibility in daily life and routines (Rao & Beidel, 2009). According to McKee and colleagues (2020) practitioners working with families of children with autism helped families better their overall adjustment by encouraging families to capitalize on their strengths in order to improve aspects in which they find difficult. Efforts to improve family resilience through targeted programs have been shown to aid in familial adjustment by decreasing dysfunction among families measured through pre- and post-test scores on the Parenting and Family Adjustment Scale (Pandya, 2018). A high number of externalizing or challenging behaviors exhibited from a child with autism in the family has been associated with poorer family functioning (Sikora et al., 2013) and has been linked to increased parent stress. Parental stress has long been evidenced as a common factor associated with parents of children with autism and has also been shown to contribute to dysfunction when examined through the lens of family adjustment (McKee et al., 2020). Therefore, it could be of value for practitioners to evaluate family adjustment prior to intervention implementation in an effort to target family strengths and protective factors and to alleviate risk factors and improve overall family adjustment. Additionally, evaluating the link between family need and family adjustment could further shed light on the type of risk factors and protective factors families embody prior to intervention work.

Research Questions and Hypotheses

The current study addressed the following research questions:

1. Do families that report a higher number of needs endorse lower family adjustment when controlling for child age, child gender, and number of interventions received by parents?
2. How do parent and family needs differ based on parental involvement in a parent behavior skill-focused intervention when compared to parental involvement in a parent-focused intervention without a behavioral component when controlling for child age, child gender, and number of interventions received by parents?

3. How does family adjustment differ based on parental involvement in a parent behavior-skill focused intervention compared to parental involvement in a parent-focused intervention without a behavioral component when controlling for child age, child gender, and number of interventions received by parents ?

Families living with unmet needs are shown to experience higher levels of stress compared to their peers with met needs, therefore, it was hypothesized that families with a higher number of unmet needs would endorse lower family adjustment. Due to evidence suggesting the severe strain challenging behaviors can have on parental mental health and family factors, it was hypothesized that families with experience in a parent skill behavior-focused intervention would report fewer needs compared to parents with different intervention experiences (i.e., psychoeducation and parent-mediated communication-focused intervention). For the same reasons, this researcher hypothesized families with experience in a parent skill behavior-focused intervention would also endorse better overall family adjustment compared to families that had alternative intervention experiences.

Method

The current study used a quantitative research design with a survey data-collection strategy to evaluate concepts important to the field of autism research including family adjustment, parent and family need, and parent-focused interventions. The current study explored the relation between family need and family adjustment. The current study also explored the relation between specific parent-focused intervention type (i.e., parent behavior skill-focused intervention to target child challenging behaviors vs parent-mediated communication-focused intervention and psychoeducation) and parent need as well as family adjustment.

Participants

A total of 62 parents of children with an autism spectrum disorder diagnosis were recruited (see Recruitment section below) as participants for this research study. Participants included parents of 34 male children (54.84%) and 28 female children (45.16%) ranging from seven to 12 years of age (*M* = 8.52, *SD* = 1.40). The age children received an autism diagnosis ranged from 11 months to 110 months (*M* = 43.27, *SD* = 19.98). Sixty-one participants (98.39%) reported being in a two-parent household while one participant (1.61%) was part of a single-parent household. Ten participants had one child (16.13%), 21 participants had two children (33.87%), 14 participants had three children (22.58%), and 17 participants had four children (27.42%). Additionally, 59 participants reported having one child with a disability (95.16%) while three families reported having two children with disabilities (4.84%). The majority of parents reported an income level in the $50,000 to $75,000 range. Additional demographic information about race/ethnicity and household income can be found in Table 1.

Table 1

Demographic Information for Participants

Characteristic		Sample n (%)
Race	American Indian/Alaska Native	1 (1.61%)
	Asian	6 (9.68%)
	Black	10 (16.13%)
	Hispanic	10 (16.13%)
	Native Hawaiian/Other Pacific Islander	5 (8.06%)
	White	34 (54.84%)
Household Income	$15,000 - $24,999	1 (1.61%)
	$25,000 - $49,999	10 (16.13%)
	$50,000 - $74,999	35 (56.45%)
	$75,000 - $99,999	12 (19.35%)
	$100,000 - $149,999	3 (4.84%)
	$150,000 - $199,999	1 (1.61%)

The families recruited were required to have a school-aged child with autism between the ages of 6 and 12 years old who participated in some type of therapeutic service related to their child's disability of autism.

Participants were categorized by involvement in a specific type of parent-focused intervention (i.e., psychoeducation and parent-mediated communication-focused intervention or parent skill behavior-focused intervention) to understand the differences in parent needs and family adjustment based on the type of parent-focused intervention received by the participant. Participants were able to select more than one type of intervention; sixteen participants received one intervention (25.81%), 40 participants received two interventions (64.52%), and six participants received three interventions (9.68%). A more detailed breakdown of the intervention characteristics in which participants were involved is discussed in the Results section.

Inclusionary Criteria

The inclusionary criteria for this study included (a) having a child with an autism diagnosis, (b) the child is school-aged and between the age of six and 12 years old, (c) the child is receiving a therapeutic intervention related to their disability, and (d) participants were required to be able to read English. This study did not eliminate participants based on autism severity or verbal behaviors (e.g., verbal vs. nonverbal).

Recruitment

Participants were recruited on a volunteer basis through local organizations offering treatment services for children with autism, school districts, and autism networks (e.g., Autism Society of Southeastern Wisconsin). Flyers with a quick-response code (QR Code) for the survey link were emailed to contact persons at the various recruitment locations; the contact person then distributed the flyer to their clients. The flyer can be found in the Appendix A in Figure 1. The recruitment method used did not allow for the researcher to calculate the percentage of possible recruited participants who agreed to participate in the study.

Participants involved in this research study were compensated following the completion of the survey with a 10-dollar Amazon gift card. Participants were required to complete at least 71 questions or 90% of the survey to allow for accurate data analysis; participants were made aware of this requirement prior to the start of the survey.

Settings and Materials

Setting

Participants were able to access the 79-item Family Adjustment and Need Survey from a laptop, computer, or smartphone using the QR code on the flyer. The survey was designed to determine parental involvement in specific parent-focused interventions (i.e., psychoeducation, parent-mediated for skill acquisition, and parent skill behavior-focused intervention), family adjustment, and specific parent and family needs. The Family Adjustment and Need Survey is located in Appendix B in Table 9.

Measures and Covariates

Parental and family factors are especially important when considering development for children with autism because parent outcomes are shown to heavily influence child development. The Family Adjustment and Need Survey included inclusionary criteria, family demographic information, parent-focused intervention questions, the 30-item Parenting and Family Adjustment Scale (PAFAS; Sanders & Morawska, 2010), and the 35-item Family Needs Survey-Revised (Bailey & Simmeonson, 1990). The Family Adjustment and Need Survey, created using Qualtrics, was designed to gather information about the differences in parent need and family adjustment between groups of parents involved in specific types of parent-focused interventions (i.e., psychoeducation and parent-mediated communication-focused intervention or parent skill behavior-focused intervention). Additionally, it was of interest to understand the relationship between family adjustment and needs.

Demographic Information. Participants who satisfied the inclusionary criteria questions were directed to complete the 9-item demographic information section. The demographic information section included questions about race/ethnicity, household income, household type (i.e., single-parent, two-parent, other), number of children in the household, number of children with disabilities in the household, number of people excluding parents and children living in the household, child's diagnostic age of autism, child's current age, and child gender. The current study used child age, child gender, and number of interventions received by parents as covariates to control for effects. Child age and gender are consistently considered to be important control variables for research involving children with autism. The number of interventions received by parents has produced inconsistent results in previous research, with too many interventions leading to higher stress for parents and too few interventions lacking to produce effective results. Parents involved in this study were able to report their experience in up to three interventions, therefore, it was of interest for this research to control for effects of intervention dosage on family need and adjustment.

Parent-Focused Interventions. After completing the demographic information section, participants were directed to the 3-item parent-focused intervention section. First, participants were asked whether they had been involved in a parent-focused intervention related to their child's disability. Parent-focused interventions were defined for participants as interventions requiring the parent or caregiver to work with professionals in a disability-specific area with the goal of supporting or training the parents and/or caregivers. Second, participants were asked to check all boxes describing the type of parent-focused intervention with which they had experience. Options included psychoeducation, parent-mediated interventions for skill acquisition, parent skill training for challenging behaviors, and other. Psychoeducation was defined for participants as an evidence-based intervention that provides the intervention recipient (i.e., caregivers) with systemic and structured knowledge and information about a disability or illness, treatment options, and ways to improve treatment efficacy. Parent-mediated interventions for skill acquisition was defined for participants as an intervention delivered to parents to improve parent/caregiver skills for working with their child directly on aspects related to their disability (e.g., communication, eye contact, emotional expression, etc.) The term "parent-mediated interventions for skill acquisition" has been referred to as parent-mediated communication-focused intervention throughout this paper. Parent skill training for challenging behaviors was defined for participants as an intervention delivered to parents to improve the parent/caregiver's ability to manage difficult behaviors in which their child engages (e.g., tantrums, head-banging, elopement, etc.). The term "parent skill training for challenging behaviors" has been referred to as parent-skill behavior-focused intervention throughout this paper. Finally, parents were asked if they had received care coordination from a private clinic or public entity. Care coordination was defined for participants as the process of organizing care activities such as school-based services or private clinic-based services and sharing information among all stakeholders in the child's care to improve outcomes for effective treatment.

Parenting and Family Adjustment Scale (PAFAS). The Parenting and Family Adjustment Scales (PAFAS; Sanders & Morawska, 2014) is a 30-item scale which assesses parenting and family adjustment on two scales -- PAFAS Parenting and PAFAS Family

Adjustment (Sanders et al., 2014). According to Sanders and colleagues (2014), initially a 40-item scale, the PAFAS went through rigorous psychometric evaluation, which revealed a need to remove several items from the scale. The 30-item scale supported an 18-item, 4-factor structure of the PAFAS Parenting scale and a 12-item, 3-factor structure of the PAFAS Family Adjustment scale. The PAFAS Parenting scale assesses parenting practices including parental consistency, coercive parenting, and positive encouragement and parent-child relationship; notably, these constructs are common targets for parent-focused interventions. The PAFAS Family Adjustment assesses parent and family adjustment through parental adjustment, family relationships, and parental teamwork. The PAFAS uses a 4-point Likert scale with ratings ranging from (0) Not at all, (1), a little, (2) quite a lot, and (3) very much. The scale includes questions such as “if my child doesn’t do what they’re told to do, I give in and do it myself”, “I deal with my child’s misbehavior the same way all the time”, “I get annoyed with my child”, “I cope with the emotional demands of being a parent”, and “I disagree with my partner about parenting”. Several items on the PAFAS are reversed scored in order to sum scores after the completion of the scale; higher cumulative scores are indicative of higher dysfunction or worse adjustment. This factor structure has demonstrated valid use among families with neurotypical children and children with developmental disabilities such as autism and intellectual disability (Mazzucchelli et al., 2018).

According to Sanders and colleagues (2014), the PAFAS demonstrated good construct validity. The Parenting and Family Adjustment Scale demonstrated factor loadings on the parenting practices scale that ranged from satisfactory to high (0.31 - 0.67). On the parent-child relationship subscale, the factor loadings ranged from acceptable to high (0.41 - 0.86). The scale also demonstrates good convergent and discriminant validity. The PAFAS Parenting scale yielded the following composite reliability estimates for parental consistency (0.64), coercive parenting (0.75), positive engagement (0.70), and parent-child relationship (0.78). Additionally, the Chi Square difference test determined strong evidence for discriminant validity of all constructs. The PAFAS Family Adjustment scale yielded the following composite reliability estimates for parental adjustment (0.85), family relationships (0.76), and parental teamwork (0.79). Moderate discriminant validity for constructs were observed on the Family Adjustment scale. Finally, the PAFAS also demonstrated good internal consistency for PAFAS Parenting and PAFAS Family Adjustment. The coefficients H for PAFAS Parenting were as follows for parental consistency (0.70), coercive parenting (0.78), positive encouragement (0.75), and parent-child relationship (0.85). The coefficients H for PAFAS Family Adjustment are as follows for parental adjustment (0.87), family relationships (0.84), and parental teamwork (0.85). Overall, research conducted on the Parenting and Family Adjustment Scale indicated researchers were using the tool as a whole-scale and investigating subscales for construct validity and reliability.

Family Needs Survey-Revised. The Family Needs Survey (Bailey & Simmeonson, 1990) is a 35-item scale which assesses family needs in six domains including information, family and social support, financial, explaining to others, childcare, professional support, and community services. The Family Needs Survey was originally designed in order to foster collaboration between parents and practitioners to better address parent and family needs for families with children with disabilities. The Family Needs Survey-Revised uses an answering format that instructs caregivers to answer “no”, “not sure”, or “yes” on questions if they wish to discuss a specific topic with a staff member offering treatment to their child. For the purpose of this study, participants answered questions on a one to three Likert scale ranging from definitely do not need help (1), (2) not sure, or definitely need help (3) rather than answer items based on whether the participant wants to discuss topics with a staff member. The 7-item information subscale includes questions such as "how children grow and develop" and "information about services my child might receive in the future". The 8-item family and social support subscale includes questions like "having friends to talk to" and "helping our family support each other during difficult times". Example items of the 6-item financial needs subscale include "getting any special equipment my child needs" and "paying for therapy, day care, or other services my child needs". The 5-item explaining to others subscale asks questions such as "knowing how to respond when friends, neighbors, or strangers ask questions about my child" and "explaining my child's condition to others". The 3-item childcare subscale includes questions such as "locating babysitters or respite care providers who are willing and able to care for my child" and "locating a daycare program or preschool for my child". The 3-item professional support subscale has questions like "meeting with a counselor" and "more time to talk to my child's teacher or therapist". Finally, the community services subscale includes questions such as "meeting and talking with other parents who have a child like mine" and "locating a doctor who understands me and my child's needs."

According to Ueda and colleagues (2013), the Family Needs Survey demonstrated an excellent total score of internal consistency for mothers ($\alpha = .94$) and fathers ($\alpha = .95$). A range of good to excellent internal consistency scores was found on each of the subscales including information ($\alpha = .88$; $\alpha = .91$), family and social support ($\alpha = .92$; $\alpha = .92$), Financial Needs ($\alpha = .80$; $\alpha = .85$) and Explaining to Others ($\alpha = .85$; $\alpha = .87$) respectively for both mothers and fathers. Additionally, adequate test-retest reliability was found for mothers ($r = .67$) and fathers ($r = .86$) using an intraclass correlation coefficient. Content validity was also analyzed using a panel of 130 experts with an average experience of eleven years working with children with disabilities. Approximately 91 of the 130 or 70% of the panel found 33 of the 35 items on the Family Needs Survey to be reasonable, signifying adequate content validity. According to Ahmadi and colleagues (2011) the most commonly reported needs on the Family Needs Survey occurred on the information scale and included parental need for information about their child's disability, services for their child, ways to teach their child effectively, and how to manage their child's behaviors.

Procedures

Survey Instructions

After accessing the Family Adjustment and Need Survey via QR code, participants reviewed the consent page and were instructed to complete at least 71 out of 78 questions on the survey. Participants needed to answer "yes" to all four inclusionary questions to continue with the additional questions on the Family Adjustment and Need Survey. Questions on the survey were answered with various response styles such as short-answer questions, select from multiple choice options, "yes" or "no" questions, and Likert-type scale responses. Following the completion of the Family Adjustment and Need survey, participants were rerouted to an additional survey to collect their email address without linking their email to their response so as to preserve anonymity and maintain confidentiality among participants. Personal information such as name, address, and place of employment were not collected during the survey.

Data Collection

Data were collected one time during the study in the form of the Family Adjustment and Need Survey. Data were collected between March of 2022 and May of 2022. The Family

Adjustment and Need Survey was initially estimated to take between 15 and 20 minutes to complete, however, participant completion time ranged from 5 to 19 minutes. Participant responses were attached to an identification number (e.g., 01) after survey completion. Answers were separated by construct to analyze data; constructs included demographic information, parent-focused intervention information, family adjustment, and family needs. There were no risks anticipated for participants completing the Family Adjustment and Need Survey and none were reported to the primary researcher post-data collection. Data was reviewed multiple times by the primary researcher and responses were double-checked by a second individual with research experience to confirm accuracy.

Data Analysis Plan

This research study used Statistical Package for the Social Sciences (SPSS; IBM, 2020) to analyze data in an attempt to understand three research questions. First, this research examined the relation between family adjustment and parent needs. Second, this research examined how parent and family needs differed based on parental involvement in a specific type of parent-focused intervention (i.e., behavior skill-focused, mediated communication skill-focused). Finally, this research examined how family adjustment differed based on parent involvement in a specific type of parent-focused intervention.

The Family Adjustment and Need survey (see Appendix B) asked participants to select the type of parent-focused intervention with which they had experience; participants were able to select multiple interventions. The responses to the intervention question determined whether parents would be in the parent behavior skill-focused intervention group or the parent-mediated communication-focused intervention and psychoeducation group or the group without a behavioral component. A parent behavior skill-focused intervention refers to a parent implementation intervention, or an intervention that is skill focused and involves parent-mediated directives for teaching parents how to manage minor and major challenging behaviors; the child is the direct beneficiary in a parent implementation intervention. A parent-mediated communication-focused intervention refers to a parent implementation intervention, or an intervention that is skill focused and involves parent-mediated strategies for teaching parents how to help develop their child's verbal and non-verbal communication skills. Psychoeducation is knowledge-based parent support intervention designed to build foundational knowledge for the recipient in a specific area; the child is the indirect beneficiary of a parent-support intervention.

Data was analyzed with reference coding for nominal data. Covariates including child age and number of interventions received by parents were not reference coded, as they were continuous data points. Child gender was used as a covariate in all analyses with male being the reference code in the model. Family need and family adjustment were continuous variables used in multiple analyses discussed below. Parent-intervention type was used as an independent variable in research questions two and three with non-behavior focused used as the reference code in the model.

Research Question 1 (RQ 1)

A linear regression was conducted to address RQ 1. RQ1 explored whether family need was significantly associated with family adjustment. It examined whether families who reported a higher number of family needs endorsed lower family adjustment when controlling for child age, child gender, and number of interventions received by parents. Family need was the independent or predictor variable while family adjustment was the dependent variable.

Research Question 2 (RQ 2)

A linear regression was conducted to address RQ 2 and examined the differences in parent and family needs based on the specific type of parent-focused intervention (i.e., parent behavior skill-focused intervention or parent-mediated for skill development and psychoeducation). The analysis controlled for child age, child gender, and number interventions received by parents by using them as covariates. Type of intervention was the independent variable while parent/family need served as the dependent variable.

Research Question 3 (RQ 3)

A linear regression was conducted to address RQ 3, which examined the differences in family adjustment based on the specific type of parent-focused intervention. Again, the analysis controlled for child age, child gender, and number of interventions received by parents by using them as covariates. Type of intervention was the independent or predictor variable while family adjustment was the dependent variable.

Assumptions

The assumptions of a linear regression include normality, homoscedasticity, linearity, and an absence of multicollinearity. Multivariate normality assumes all residuals are normally distributed. A normal P-P Plot was visually inspected to confirm the residuals followed a normal distribution for each regression model. Although there was some deviation observed, the points generally appeared to conform to the diagonal plot line for each model. Homoscedasticity assumes the variances are equally distributed at every value of the independent variable rather than clustering together at certain values of the independent variable which would indicate heteroscedasticity. A standardized residuals versus predicted values scatterplot was visually inspected to confirm homoscedastic residuals. The residuals appeared to be evenly distributed for the most part for each regression analysis. Linearity assumes a linear relationship between the predictor and response variables. If normality and homoscedasticity assumptions are reasonably satisfied for each regression model, linearity can be assumed. Multicollinearity refers to high correlations amongst predictor variables. Regression models must satisfy the assumption that predictor variables are not highly correlated with each other. Multicollinearity can be assessed by examining the correlations among predictor variables in the model using a correlation matrix. Multicollinearity may also be assessed by examining the Variance Inflation Factor (VIF) values. In order to determine a lack of multicollinearity, correlations between predictors should be lower than a value of .70 and VIF values should be lower than 5. For each regression analysis, the correlations among predictor variables ranged from -.14 to .34. None of the VIF values exceeded 1.20. The visual analyses for assumptions are presented in Appendix D.

Results

This section discusses participant flow and missing data, unexpected events, descriptive statistics, and results of the statistical analyses. The results detail each research question in order. Assumptions for each linear regression were reviewed prior to running the analyses and all assumptions were determined to be met. It should be noted that higher scores on the Parenting and Family Adjustment Scale indicated lower levels of family adjustment. On the Family Needs Survey higher scores indicated more needs. Adjusted R^2 was used in the analysis of research questions one, two, and three instead of R^2 to produce a more accurate regression model. According to Berger (2003), adjusted R^2 only increases if the variables added to the model by improving the fit, whereas R^2 increases with the addition of new variables for a number of reasons such as correlation with outcome variables, small sample size, or number of variables considered in the model. Due to the number of variables in the regression model and the sample size, the researcher determined adjusted R^2 was the most appropriate and reliable metric to utilize for data analysis for all regression models in the current study. This study used a p-value of .05 for statistical significance.

Participants and Missing Data

Of the 102 participants who initially began the Family Adjustment and Need Survey, 17 (16.7%) participants were excluded for not meeting the study criteria, as they were not the caregiver of a child with autism (1.0%), their child with autism was not between the ages of six and 12 years old (14.7%), or their child with autism was not currently receiving services related to their disability in a clinical, home-based, or school setting (1.0%).

The remaining 85 participants were invited to complete the online survey in exchange for a 10-dollar electronic gift card. However, 13 (15.3%) participants failed to complete at least 90% of the survey. Additionally, seven (8.2%) participants were removed from the study due to inconsistent responses such as marking they had zero children with disabilities (3.5%) or marking they had more children with disabilities than total children (4.7%). Finally, three (3.5%) participants were removed due to their survey completion time being under three minutes, resulting in a final total of 62 participants. All 62 participants in the sample completed the full survey. There was no missing data for the participants involved in data analysis.

As previously stated, participants were divided into two groups based on the type of parent-focused intervention received. Participants were allowed to select multiple intervention experiences and responded in a variety of different combinations. The first group included parents with experience with parent behavior skill-focused interventions. The parent behavior-focused intervention group included participants who responded with experience with solely the behavior-focused intervention OR the behavior-focused intervention and/or the other two interventions (i.e, mediated communication-focused, psychoeducational), as long as they selected experience with a behavior-focused intervention. Eight participants (12.90%) responded as only having experience with a parent behavior skill-focused intervention. Six participants (9.68%) responded as having experience with parent behavior skill-focused interventions and parent-mediated communication-focused interventions. Eleven participants (17.74%) responded as having experience with parent behavior skill-focused interventions and psychoeducation. Six participants (9.68%) responded as having experience with all three interventions (i.e., behavior skill, communication, and psychoeducational. There were 31 total participants in the parent behavior skill-focused intervention group. The second group included parents with experience in parent-mediated communication-focused interventions and/or psychoeducation, however, they did not have experience with a behavior-focused intervention. Five participants (8.06%) indicated they had only had experience with parent-mediated communication-focused interventions. Three participants (4.84%) indicated they only had experience with psychoeducation. Twenty-three participants (37.10%) responded as having experience with parent-mediated communication-focused interventions and psychoeducation. There were 31 total participants in the second group. The detailed breakdown of participant responses and group assignment can be reviewed below in Table 2.

Table 2

Group Assignment for Parent Intervention

Group 1: Behavioral Component		Group 2: No Behavioral Component	
Participant Response	Sample n= 31 (50%)	Participant Response	Sample N= 31 (50%)
Skill training- behavior	8 (12.90%)	Parent-mediated- comm.	5 (8.06%)
Parent-mediated- comm. & Skill training- behavior	6 (9.68%)	Psychoeducation	3 (4.84%)

Psychoeducation & Skill training- behavior	11 (17.74%)	Parent-mediated- comm. & Psychoeducation	23 (37.10%)
All interventions	6 (9.68%)		
Total Participants	31	Total Participants	31

Unexpected Events

Initially, this study set out to understand how parent and family needs differ based on parental involvement in a parent-focused intervention as well as the impact of care coordination services on parent and family needs. However, all 62 (100%) participants had experience with parent-focused interventions and only one (1.61%) participant reported never receiving any type of care coordination services. To overcome this barrier, the research questions were modified to examine the effect of a specific parent-focused intervention (i.e., parent behavior skill-focused intervention) compared to other parent-focused interventions without a behavioral component (i.e., parent-mediated communication-focused intervention and psychoeducation) on parent and family needs and family adjustment. Groups were formed based on whether parents had experience with a parent behavior skill-focused intervention or a parent-focused intervention without a behavioral component (i.e., psychoeducation or parent-mediated communication-focused intervention). Group 1 included parents who participated in a behavior skill-focused intervention (key criteria); Group 2 included parents who did NOT participate in a behavior skill-focused intervention.

Descriptive Statistics

The descriptive statistics for family needs and family adjustment are presented in Table 3. As previously stated, higher scores on the Parenting and Family Adjustment scale indicated lower levels of family adjustment; higher scores on the Family Needs Survey indicated higher endorsement of parent and family needs. The Parenting and Family Adjustment Scale demonstrated adequate internal consistency on the overall scale (α = .72). Internal consistency for the Parenting and Family Adjustment subscales in the current study and previous studies are presented in Table 4. The internal consistency for individual subscales on the Parenting and Family Adjustment Scale yielded low alphas. Therefore, analysis on subscale constructs could not be supported in this conducted with reliability. The secondary order reliabilities for the PAFAS Parenting scale (α = .43) and the PAFAS Adjustment scale (α = .55) were also not high enough to conduct further exploratory analyses. The item-total statistics and item-total correlations for the overall PAFAS can be observed in Appendix E. The Family Needs Survey demonstrated good internal consistency on the overall scale (α = .83). Internal consistency for the Family Needs survey subscales in the current study and previous studies are presented in Table 5. The internal consistency for individual subscales on the Family Needs Survey yielded low alphas. Therefore, analysis on subscale constructs could not be supported in this conducted study due to the low reliability. The item-total statistics and item-total correlations for the overall FNS can be observed in Appendix F. The correlations for predictor and outcome variables can be found in Appendix G.

Table 3

Family Need & Adjustment Descriptive Statistics

Scale	Mean	Std. Deviation	Variance	Minimum	Maximum
Family Adjustment	39.97	10.21	104.20	17.00	65.00
Family Needs	37.10	10.40	108.12	2.00	58.00

Note. n = 62

Table 4

Internal consistency for PAFAS compared to current study

Scale	Sanders & Morawska (2014)	Current Study

Parental Consistency	.70	-.072
Coercive Parenting	.78	.22
Positive Encouragement	.75	-.12
Parent-Child Relationship	.85	.49
Parental Adjustment	.87	.31
Family Relationships	.84	.31
Parental Teamwork	.85	.77

Table 5

Internal consistency for FNS compared to current study

Scale	Ueda and Colleagues (2013)	Current Study
Information	.88	.45
Family and Social Support	.92	.40
Financial	.80	.44
Explaining to Others	.85	.55
Childcare		.14
Professional Support		.05
Community Services		.29

Note. Internal consistency was not computed for childcare, professional support, and community services in the previous study

Research Question 1 (RQ 1)

Research question one focused on whether families that report a higher number of needs endorse a lower family adjustment when controlling for child age, child gender, and number of interventions received by parents. A multiple linear regression was used to determine whether there was a significant effect of family need on family adjustment after controlling for child age, child gender, and number of interventions. The overall regression model at the final step was significant $F(4,57) = 3.131$, $p< .05$ with a medium effect size ($R^2= .180$, Adjusted $R^2 = .123$, $p< .01$), Family need is a significant predictor of family adjustment and accounts for approximately 12.3% of the variance in family adjustment after controlling for child age and gender, and number of interventions $t(60)= 3.168$, $p = .001$. For every additional need reported by a family, scores on a measure of family maladjustment are predicted to rise by .395 points. Child age and gender were not significant predictors of family adjustment in the first block of the regression model [F (2,59)= 1.092, Adjusted R^2= .003, p= .342]. The addition of number of interventions in the second block did not significantly improve the overall regression model [F (3,58)= 0.718, Adjusted R^2 = .014, p= .545]. The regression model was not improved by adding child age, child gender, or number of interventions; the covariates did not significantly account for the variance in family adjustment. The output for research question one can be found below in Table 6.

Table 6

Linear regression results by family need and family adjustment

Model	Predictor	*B*	95% CI	β	*SE*	Adjusted R^2	*t*	*p*
1						.003		
	Intercept	35.147	[16.576, 53.718]		9.281		3.787	<.001
	Child Age	-0.084	[-1.960, 1.792]	-.011	0.938		-0.089	.929
	Child Gender	3.812	[-1.421, 9.045]	.187	2.615		1.458	.150
2						.014		
	Intercept	34.865	[15.073, 54.656]		9.887		3.526	<.001
	Child Age	-0.100	[-2.030, 1.829]	-.014	0.964		-0.104	.917
	Child Gender	3.841	-1.479, 9.160]	.189	2.657		1.445	.154
	Num of Int	0.208	[-4.484, 4.900]	.012	2.344		0.089	.930
3						.123		
	Intercept	20.222	[-0.390, 40.833]		10.293		1.965	.054
	Child Age	0.261	[-1.549, 2.071]	.036	.904		0.289	.774
	Child Gender	4.530	[-0.439, 9.499]	.223	2.481		1.826	.073
	Num of Int	-2.020	[-6.608, 2.567]	-.114	2.291		-0.882	.382
	Family Need	0.395	[0.145, 0.645]	.403	.125		3.168	.002

Note.

Research Question 2 (RQ 2)

Research question two aimed to understand how family needs differ based on parental involvement in a parent skill behavior-focused intervention compared to parental involvement in parent-focused intervention without a behavioral component when controlling for child age, child gender, and number of interventions received by parents. A multiple linear regression was used to determine whether there was a significant effect of parent intervention type on family need after controlling for covariates. In the first step of the regression model, child age and gender were added as covariates. In the second step of the regression model, number of interventions was added as a covariate. In the final step of the regression model, intervention type was added as the independent variable. The results of the first block of the regression model were not statistically significant [F (2,59)= 0.515, Adjusted R^2 = .02, p= .600]. The results of the second block of the regression model were statistically significant [F(3,58)= 2.385, Adjusted R^2= .06, p = .017], however, this will not be interpreted since the overall model did not support the hypothesis. The overall model was not significant [F (4,57)= 1.879, Adjusted R^2 = .05, p = .127]. The variance in family need cannot be explained by child age, child gender, number of interventions received by parents, or whether the intervention had a behavioral component. The overall model was not predictive of family need. The output for research question two can be found below in Table 7.

Table 7

Linear regression results by intervention type and family needs

Model	Predictor	*B*	95% CI	β	*SE*	Adjusted R^2	*t*	*p*
1						.016		
	Intercept	44.706	[25.608, 63.804]		9.544		4.684	<.001
	Child Age	-0.463	[-2.392, 1.466]	-.062	0.964		-0.480	.633
	Child Gender	-2.525	[-7.907, 2.857]	-.122	2.690		-0.939	.352
2						.064		
	Intercept	37.042	[17.670, 56.415]		9.678		3.828	<.001
	Child Age	-0.913	[-2.802, 0.975]	-.123	0.943		-0.968	.337
	Child Gender	-1.744	[-6.950, 3.463]	-.084	2.601		-0.670	.505
	Num of Int	5.637	[1.044, 10.229]	.313	2.294		2.457	.017
3						.054		
	Intercept	36.159	[16.499, 55.819]		9.989		3.683	<.001
	Child Age	-0.735	[-2.710, 1.239]	-.099	0.986		-0.745	.459

	Child Gender	-1.781	[-7.016, 3.455]	-.086	2.615		-0.681	.459
	Num of Int	5.806	[1.160, 10.451]	.323	2.320		2.503	.015
	Int Type	-1.783	[-7.215, 3.648]	-.086	2.712		-0.657	.514

Research Question 3 (RQ 3)

Research question three sought to understand how family adjustment differs based on parental involvement in a parent skill behavior-focused intervention compared to parental involvement in a parent-focused intervention without a behavioral component when controlling for child age, child gender, and number of interventions received by parents. A multiple linear regression was used to determine whether there was a significant effect of parent intervention type on family adjustment after controlling for covariates. In the first step of the regression model, child age and gender were added as covariates. In the second step of the regression model, number of interventions was added as a covariate. In the final step of the regression model, intervention type was added as the independent variable. The results of the first block of the regression were not statistically significant [F (2,59)= 1.092, Adjusted R^2 = .003, p = .342]. The results of the second block of the model were not statistically significant [F(3,58)= 0.718, Adjusted R^2 = .01, p = .545]. The overall model was not significant [F(4,57)= 0.618, Adjusted R^2= .04, p = .652]. The variance in family adjustment cannot be explained by child age, child gender, number of interventions received by parents, or whether the intervention had a behavioral component. The overall model was not predictive of family adjustment. The output for research question three can be found below in Table 8.

Table 8

Linear regression results by intervention type and family adjustment

Model	Predictor	*B*	95% CI	β	*SE*	Adjusted R^2	*t*	*p*
1						.003		

	Intercept	35.147	[16.576, 53.718]		9.281		3.787	<.001
	Child Age	-0.084	[-1.960, 1.792]	-.011	0.938		-0.089	.929
	Child Gender	3.812	[-1.421, 9.045]	.187	2.615		1.458	.150
2						.014		
	Intercept	34.865	[15.073, 54.656]		9.887		3.526	<.001
	Child Age	-0.100	[-2.030, 1.829]	-.014	0.964		-0.104	.917
	Child Gender	3.841	[-1.479, 9.160]	.189	2.657		1.445	.154
	Num of Int	0.208	[-4.484, 4.900]	.012	2.344		0.089	.930
3						.026		
	Intercept	34.063	[13.961, 54.165]		10.039		3.393	.001
	Child Age	0.061	[-1.958, 2.080]	.008	1.008		0.061	.952
	Child Gender	3.807	[-1.546, 9.160]	.187	2.673		1.424	.160
	Num of Int	0.361	[-4.389, 5.111]	.020	2.372		0.152	.880
	Int Type	-1.618	[-7.171, 3.936]	-.080	2.773		-0.583	.562

Discussion

The current survey research study examined the dynamic between family need and family adjustment as well as the effects of parent-focused interventions with a behavioral component vs. no behavior component on family need and family adjustment while controlling for factors including child age, child gender, and number of interventions received by parents in a sample of parents with school-aged children with autism involved in a therapeutic service related to their disability. The results yielded evidence to suggest families who report a higher number of needs are more likely endorse higher scores on a measure of family maladjustment. This means the more unmet needs reported by a family are associated with lower levels of family adjustment. Parent-intervention type (i.e., behavioral component vs. no behavioral component) was not found to be predictive of family need or family adjustment. This is to say, a parent-focused intervention with a behavioral component did not have a more significant association to family need and family adjustment than a parent-focused intervention without a behavioral component. Further, a parent behavior skill-focused intervention does not have a stronger association with family need or family adjustment compared to interventions without a behavioral component. These findings contribute to a larger body of autism research in that the current results suggest supporting families in meeting their needs should facilitate better overall family adjustment. As previously stated, family adjustment refers to family units applying their strengths to maintain positive functioning during difficult situations. The association between unmet needs and family adjustment, while not surprising, reinforces the necessity for practitioners, clinicians, and educators to connect families with individualized resources and support as a standard part of practice.

Family Adjustment and Parent Need

Prior research has suggested that family adjustment can be influenced by coping, stress, and resource availability such as social support, financial assistance, and service options (Stancin et al., 2008). As previously discussed, social support, financial assistance, and information about services are common unmet needs reported by parents of children with autism. Results of the current study substantiated the hypothesis, which suggested a higher number of unmet needs would be associated with lower overall family adjustment. Due to the impact that parenting a child with autism can have on family adjustment as well as the rate to which parents of children with autism endorse unmet needs, this finding did not come as a surprise. While a child with autism can negatively impact family outcomes like parent stress, family outcomes like maladjustment can also negatively impact child outcomes such as emotion- or self-regulation or behavior. Therefore, it is imperative that practitioners address each aspect of family functioning, adjustment, and needs so as to provide the best possible outcomes for the child with autism and their family. This study was the first known of its kind to examine the relation between family adjustment and family needs in a sample of parents of school-aged children with autism.

Additional research is needed in this area to further develop an understanding of types of met needs such as respite care or financial support that may contribute to a more positive family adjustment. Future studies may investigate family need and adjustment before and after parent-focused interventions delivered to parents of children with autism and take a further look into specific subscales such as parenting practices, coercive parenting, information, or social support.

Child age, child gender, and number of interventions were not significantly associated with family adjustment, which was an unexpected finding. Child age was expected to be associated with family adjustment for families of children with autism because externalizing behaviors are typically at their peak during childhood (Tremblay, 2000). Further, McKee and colleagues (2020) found families perceive stress differently at various points in their child's life, which had an overall impact on family adjustment. The current study examined differences in family adjustment in a school-aged sample for children with autism, which may be responsible for low variability within the pool of families surveyed. However, major developmental milestones are expected to occur in children between the ages of six and twelve years old (CDC, 2021). As the child with autism ages, meets milestones, and masters various skills, the family will experience changes in barriers, needs, and stress (McKee et al., 2020; Seltzer et al., 2003). Therefore, it was interesting to find in the current study that child age did not explain partial variability in family adjustment among participants. Child gender was also expected to contribute to the variability in family adjustment for families of children with autism in ways with and without associations to age. Certain differences in child gender such as behavioral and social camouflaging were expected to have an impact on diagnostic age due to the connection between age and gender. According to Wood-Downie and colleagues (2021), girls with autism were more likely to camouflage or exhibit fewer autistic symptoms than their male counterparts with similar diagnostic traits. Camouflaging makes it more difficult for girls to be diagnosed with autism, resulting in later diagnosis and start to treatment, both negatively contributing to an individual's mental health (Hull et al., 2017). Late diagnoses have also been shown to impact family members of the individual with autism, with families who reported more recent diagnoses experiencing greater distress (Gray, 2002). The current study had a sample of twenty-eight girls and thirty-four boys. The girls' average diagnostic age was approximately 4 years-old while the boys' average diagnostic age was approximately 3 years-old. Although girls in this sample were diagnosed on average almost a year later than their male counterparts, the average age for girls and boys in this sample was 8.5 years old. Families of girls with autism had less time than families of boys with autism to adjust to their child's disorder and engage in treatment, however, this did not significantly contribute to the differences in family adjustment for this sample. Another reason child gender was hypothesized to associate with family adjustment was due to boys with autism exhibiting externalizing behaviors at a higher rate than their female counterparts (Lahey et al., 2000). Overall, child gender was not a significant predictor for family adjustment in the current study. Although parents of boys and girls with autism experience somewhat different struggles with their children, a possible reason child age and gender were not significant predictors of family adjustment is due to both contributing to parental distress to a similar extent for different reasons.

The number of interventions received by families of children with autism was expected to be significantly associated with family adjustment due to the various benefits experienced by parents engaged in parent-focused interventions. As parents have the opportunity to be engaged in treatment over time with and without their child, the knowledge and techniques are reiterated and reinforced. Paul and Fahim (2015) discussed a number of essential terms associated with treatment for children with autism important for parents to be familiar including applied behavior analysis, antecedent, differential reinforcement, discrete trial training, extinction, functional behavioral assessment, functional communication training, joint attention/mediated learning (JAML), joint attention and symbolic play engagement regulation (JASPER), modeling, naturalistic intervention, parent-implemented intervention, peer-mediated instruction and intervention, picture exchange communication system, pivotal response training, prompting, reinforcement, and many, many more. Each of these treatment terms has an extensive catalogue for understanding meaning, purpose, and execution of strategies. Even for the seasoned psychologist, the amount of information necessary for parents of children with autism to retain is extensive. Parents involved in multiple interventions would have the most exposure to relevant language and strategies, opportunities for practice, and access to social support and feedback. Additionally, families report finding parent-focused interventions valuable, which may also serve as a protective factor for overall adjustment (Faldt et al., 2020). Therefore, it was suspected that experience with multiple intervention types would have a positive effect on family adjustment. However, ratings of family adjustment were surprisingly similar for parents regardless of their intervention experiences. Although intervention type was recorded for participants, the scope of information was limited in that participants could only record the type of intervention rather than the total number of interventions they had received nor the duration of the intervention. Participants with the most intervention type experience did not necessarily have the most experience with interventions overall. In addition, the current study did not examine the recency of intervention (how recent the intervention occurred), which may be an important factor to evaluate.

Parent Need and Parent-Intervention Type

According to Ellis and colleagues (2002), information about teaching strategies, behavior management, and support for behavior management were among the top reported needs for parents of children with developmental disabilities using a modified version of the Family Needs Survey. These findings are consistent with research conducted by Derguy and colleagues (2015), which revealed parental guidance (i.e., development of parenting skills to effectively address child behavior and emotion) along with materials, information, and emotional support were the top areas of need reported amongst parents of children with autism. Additionally, Siklos and Kerns (2006) found when children engaged in more challenging behaviors, families were more likely to endorse a greater number of needs as "important." As previously discussed, challenging behaviors are a huge source of stress and dysfunction for families of children with autism. As aspects of communication and social interaction are heavily focused on during child interventions, it was hypothesized that a parent skill behavior-focused intervention would contribute to more variability in family needs than an intervention without a behavioral component. Specifically, that a skill behavior-focused intervention would add a layer of support for families in both knowledge and skill acquisition, resulting in fewer unmet needs. However, the results did not suggest the type of intervention experience could explain the difference in needs reported by families in the current sample. This finding came as a surprise given the positive impact interventions focused on managing behaviors have had on family outcomes, child behaviors, and child outcomes (Hodgson et al., 2018). According to a qualitative study conducted by Hodgson and colleagues (2018), caregivers involved in a parent-focused intervention to manage behaviors in children with autism reported a deeper understanding on autism and perspective of their child's disability, more realistic expectations for their child, and growth in the area of parenting and behavior management skills. Parents also reported improvements in their child's overall behavior. Additionally, parents reported improvements in the ways they were able to explain their child's disability to friends and family members, even coaching others how to make stronger connections with their child. Skill-behavior focused interventions were expected to directly target certain areas on the Family Needs Survey such as information needs, family and social support, and explaining to others, yet intervention type was not significantly related to family need. A possible explanation for the absence of supportive evidence is the connection between child communication and co-occurring behavior problems for children with autism. According to Boonen and colleagues (2014), pragmatic language difficulties, such as a lack of understanding of the conversational process, contributed to an increase of engagement in externalizing behaviors as a means to communicate and more internalizing behaviors as a response to negative or difficult social interactions. Participants in the current sample could have similar family needs as a result of the interventions supporting multiple areas of child functioning rather than just the targeted focus for the intervention (e.g., communication-focused vs behavior-focused). For example, parents involved in communication-focused interventions may have learned skills to help their child communicate needs and desire in a more appropriate way, which in turn reduced their child's externalizing behavior by removing the function and replacing the behavior with a more developed form of communication. Additional research is necessary to understand the true association between parent-focused interventions for behavior and outcomes like family needs and how interventions may be modified in the future to better address family needs while targeting similar intervention targets (e.g., behavior management). Future researchers could investigate how embedding an ongoing assessment of family need and responsive support to unmet needs would reduce family need.

Family Adjustment and Parent-Intervention Type

According to Ewigman (2018), family adjustment is altered when a significant stressor, such as parenting a child with a disability, develops within the family system. Given the diverse nature of each family unit, there is much variability in the ways families respond to a stressor such as having a child who receives an autism diagnosis and attempt to maintain homeostasis within the family (i.e., positive family adjustment). A response to a stressor, in an attempt to maintain familial adjustment, can be affected by the psychological health of family members, financial resources available to the family, coping strategies used by the family, and family perceptions of the stressors. According to Sikora and colleagues (2013), aspects of family functioning have also been shown to be influenced by externalizing behaviors in children with autism. Higher externalizing behaviors exhibited by children were found to be correlated with poorer overall family functioning specifically in the areas of negative feelings about parenting, social relationships, impact to siblings, and impact to marriage. Therefore, this research hypothesized parent skill behavior-focused interventions would contribute to more variability in scores of family adjustment than parent-focused interventions without a behavioral component. Specifically, that interventions focused on teaching parents how to manage and prevent minor and major challenging behaviors would yield more favorable scores of family adjustment compared to interventions that facilitated psychoeducation or communication-focused skills. A parent skill behavior-focused intervention focused intervention was thought to be more beneficial in supporting family adjustment due to the extreme stress reported by parents of children with autism in a state of chronic hypervigilance towards their child’s unpredictable and challenging behaviors (Sikora et al., 2013). However, results did not indicate parent intervention type was responsible for explaining the differences in scores of family adjustment for participants in the current study. This finding came as a surprise since parent-focused interventions for behavior are shown to be effective in improving child behavior (Rosenbrock et al., 2021). Although child challenging behaviors are reduced when parents serve as interventionists with skills learned during behavior-focused parent-mediated interventions, Rosenbrock and colleagues (2021) identified internal experiences of parents as an important factor in successful treatment for child and family outcomes. Thus, one possibility for the lack of significance could be contributed to a missing link between parent-focused interventions to improve child outcomes with an added therapeutic focus to support parent internal experiences. In other words, improved child behavior as a single benefit may not be enough to significantly associate with family adjustment. Additional research is needed to understand the effectiveness of parent-focused interventions targeting both child behavior and parent emotional well-being on important family outcomes such as adjustment.

MacKenzie and Eack (2022) conducted a recent meta-analysis examining the effects of parent interventions on parental outcomes for parents of children with autism which produced results similar to the current study. Researchers examined the effect of both parent support interventions and parent implementation interventions on parenting confidence, parent mental health, caregiving burden, family adjustment, physical health, and stress. As previously stated, psychoeducation is an example of parent support while parent-mediated is an example of parent implementation. The meta-analysis revealed there were no significant effects of parent support or parent implementation interventions on caregiving burden, family adjustment, physical health, and stress. However, these results contradict a meta-analysis conducted by Tarver and colleagues (2019) as well as various other studies (Argumedes et al., 2018; Estes et al., 2014; Ji et al., 2014; Koegel, 2000; Patra et al., 2015), which concluded parent interventions did effectively reduce parenting stress. The results of the current study as well as MacKenzie and Eack (2022) were surprising due to the well-established relationship between parenting stress and overall family functioning (Rao & Beidel, 2009; Hall et al., 2012). Overall, family adjustment presents as a complex aspect of family life. Despite insignificant findings, this study demonstrates the importance of more research dedicated to understanding healthy family adjustment and how to best address family maladjustment in families of children with autism. Future research may attempt to consolidate recommended measures to address and support family adjustment. Research is also needed to understand how to target family adjustment during parent-focused interventions and ongoing care with the family. Additionally, more research is needed to fully understand the aspects associated with family adjustment.

Limitations

The current study used survey research distributed electronically as the method to learn more about family life of parents of children with autism and their functioning and experience with parent-focused interventions. A survey self-report measure has some notable limitations including honesty, introspective ability, and interpretation of questions. Participants may answer dishonestly in an attempt to appear more socially acceptable (Fisher, 1993). According to Kim and Kim (2013), individuals may over-report or under-report certain questions on the self-report measure in an effort to appear more socially conventional or desirable, also known as self-deceptive enhancement and impression management. Brener and colleagues (2003) also explained systematic biases in responding which occurred using self-report measures in research. Participant errors made at any point or during multiple points in the cognitive process innately used for answering questions has been theorized to contribute to problems with validity. The cognitive process includes comprehension or interpretation of the question, retrieval, decision-making, and response generation. When errors are made, participants may struggle to assess themselves with accuracy or interpret the questions to have different meanings than intended.

When families endorse higher scores on measures of family adjustment, they are more likely to engage in strategies to problem solve, cope, learn, and advocate for support (Daire et al., 2014). Therefore, the self-selection bias must be considered when interpreting the results of this research. The families participating in this research volunteered to participate after receiving an informational flyer from a contact person at an organization with which they were involved. Survey responses revealed that 100% of the families in this study also sought parent-focused interventions related to their child's disability. Thus, the current study sample is not likely fully representative of the population of parents of children with autism.

The Family Adjustment and Need Survey instructed parents to select all parent-focused interventions with which they had experience. The selections included psychoeducation, parent-mediated interventions for skill acquisition, and parent skill behavior-focused intervention. There was also an option for parents to select "other" and provide a short answer. A brief description of each intervention type was listed for the participant. Psychoeducation was defined as an evidence-based intervention which provides the intervention recipient (i.e., caregivers) with systemic and structured knowledge and information about a disability or illness, treatment options, and ways to improve treatment efficacy. Parent-mediated intervention for skill acquisition was defined as interventions delivered to parents to improve parent/caregiver skills for working with their child directly on aspects related to their disability (e.g., communication, eye contact, emotional expression, joint attention, etc.). Parent skill training for challenging behaviors was defined as interventions delivered to parents to improve the parent/caregiver's ability to manage difficult behaviors in which their child engages (e.g., tantrums, head-banging, elopement, destructive behaviors, etc.). Although the different types of parent-focused interventions were accurately described on the survey, this may have limited the full scope to which parents explained their intervention experiences. A short answer option for intervention experiences followed by coding of participant responses could have offered more insight into any overlap between intervention components, specific foci of interventions, and intervention delivery methods, duration, and frequency. Questions could have also been added to the survey to learn about the number of intervention sessions received by parents, the full number of different interventions rather than only intervention type, when the parent participated including whether the parent was currently involved in a parent-focused intervention, what type of interventions their child receives, and the symptoms their child exhibits. In addition to a lack of understanding of the full range of interventions received by parents, the opportunity for parents to select multiple interventions limited the ability to analyze the true differences between groups. The current study initially aimed to investigate the differences between parents who had and had not received an intervention, specific intervention type was intended to be an area of further exploration once the initial differences had been identified. However, the data revealed all participants had received at least one type of parent intervention. This result and the specific participant responses caused the group options to be very narrow, in that the only option was to examine the differences between participants who had and had not received a behavior-focused intervention. Additionally, a further exploration of differences between groups based on subscales from the survey measures such as parenting practices or financial needs, could not be completed due to the low internal consistency on the subscales of the Family Needs Survey and Parenting and Family Adjustment Scale. A possible reason for low internal consistencies on the subscales may be due to the three-point Likert scale; with only three-points on the scale, the sensitivity of the measure may have been impacted.

Another limitation in this study is the small sample size. A small sample size can introduce issues with the interpretations of results. The power of a study, which is used to find significant results, is reduced when a sample size is too small. Additionally, the likelihood of a type II error, or a false positive, increases when sample size is too small. These factors limit the ability to generalize the results to a broader population. A qualitative approach could have been utilized in this study to better understand the types of parent-interventions parents involved in the study received. As previously stated, a short answer option for participants to provide a description of their intervention experiences followed by themed response coding would have been a valuable qualitative addition to use during data collection. Participant responses may have revealed meaningful insight about group format or style, teaching approaches, and intervention buy-in and follow-through that could have offered relevance in a broader discussion. Short answer options could have also been made available for other aspects relevant to the study such as parenting practices, family life, and child symptoms which similarly could have contributed meaningfully to the discussion of results. Additionally, parents could have been asked to explain their perception of their intervention experience, the effectiveness of the intervention in practical everyday use, and the different intervention components such as duration, frequency, method, group size, etc.

Implications

Despite the acknowledged limitations in this study, there remains important practical implications for working with families of children with autism. The current study aimed to investigate (a) the dynamic between family needs and family adjustment, (b) the association between parent-intervention types and family needs, and 3) the association between parent-intervention types and family adjustment. Although parent-focused intervention type did not significantly associate with family need or adjustment, family need was shown to explain a significant amount of the variance in scores of family adjustment. The results of this study have implications for practice and future research endeavors.

Head and Abbedato (2007) highlighted the importance of evaluating and assessing children with developmental disabilities through a systems approach. A systems approach allows for a stronger application of meaningful methods of intervention as it does not center the child as the patient, instead focusing on the family system as a whole. By evaluating specific strengths and weaknesses of individual family members, the child with a disability, and the family unit, treatment or intervention planning can include feasible and individualized support that benefits the entire family unit as well as the child. Due to the well-established relationship between child outcomes and family outcomes, in that one is constantly influencing the other, a systems approach to evaluating has strong practical implications for addressing family adjustment and family need in a therapeutic setting. Though there are barriers such as lack of time and resources, the current study results support a systems approach when working with families of children with autism to better support families with resources, information, treatment, and overall functioning.

Brown and colleagues (2012) found that when assessing family needs with parents of children with autism in an open-ended question format, parents often reported being frustrated with the service system, having to search for information rather than having that information presented to them by a practitioner. Parents of children with autism are already met with demands that exceed parenting a neurotypical child or a child with another type of disability. Rather than allowing parents to struggle while navigating through a passive service system, practitioners have a responsibility to take an active role in supporting the family in meeting their needs with best practices suited for the family. Further, evaluating family needs should not be a practice solely for families with a new diagnosis. Research indicates that after an average of five years post-diagnosis, families still reported being dissatisfied with the information they had about treatment options for their children (Brown et al., 2012). This finding suggests that family needs should not be assessed in a one-and-done approach, instead family needs ought to be an ongoing conversation between a practitioner and the family system. The dynamic between family adjustment and family need has an important place in a school setting. School psychologists often work with parents for a number of reasons including consultation, special educational needs, and mediation. Prior to working with families to better serve their children in schools, it would be helpful for school psychologists to understand the specific needs of the student's family. Including a family needs assessment in practice could be a beneficial way for school-based practitioners to gather information about needs and goals prior to engaging in the evaluation process, starting therapy with a student, and helping to connect families with resources.

Future Directions

Additional research is needed to fully understand the relation between parent-focused interventions and family need and adjustment. Further, altering the focus of assessment and evaluation of children with autism to encompass the whole family system shows promise in treatment planning that better addresses the overall family adjustment (e.g., functioning, weaknesses, strengths, etc.) and family needs to lead to more positive outcomes. Future researchers may address family adjustment and parent need before and after specific types of interventions or use measures of family adjustment and need to inform their therapeutic focus and planning. Additionally, future research should utilize available measures of family adjustment and need in an open-ended format, allowing for practitioners to clarify certain responses or response patterns, which may further the benefits experienced by families and their children with autism.

According to Da Paz and colleagues (2018), the adjustment period for a family after a child has been diagnosed with autism has been shown to vary based on self-reported factors including acceptance of the diagnosis, self-blame, and despair. Families that reported higher levels of acceptance towards the autism diagnosis at the start of the study as well as after the 18-month period also reported fewer symptoms of depression and stress. Additionally, families who experienced decreased feelings of self-blame and despair after the 18-month period also reported better parental adjustment. Stress management programs that focus on teaching parents to engage in practices that help remove parent guilt, improve coping, problem solving, and direct communication skills produce significant effects in reducing emotional distress for parents of children with disabilities in addition to fostering improved parental adjustment, coping strategies, and overall functioning of the child (Lopez-Liria et al., 2020). Future research should evaluate the effectiveness of different stress management programs on family adjustment. Perhaps parent-focused interventions related to a child’s disability are not sufficient in aiding families with the other skills necessary in parenting a child with autism such as resiliency, coping, communication within the family, seeking support, and cognitive restructuring. Resiliency building and healthy stress management skills could be considered as a supplemental focus in future parent-focused interventions with the primary goal of improving child characteristics.

An evaluation of occurrence and methodology used by practitioners to assess parent and family need and family adjustment could also be a valuable research venture. Understanding the number of practitioners using a systems approach and the tools used to evaluate family adjustment and need could shed light on possible discrepancies based on income, location, age, and other factors unique to families and service delivery options. Additionally, examining these aspects could highlight more preferable or feasible methods for working with families to meet their needs and support more positive family adjustment. A growing body of research supports addressing the family unit to optimize therapeutic services for children with autism and their families. Research also ought to explore reasons as to why practitioners may not engage in these systems approach practices such as burnout, lack of time and resources, lack of quality services in an area, and other reported barriers.

Families of children with autism often work with some type of care coordinator so as to have an individual with professional level knowledge of disabilities and treatments in healthcare also advocating on behalf of their child. Care coordination has many benefits including centering care around strengths, family needs, and family values as well as support navigating intervention options. According to Morris and colleagues (2018), social workers often support families of children with autism while coordinating care. While social workers are effective in fostering a family-centered approach to treatment, they report barriers to working with patients with autism due to ambiguity in their roles and responsibilities and lack of training. According to hospital social workers, their role in working with families of children with autism presents overlap with other staff. Additionally, given the unique characteristics of individuals with autism and the needs of their families, many social workers reported feeling undertrained and unprepared to manage such complex cases. Healthcare settings have observed improvements in quality and efficiency after autism-related staff receive knowledge and skill-related trainings. When lack of training and role ambiguity are driving forces against best-practice care for a group of individuals, a systems-level issue can be identified. In this instance, evidence already exists to suggest psychoeducation and training are an effective approach to removing barriers for families with autism to receive the best possible care. With the niche understanding of autism school psychologists acquire through formal education and experience, there is an opportunity for future research to pilot autism-focused training programs to social workers, care coordinators, and other professionals. School psychologists could also take a more formal role in the healthcare setting to advocate and work with families of children with autism and other developmental disabilities. In addition to their knowledge of autism, behavior, interventions, and family-centered care, school psychologists have experience embedded in the school setting, where children spend a great deal of their waking hours and are engaging in learning, social exploration, and impulse control. School psychologists may also be helpful in better defining the roles and responsibilities of service providers working with children with autism and their families. Similar to the evaluation process, a multidisciplinary approach may be better utilized when role ambiguity and overlap of responsibilities are not factors limiting care and efficiency. Thus, school psychologists could play a systems level and/or collaborative consultation role in healthcare to facilitate streamlined care for children with autism and other developmental or behavioral disabilities. The implications for future research that examines the competencies of school psychologists and other support service personnel in addressing parent needs and capacity to parent their child with autism are broad.

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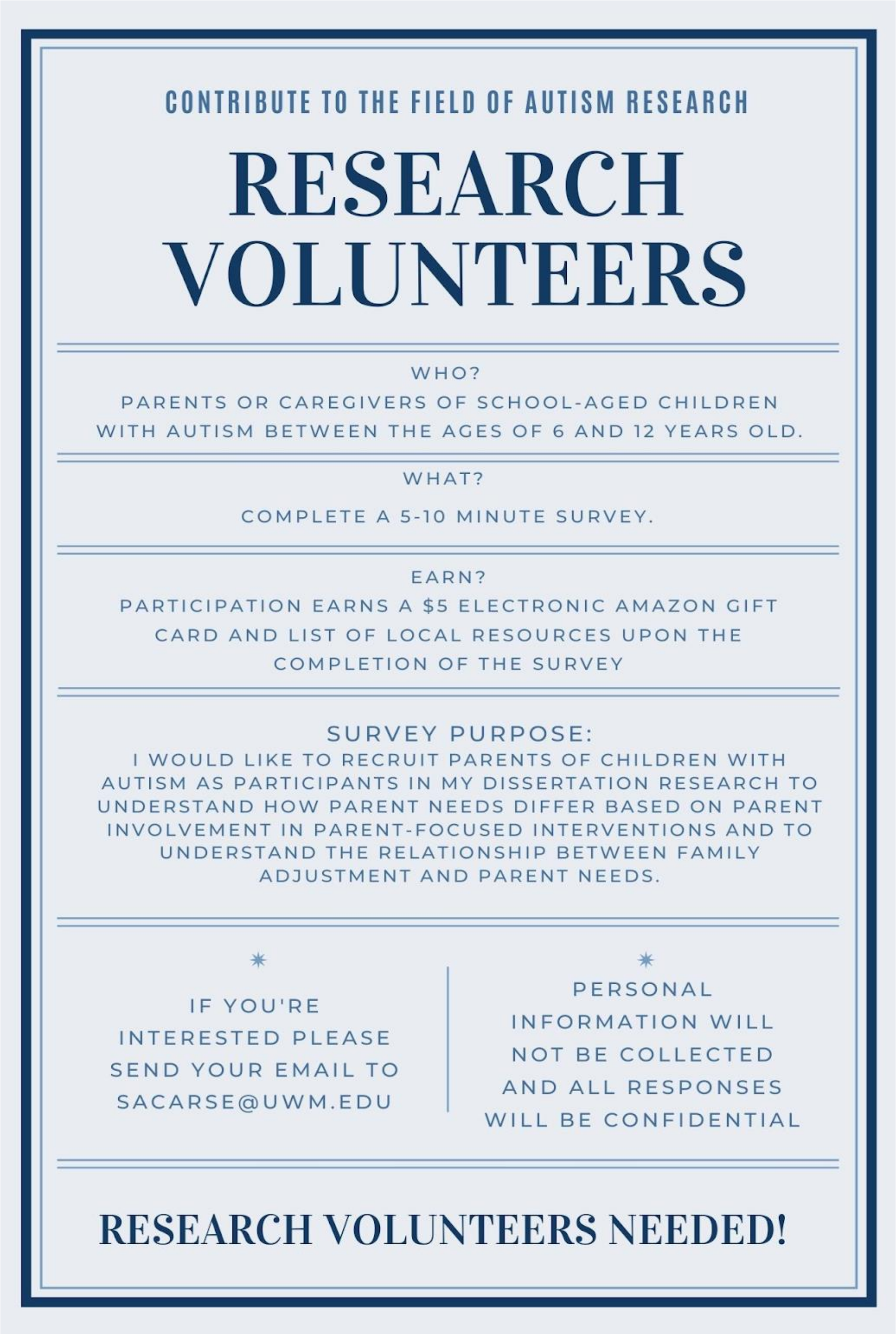
Appendix A

Recruitment Flyer



CONTRIBUTE TO THE FIELD OF AUTISM RESEARCH

RESEARCH VOLUNTEERS

WHO?

PARENTS OR CAREGIVERS OF SCHOOL-AGED CHILDREN WITH AUTISM BETWEEN THE AGES OF 6 AND 12 YEARS OLD.

WHAT?

COMPLETE A 5-10 MINUTE SURVEY.

EARN?

PARTICIPATION EARNS A $5 ELECTRONIC AMAZON GIFT CARD AND LIST OF LOCAL RESOURCES UPON THE COMPLETION OF THE SURVEY

SURVEY PURPOSE:

I WOULD LIKE TO RECRUIT PARENTS OF CHILDREN WITH AUTISM AS PARTICIPANTS IN MY DISSERTATION RESEARCH TO UNDERSTAND HOW PARENT NEEDS DIFFER BASED ON PARENT INVOLVEMENT IN PARENT-FOCUSED INTERVENTIONS AND TO UNDERSTAND THE RELATIONSHIP BETWEEN FAMILY ADJUSTMENT AND PARENT NEEDS.

IF YOU'RE INTERESTED PLEASE SEND YOUR EMAIL TO SACARSE@UWM.EDU

PERSONAL INFORMATION WILL NOT BE COLLECTED AND ALL RESPONSES WILL BE CONFIDENTIAL

RESEARCH VOLUNTEERS NEEDED!

Appendix B: Measures Family Adjustment and Need Survey

Table 9. Family Adjustment and Need Survey

Inclusionary Criteria:
Participants must answer YES to all 4 inclusionary criteria questions. If you **do not answer yes** to all of these questions your answers **will not be included** in the research and you will not receive the Amazon gift card at the end of the study.

	Yes	**No**
1. I am the parent or caregiver of a child with autism	☐	☐
2. My child with autism is currently between the ages of 6 and 12 years old.	☐	☐
3. My child is currently receiving therapeutic services related to their disability. *Therapeutic services refer to any clinical, school-based, or medical treatment to increase, maintain or improve the functional capacities of individuals with disabilities.*	☐	☐
4. I am able to read English.	☐	☐

Demographic Information

1. What is your race/ethnicity?

   Options:
   - American Indian or Alaska Native
   - Asian
   - Black or African American
   - Hispanic or Latinx
   - Native Hawaiian or Other Pacific Islander
   - White

2. Please state your household income to the nearest dollar.

   Options:
   - Under $15,000
   - $15,000 to $24,999
   - $25,000 to $34,999
   - $35,000 to $49,999
   - $50,000 to $74,999
   - $75,000 to $99,999
   - $100,000 to $149,999
   - $150,000 to $199,999
   - $200,000 to $249,000
   - $250,000 to $299,999

- Over $300,000

3. What type of household do you have? (e.g., single-parent, two-parent, other).

4. How many children do you have?

5. How many children with disabilities do you have?

6. How many people excluding you, your partner, and your children live in your household? (e.g., extended family, friends, etc.).

7. At what age did your child receive an autism diagnosis? (*Please state in months).*

8. What is your child's current age? (*Please state in years and months).*

9. What is your child's gender? (e.g., male, female, non-binary, other),

Parent-Focused Interventions

Parent-focused interventions refer to interventions requiring the parent or caregiver to work with professionals in a disability-specific area with the goal of supporting or training the parents and/or caregivers.

Psychoeducation is an evidence-based intervention which provides the intervention recipient with systematic and structured knowledge and information about a disability or illness, treatment options, and ways to improve treatment efficacy.

Parent-mediated interventions for skill acquisition refer to interventions delivered to parents to improve parent/caregiver skills working with their child directly on aspects related to their disability (e.g., communication, eye contact, emotional expression, etc.)

Parent skill training for challenging behaviors refers to interventions delivered to parents to improve the parent/caregiver's ability to manage difficult behaviors in which their child engages (e.g., tantrums, head-banging, elopement, etc.)

Care coordination is the process of organizing care activities such as school-based services or private clinic-based services and sharing information among all stakeholders involved in the child's care to improve outcomes for effective treatment.

	Yes	No
1. Are you or have you been involved in a parent-focused intervention related to your child's disability?	☐	☐

2. Please check all the boxes that describe the type of parent-focused intervention in which you have had experience?
    - ☐ Psychoeducation (i.e., knowledge-based)
    - ☐ Parent-mediated intervention for skill acquisition
    - ☐ Parent skill training for challenging behaviors
    - ☐ Other (*Please briefly describe)*

		Yes	No
3.	Are you receiving care coordination from a private clinic or the state?	☐	☐

Parenting and Family Adjustment Scale (PAFAS)

	How true is this of you?			
	Not at all	A little	Quite a lot	Very much
1. If my child doesn't do what they are told to do, I give in and do it myself	0	1	2	3
2. I give my child a treat, reward or fun activity for behaving well	0	1	2	3
3. I follow through with a consequence (e.g., take away a toy) when my child misbehaves	0	1	2	3
4. I threaten something (e.g., to turn off the TV) when my child misbehaves but I don't follow through	0	1	2	3
5. I shout or get angry with my child when they misbehave	0	1	2	3
6. I praise my child when they behave well	0	1	2	3
7. I try to make my child feel bad (e.g., guilt or shame) for misbehaving to teach them a lesson	0	1	2	3
8. I give my child attention (e.g., a hug, wink, smile, or kiss) when they behave well	0	1	2	3
9. I spank (smack) my child when they misbehave	0	1	2	3

10. I argue with my child about their behavior/attitude	0	1	2	3
11. I deal with my child’s misbehavior the same way all the time	0	1	2	3
12. I give my child what they want when they get angry or upset	0	1	2	3
13. I get annoyed with my child	0	1	2	3
14. I chat/talk with my child	0	1	2	3
15. I enjoy giving my child hugs, kisses, and cuddles	0	1	2	3
16. I am proud of my child	0	1	2	3
17. I enjoy spending time with my child	0	1	2	3
18. I have a good relationship with my child	0	1	2	3
19. I feel stressed or worried	0	1	2	3
20. I feel happy	0	1	2	3
21. I feel sad or depressed	0	1	2	3
22. I feel satisfied with my life	0	1	2	3
23. I cope with the emotional demands of being a parent	0	1	2	3
24. Our family members help or support each other	0	1	2	3
25. Our family members get on well with each other	0	1	2	3
26. Our family members fight or argue	0	1	2	3

27. Our family members criticize or put each other down	0	1	2	3

If you are in the relationship, please answer the following 3 questions	**How true is this of you?**			
	Not at all	A little	Quite a lot	Very much
28. I work as a team with my partner in parenting	0	1	2	3
29. I disagree with my partner about parenting	0	1	2	3
30. I have a good relationship with my partner	0	1	2	3

Family Needs Survey

	Definitely do not need help	Not Sure	Definitely need help
Information			
1. How children grow and develop	1	2	3
2. How to play or talk with my child	1	2	3
3. How to teach my child	1	2	3
4. How to handle my child's behavior	1	2	3
5. Information about any condition or disability my child might have	1	2	3
6. Information about services that are presently available for my child	1	2	3
7. Information about the services my child might receive in the future	1	2	3
Family & Social Support			
1. Talking with someone in my family about concerns	1	2	3

2. Having friends to talk to	1	2	3
3. Finding more time for myself	1	2	3
4. Helping my spouse accept any condition our child might have	1	2	3
5. Helping our family discuss problems and reach solutions	1	2	3
6. Helping our family support each other during difficult times	1	2	3
7. Deciding who will do household chores, childcare, and other family tasks	1	2	3
8. Deciding on and doing recreational activities	1	2	3

Financial

1. Paying for expenses such as food, housing, medical care, clothing, or transportation	1	2	3
2. Getting any special equipment my child needs	1	2	3
3. Paying for therapy, day care, or other services my child needs	1	2	3
4. Counseling or help in getting a job	1	2	3
5. Paying for babysitting or respite care	1	2	3
6. Paying for toys that my child needs	1	2	3

Explaining to Others

1. Explaining my child’s condition to my parents or my spouse’s parents	1	2	3
2. Explaining my child’s condition to his or her siblings	1	2	3
3. Knowing how to respond when friends, neighbors, or strangers ask questions about my child	1	2	3

4. Explaining my child’s condition to other children	1	2	3
5. Finding reading material about other families who have a child like mine	1	2	3

Child Care

1. Locating babysitters or respite care providers who are willing and able to care for my child	1	2	3
2. Locating a day care program or preschool for my child	1	2	3
3. Getting appropriate care for my child in a church or synagogue during religious services	1	2	3

Professional Support

1. Meeting with a minister, priest, or rabbi	1	2	3
2. Meeting with a counselor (psychologist, social worker, psychiatrist)	1	2	3
3. More time to talk to my child’s teacher or therapist	1	2	3

Community Services

1. Meeting and talking with other parents who have a child like mine	1	2	3
2. Locating a doctor who understands me and my child’s needs	1	2	3
3. Locating a dentist who will see my child	1	2	3

Appendix C

Consent Template for Online Survey

University of Wisconsin-Milwaukee
Informed Consent to Participate in Research

Study title: Parent-focused interventions, family need, and family adjustment for parents of children with autism

Researcher[s]: Sara Carse, M.S. (Student Primary Investigator) & Dr. Karen Stoiber (Principal Investigator) School of Education (Educational Psychology)

We're inviting you to take a survey for research. This survey is completely voluntary. There are no negative consequences if you don't want to take it. If you start the survey, you can always change your mind and stop at any time.

What is the purpose of this study?

We want to understand how parent and family needs differ based on parental-involvement in parent-focused interventions and care coordination services as well as how parent and family needs differ based on family adjustment.

What will I do?

The 79-item Family Adjustment and Need Survey will ask questions about family demographics, parent involvement in parent-focused interventions (e.g., psychoeducation and skills training), and parent reception of care coordination services. The survey will also include the Parenting and Family Adjustment Scale (PAFAS) and the Family Needs Survey. The survey will take approximately 15-20 minutes to complete.

Risks

- Some questions may be personal or upsetting. You can skip them or quit the survey at any time.
- Online data being hacked or intercepted: Anytime you share information online there are risks. We're using a secure system to collect this data, but we can't completely eliminate this risk. Participants will not be asked to share any personal information.
- Breach of confidentiality: There is a chance your data could be seen by someone who shouldn't have access to it. We're minimizing this risk in the following ways:
    - Participant information will not be collected during this study; each survey response will be linked to an ID number so all data will remain anonymous.

Possible benefits: Participants will be contributing to research by informing knowledge to the area of study, specifically autism research and parent-focused outcomes for parents of school-aged children with autism.

Estimated number of participants: 60 participants

How long will it take? The survey will take approximately 15-20 minutes to complete. Data will only be collected once during the study.

Costs: None

Compensation: An electronic $10 Amazon gift card

Future research: This data will not be used in any future studies.

Confidentiality and Data Security
All survey responses will be assigned to an ID number. No personal information (e.g., names, email addresses) will be collected during this study.

Where will data be stored? Anonymous data will be stored in a password protected file on the researcher's password protected computer.

How long will it be kept? The data will be stored on the password protected computer and deleted after the completion of the study.

Who can see my data?

- We (the researchers) will have access to the coded data (i.e., participants will be given an ID).
- Agencies that enforce legal and ethical guidelines, such as
    - The Institutional Review Board (IRB) at UWM
    - The Office for Human Research Protections (OHRP)
- We may share our findings in publications or presentations. If we do, the results will be aggregate or grouped data and all responses will be anonymous.

Questions about the research, complaints, or problems: Contact: Sara Carse at (815) 735-1819 or sacarse@uwm.edu or Dr. Karen Stoiber at kstoiber@uwm.edu

Questions about your rights as a research participant, complains, or problems: Contact the UWM IRB (Institutional Review Board) at (414) 662-3544 / irbinfo@uwm.edu

Please print or save this screen if you want to be able to access the information later.
IRB #: 22.146

IRB Approval Date: 01/10/2022

Agreement to Participate:
Your participation is completely voluntary, and you can withdraw at any time.
To take this survey, you must be:

- At least 18 years old
- The parent or caregiver of a child with autism between the ages 6 and 12 years old
- Your child with autism must currently be receiving therapeutic services related to their disability (e.g., school-based, in-home, clinic-based, etc.)
- Must be able to read English

If you meet these criteria and would like to take the survey, click the button below to start.
The consent document will be the first question/page of the survey.
Since a signature cannot be collected with an online survey, a request to waive documentation of consent will be submitted to the IRB upon committee approval of the study.

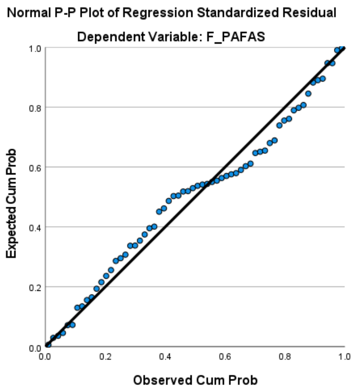
Appendix D

Multiple Regression Assumptions

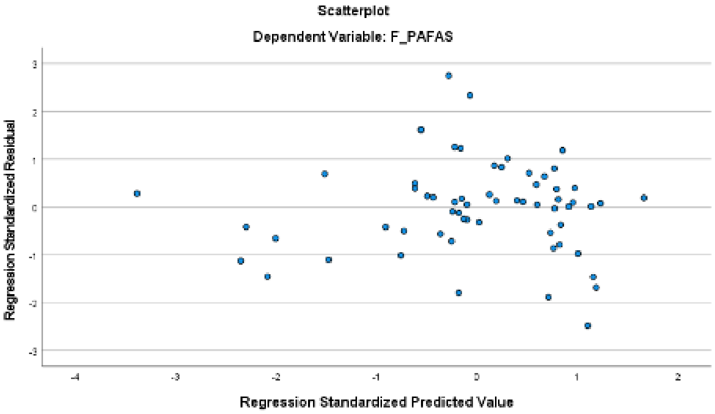
The following presents data for visual inspection of the multiple regression assumptions of normality and homoscedasticity for each regression model. The methods section reviews additional information about multiple regression assumptions, linearity, and multicollinearity.

Research Question 1- Family Need on Family Adjustment

Normality

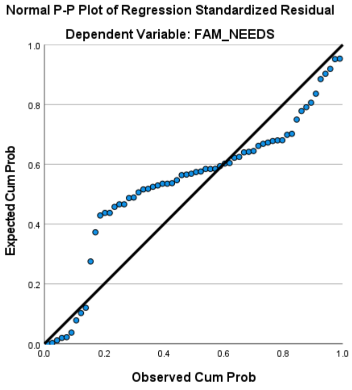


Homoscedasticity

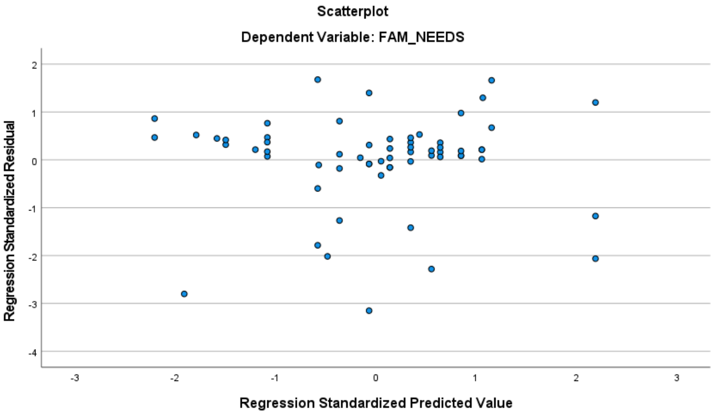


Research Question 2- Intervention Type on Family Need

Normality

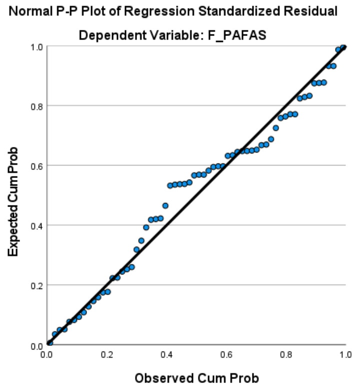


Homoscedasticity

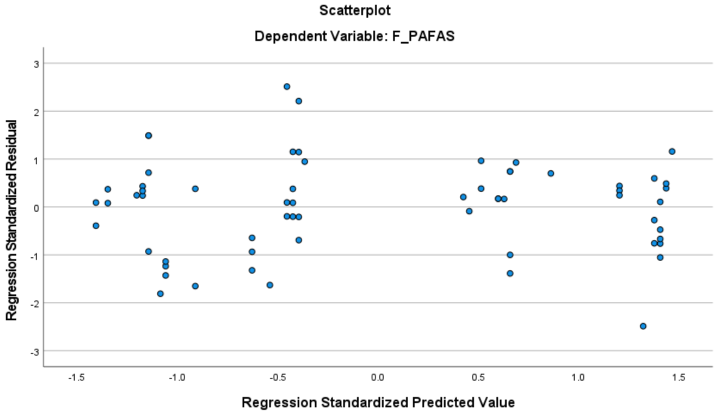


Research Question 3- Intervention Type on Family Adjustment

Normality



Homoscedasticity



Appendix E

PAFAS Item-Total Statistics

	Scale Mean if Item Deleted	Scale Variance if Item Deleted	Correlated Item-Total Correlation	Cronbach's Alpha if Item deleted
PP1	39.10	100.87	.16	.72
PP2	39.10	108.80	-.22	.75
PP3	38.90	102.24	.08	.73
PP4	38.95	105.45	-.07	.74
PP5	39.10	98.41	.29	.71
PP6	39.34	97.14	.33	.71
PP7	39.03	97.37	.31	.71
PP8	39.14	96.58	.36	.71
PP9	39.19	93.60	.46	.70
PP10	38.98	98.89	.26	.72
PP11	38.91	106.33	-.11	.74
PP12	39.02	98.37	.25	.72
PP13	39.22	103.51	.04	.73
PP14	39.09	95.55	.38	.71
PP15	39.21	97.50	.37	.71
PP16	39.28	98.00	.27	.72
PP17	39.24	97.66	.32	.71
PP18	39.28	96.77	.37	.71
PA1	39.03	101.58	.10	.73
PA2	38.91	98.75	.31	.71
PA3	39.24	101.60	.14	.72
PA4	39.03	97.02	.33	.71
PA5	38.91	98.01	.31	.71
PA6	39.22	97.48	.34	.71
PA7	39.05	96.26	.39	.71
PA8	39.29	100.42	.20	.72
PA9	39.29	95.23	.44	.70
PA10	39.59	100.21	.25	.72
PA11	38.59	98.28	.30	.71
PA12	39.74	98.37	.34	.71

Note. PAFAS Parenting Scale labeled “PP” and PAFAS Adjustment Scale labeled “PA”.

Appendix F

FNS Item-Total Statistics

	Scale Mean if Item Deleted	Scale Variance if Item Deleted	Correlated Item-Total Correlation	Cronbach's Alpha if Item deleted
FNS1	35.95	104.08	.23	.83
FNS2	35.97	102.39	.35	.82
FNS3	36.00	102.13	.35	.82
FNS4	35.84	101.71	.35	.82
FNS5	35.98	104.11	.25	.83
FNS6	35.84	104.04	.22	.83
FNS7	36.05	105.49	.13	.83
FNS8	35.85	103.77	.22	.83
FNS9	35.89	103.12	.28	.83
FNS10	35.94	105.08	.15	.83
FNS11	36.02	105.20	.14	.83
FNS12	36.10	100.52	.46	.82
FNS13	35.98	101.36	.36	.82
FNS14	36.15	101.96	.37	.82
FNS15	36.05	100.70	.42	.82
FNS16	36.05	103.00	.27	.83
FNS17	36.00	99.80	.46	.82
FNS18	35.98	104.61	.18	.83
FNS19	36.02	100.38	.45	.82
FNS20	36.16	103.09	.26	.83
FNS21	35.97	102.07	.35	.82
FNS22	36.13	100.28	.47	.82
FNS23	36.03	99.70	.47	.82
FNS24	36.11	101.38	.39	.82
FNS25	36.02	100.90	.43	.82
FNS26	35.92	103.85	.25	.83
FNS27	36.03	103.08	.26	.83
FNS28	35.95	103.72	.24	.83
FNS29	36.21	105.68	.11	.83
FNS30	36.03	100.43	.44	.82
FNS31	35.97	100.62	.43	.82
FNS32	36.00	102.01	.31	.83
FNS33	36.05	100.67	.45	.82
FNS34	35.94	100.03	.46	.82
FNS35	35.67	100.01	.48	.83

Appendix G

Correlations for Predictors and Outcome Variables

	M	SD	1	2	3	4	5	6
1. Child Gender	8.52	1.40	1.00					
2. Child Age	1.45	0.50	-.10	1.00				
3. Num Intervention	1.84	0.58	-.14	.21	1.00			
4. PFI Group	0.50	0.50	-.07	.30	.17	1.00		
5. Family Need	39.97	10.21	-.12	-.05	.30	-.06	1.00	
6. Family Adjustment	37.10	10.40	.19	-.03	-.02	-.09	.34	1.00