Spring 2019

A Collaborative Perspectives Approach for Understanding Effective Care Coordination in Autism Spectrum Disorder

Rachel Severs
Western Kentucky University, rachel.severs@wku.edu

Recommended Citation

Severs, Rachel, "A Collaborative Perspectives Approach for Understanding Effective Care Coordination in Autism Spectrum Disorder" (2019). *Dissertations.* Paper 164.
https://digitalcommons.wku.edu/diss/164

A COLLABORATIVE PERSPECTIVES APPROACH FOR UNDERSTANDING EFFECTIVE CARE COORDINATION IN AUTISM SPECTRUM DISORDER

A Dissertation
Presented to
The Faculty of the Applied Psychology Doctoral Program
Western Kentucky University
Bowling Green, Kentucky

In Partial Fulfillment
Of the Requirements for the Degree
Doctor of Psychology

By
Rachel Severs

May 2019

A COLLABORATIVE PERSPECTIVES APPROACH FOR UNDERSTANDING EFFECTIVE CARE COORDINATION IN AUTISM SPECTRUM DISORDER

Date Recommended 3/22/19

Ronda C. Talley, PhD, MPH
Ronda C. Talley, Director of Dissertation

Yvette Getch PhD CRC
Yvette Getch

PhD
Frederick Grieve

Christina Noel PhD
Christina Noel

Cheryl D. Davis 4/30/19
Dean, Graduate Studies and Research Date

ACKNOWLEDGMENTS

I owe my utmost gratitude and appreciation to my dissertation committee’s high level of involvement and guidance throughout this process. First, I would like to thank Dr. Ronda Talley for her expertise in policy and practice considerations surrounding caregiving and service delivery. Next, I would like to thank Dr. Christina Noel for her guidance and knowledge of the ASD population, as well as insights in data analysis. I would also like to thank Dr. Yvette Getch on her experience with qualitative research and in helping me apply this information to my study. Finally, I would like to thank Dr. Rick Grieve for his guidance and support in helping me meet my dissertation requirement.

I would also like to thank my spouse, Brandon, for his support and patience in this process. His knowledge of patient satisfaction and quality improvement research was pivotal in giving me a high-level perspective when considering and analyzing my data. I must also give thanks to my parents and in-laws for their love and support over the years. They were truly my cheerleaders throughout this process, and I thank them wholeheartedly.

TABLE OF CONTENTS

LIST OF TABLES

A COLLABORATIVE PERSPECTIVES APPROACH FOR UNDERSTANDING EFFECTIVE CARE COORDINATION IN AUTISM SPECTRUM DISORDER

Rachel Severs May 2019 125 Pages

Directed by: Ronda Talley, Yvette Getch, Frederick Grieve, and Christina Noel

Department of Psychology Western Kentucky University

Autism spectrum disorder (ASD) is a neurodevelopmental disorder that causes significant impairment in social and communication areas. The severity of the disorder can often result in a substantial degree and amount of service access and expenditures relating to a child’s needs. This study examined the experiences of how family caregivers and service providers of children with ASD view service delivery using a basic qualitative research design. For the study, 10 participants (five family caregivers and five service providers) were enrolled and interviewed. Interview data were collected and coded to produce a qualitative analysis of the experiences of these individuals who either care for, or deliver services to, children with ASD. Results indicate the top five themes for service providers and family caregivers included areas of: a) collaboration, b) education, c) family support, d) child-centered care, and e) accessibility and availability. These findings can inform and improve future service delivery to support family caregivers and their children with ASD.

Chapter One: Introduction

Autism spectrum disorder (ASD) is a diagnostic term that encompasses a range of neurodevelopmental disorders; most notably, individuals with ASD may struggle with social skills, repetitive behaviors, speech, and nonverbal communication. A spectrum approach for understanding ASD includes considering a wide range of an individual's challenges and strengths. There are many presentations for this disorder due to varying genetic and environmental contributions (Autism Speaks, 2018d). Children with ASD often require a variety of supports in terms of development, socialization, and academics. The current prevalence rate for ASD is 1 in 59 children (Baio et al., 2018).

Prevalence rates, severity of the disorder, and the resulting expenditures required for services are just a few of the many considerations that dictate service delivery. In part, the types and variety of services available to the ASD population are dependent on potential changes and updates to current policy, as existing gaps between policy and clinical care are often overlooked (Doehring & Volkmar, 2016). Hence, it is important to assess the effectiveness of ASD-related services and how these benefit children and their families. For example, Kohler's (1999) study identified multiple ways that service delivery was ineffective for families, including parents lacking information about how to access services, failure of collaboration between parents and service providers, and a lack of continuity between service providers. While this research was helpful in addressing service delivery for this population, a limitation of the study was a focus of only interviewing family caregivers. By interviewing both family caregivers and service providers, a more comprehensive picture may emerge for better understanding not only how services impact families of children with ASD, but also in how services are being delivered and perceived by those professionals also working with these individuals.

The purpose of the current study was to assess the perceptions and experiences of service providers and family caregivers of the ASD population to better understand what constitutes effective care coordination. This included an emphasis on collaboration and communication, as noted as an area of need by Kohler (1999). Attempts to expand research in this area were assessed using a basic qualitative research design. An open-ended survey was implemented using questions from Kohler's *Survey for Family Services,* with adaptations made to the instrument, so that service providers would also be included.

Chapter Two presents the literature on a historical background of ASD and service delivery over the last few decades. More specifically, this chapter includes information on service delivery implications with this population, including a need for policy change. In addition, this chapter provides a presentation of gaps in existing services based on what has been found in research. The research questions of this study are outlined at the end of Chapter Two. Chapter Three discusses the nature and purpose of a qualitative research design. In addition, Chapter Three presents a rationale for why this type of research is an adequate technique and tool for the study. Chapter Four outlines the methodology of the conducted study, including information on materials needed for data collection, procedural steps taken to collect data, data treatment, and data analysis.

Chapter Five presents the results of the study, particularly emphasizing themes and thematic statements among participants. In order to present the experiences of service provider and family caregiver experiences with children of the ASD population accurately, the central themes from interviews, individual accounts of the participants' experiences, and specific quotes are presented according to questions asked during the interview process. In addition, this chapter presents the participants' recommendations about how services may be improved for the ASD population. Furthermore, the results from this study are compared to findings from other qualitative studies that have been previously conducted in this area in order to understand both the similarities and differences among studies. This is important for highlighting not only the limitations of the current study, but also to provide recommendations for future research in ASD service delivery. Chapter Six is a discussion of the results from the qualitative interviews. This chapter reviews the goals of the study and provides a summary of the results. The summary of results also includes a discussion of how the findings from this study are important and relevant to the existing literature and how they affect the overall understanding of ASD service delivery and effective care coordination. In addition, this chapter includes the limitations of the study as well as recommendations for future research.

A basic qualitative research design was chosen to explore the experiences and perceptions of family caregivers and service providers of children with ASD. The area of interest explored was the experience of these individuals in relation to effective care coordination and what they perceive regarding improvements for service delivery with this population. The increased research in this area is due to a variety of issues, including current prevalence rate of the disorder, symptomatology presentation, severity impact, and the resulting required services to meet the ongoing needs of this population.

The research questions explored for this study were:

1) What are the components of effective care coordination as perceived by family caregivers and service providers?
2) What are the elements of care coordination and communication that affect family caregivers’ degree of satisfaction with services?
3) In the areas of care coordination and communication, what are the recommendations of family caregivers and service providers?

Chapter Two: Literature Review

Present Issue and Requirement of Services

Prevalence. According to the Centers for Disease Control and Prevention (CDC), ASD is now diagnosed in 1 out of 59 cases for diagnoses made among 8-year-old children, a 15% increase in prevalence since 2016, when the prevalence rate was 1 in 68 children based on 2012 data (Baio et al., 2018). With autism now classified as a spectrum disorder (American Psychological Association, 2013), the true prevalence may be even higher when considering those who are not yet diagnosed but would meet criteria, as the current prevalence rate does not provide a representative sample for the entire United States (Baio et al.) Due to a rise in prevalence rates over the years, the demand for service providers with knowledge of and experience with treating the disorder has also grown (Mereoiu, Bland, Dobbins, & Niemeyer, 2015). Continued monitoring of the prevalence rate for ASD is essential (Xu, Strathearn, Liu, & Bao, 2018), as increasing rates directly impact service delivery for this population.

Because ASD is an emerging health problem, education is needed for the general public, as well as families who have children on the spectrum (Newschaffer & Curran, 2003). Public health initiatives and collaborations, such as the Autism and Developmental Disabilities Monitoring (ADDM) network, have been set in place to specifically conduct surveillance and other research pertaining to ASD (Rice, Baio, Van Naarden Braun, Doernberg, Meaney, & Kirby, 2007). There is no known singular cause for the disorder, as research suggests that ASD develops as a combination of genetic and nongenetic (e.g., environmental) influences (Autism Speaks, 2018c). Therefore, considering the high prevalence rate, as well as unknown causes of autism spectrum—a disorder with no present cure—significant focus should be placed on the development of beneficial and effective interventions for this population. With a high prevalence in the number of individuals being diagnosed with ASD (Centers for Disease Control and Prevention, 2018), comprehensive care over the individual's lifespan is most essential, which should inform what constitutes effective service delivery. Assessing comprehensive care can be accomplished through evaluating experiences of service providers and family caregivers who care for children, adolescents, and young adults on the spectrum (Sperry, Whaley, Shaw, & Brame, 1999). Their shared experiences may include, but are not limited to, effective care coordination components, recommendations for improving services, and how the factors of collaboration and communication affect the degree of satisfaction with services.

Defining the population. ASD is a lifelong developmental disability, with signs of the disorder generally emerging during early childhood that often affect areas of communication, interactions with others, behavior, and learning (CDC, 2018). There have been many attempts to define and classify autism; previously in the *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition Revised* (*DSM-IV-TR*), autism was defined through a variety of diagnoses that included autistic disorder, Asperger's syndrome, and pervasive developmental disorders-not otherwise specified (PDD-NOS; Klin, McPartland, & Volkmar, 2005); however, all of these disorders are now placed in one umbrella category known as the autism spectrum. A spectrum approach has evolved as a shift away from thinking of autism a specific category and more toward a view of autism ranging in severity on an individual level. The idea of classifying autism as a spectrum disorder comes from the understanding that each individual can range in terms of functioning, from those who are gifted to those who are severely challenged, which can dictate the level of support required to properly address individual needs. However, those on the spectrum will also often share similar symptomology with some level of communication difficulty and selective and repetitive interests and activities (APA, 2013). Additionally, other developmental disorders and syndromes (e.g., Asperger's Syndrome, Pervasive Developmental Disorder-Not Otherwise Specified) were also placed on the spectrum because of the behavioral similarities and genetic factors shared among them (Filipek, 2005). Volkmar and Klin (2005) address that, as the definition of autism has become more complex, so has an understanding of the broader phenotype that includes autism. This phenotype, also known as the autism spectrum, includes genetic components of classical autism but also areas of functioning that are impacted, including social development, communication, and behavior.

Signs and symptoms of ASD. The only way to diagnose ASD is through behavioral observations (Newschaffer & Curran, 2003). Individuals on the ASD continuum often endure significant impairment, in which problems typically manifest in social settings, language and communication, play and imagination, and isolated or limited interests and behaviors (Klin et al., 2005). While these problems commonly include developmental delays, social deficiencies, language and communication impairments, and behavioral issues, in some cases intellectual disabilities can also manifest. Developmental delays in ASD often begin during early infancy and tend to become more apparent over time, although symptom presentation and manifestation differ based on the individual. Parents of children with ASD often report possible "red flags" that their child is acting "differently" than other children (e.g., no babbling by 12 months, loss of speech at any age, upset with minor changes, flapping hands or rocking their bodies; Autism Speaks, 2016c). In terms of social impairments as they pertain to ASD, children may be noted to be non-responsive to their names being called, prefer to play alone, or not share interests with others. Regarding language and communication signs for ASD, a delay in speech and/or language skills, failure to pointing at objects, or not engaging in pretend play are several examples that can be evident (CDC, 2018).

Behavioral issues and unusual interests in a child with ASD may include lining up toys, insistence on following certain routines, or becoming fixated with specific parts of objects (e.g., wheels on a car), which can become obsessive and disruptive to daily living. Another behavioral facet in ASD is emotional dysregulation (e.g., becoming upset easily) with minor changes or with novel situations, which can lead to tantrums or a loss of self-control. In addition, self-stimulation, known as “stimming,” (e.g., hand flapping, rocking body) or repetitive body movements, and lack of imaginative play or playing with toys in the same manner every time are other features that can be inherent to ASD (CDC, 2018).

Also potentially present with ASD are co-morbid conditions or symptoms, which may include, but are not limited to, other neurodevelopmental, genetic (e.g. Rett syndrome, Fragile X syndrome, Down syndrome), cognitive (e.g., language delays, executive dysfunction), psychological (e.g., emotional dysregulation), behavioral (e.g., tantrums, aggression, impulsivity), physical, and medical (e.g., epilepsy), or environmental exposure (e.g., fetal alcohol syndrome, very low birthweight) issues (APA, 2013) that typically exacerbate the disorder’s presentation. Sleep problems, gastrointestinal issues (Autism Speaks, 2016b), and unusual eating habits (CDC, 2018) are also common to this population, along with the possibility of anxiety, vision problems, and attention deficits (CDC, 2014b). It is important to note that this is not a comprehensive list of associated medical problems but more of a way to highlight the extensive nature of what often coincides with ASD. In turn, the number and type of services required for this population may be even more extensive when considering associated features outside of the classical autism spectrum criteria (Treating Autism, 2013). This reinforces the need for accessing a number and variety of services, which will likely include differing health professionals and specific areas of expertise.

Because of these lifelong impairments and the pervasive nature of ASD, having a diagnosis of ASD can contribute to significant problems within the family system. For children diagnosed with ASD, a number of problems exist, not only for the child, but also within the child's family unit (Becker-Cottrill, McFarland, & Anderson, 2003; Hutton & Caron, 2005). As a result, families are faced with many unique challenges required to meet the needs of the child with ASD (Hutton & Caron, 2005). For example, findings from the National Survey of Children's Health (Bitsko et al., 2016) showed that parents reported having struggles in terms of their own mental health status (ranging from fair to poor), along with other problems, including family income, adequate child care, and the lack of a medical home, or patient-centered model. Therefore, families who already face financial burdens are placed at an even more disadvantaged state in terms of vulnerability.

In turn, this may put people from lower socioeconomic groups at an even greater increased risk of failing to meet their children's diagnostic needs, and therefore, understanding the social influences that surround each family needs to be another area of focus for researchers (Bitsko et al., 2016). Overall, there is a growing population of families who will require specific services. An additional consideration is that autism is a lifelong disability, so the continuation of services is key. Therefore, continuous consultation among professionals and with parents is necessary (Ruble & Dalrymple, 2002).

Early detection and early intervention. In addition to professionals being better educated about ASD, working to identify signs of the disorder at earlier ages has proven beneficial to children with ASD and often yields better positive outcomes versus being diagnosed or treated later in life (Autism Speaks, 2018a). The CDC (2014b) recommends developmental monitoring by caregivers, health professionals, and early educators to understand whether a child is reaching the typical developmental milestones. If the child is not reaching milestones appropriately, or if there is cause for concern, early interventions may be necessary and should be implemented as early in the process as possible. This will likely involve a formal screening, behavioral evaluation, and diagnosis process from qualified professionals.

Developmental screening tools are recommended for children at the ages of 9 months, 18 months, and 24 or 30 months, which are generally quick screens to assess for developmental delays and disabilities at these time points. The behavioral evaluation is more extensive in its assessment approach, and may include clinical observations, caregiver report, psychological testing, and speech and language tests. This type of evaluation may also involve a number of professionals who will comprehensively address these areas, including teachers, psychologists, doctors, and speech-language pathologists. Once results for the evaluation are gathered, a decision for any further testing, whether psychological or medical, will occur, and a formal diagnosis may be made thereafter based on *DSM-V* criteria (CDC, 2014b).

Early intervention services can help children from birth up to three years of age in terms of learning skills for language development, walking, and social interactions (CDC, 2015b). Other research has demonstrated that children with ASD who are between ages two to four will benefit from early intervention more so than older children with ASD receiving the same type of intervention, especially when intensive intervention has been implemented. The term “intensive intervention” generally refers to 15 hours or more of targeted therapy over the span of one to two years. In comparison to other special needs groups, early intervention also shows more rapid gains for the ASD population versus using the same or similar treatments for those with other neurodevelopmental disorders, such as severe mental retardation or cerebral palsy. In addition, early intervention can lead to significant improvements in development, cognition, and language areas, as well as improve social behaviors and decrease problematic symptoms related to autism (Rogers, 1996). Children who received early intervention for speech and language problems tended to outgrow these issues versus children who did not receive these therapies as early (Bitsko et al., 2016).

Developmentally, a child undergoes a significant amount of changes early in life. Therefore, “flagging” the symptoms and signs specific to ASD can be vital in recommending the most effective treatment or interventional approach. For example, a child not responding to his or her name by 12 months, repeating words over and over, exhibiting flapping or stimulating behaviors, and having extreme reactions to stimuli involving the senses are some red flags for a diagnosis of ASD (CDC, 2014b). Some early interventions are crucial because they can begin to address problems immediately rather than later when these problems may have already manifested into a greater severity of symptoms (Rogers, 1996).

Service frequency. When considering essential services, including instructional programming, a significant portion of time is often required on behalf of the child and family. For example, in one study (Kohler, 1999), parents reported that their children on the spectrum (ages ranging from 3 to 9 years old) and family received on average 6.44 different services and approximately 37 hours of intervention each week. For the child with ASD, these services specifically included school placement, therapy, speech or occupational therapy, and for other members in the family, services included care management, educational classes, respite care, sibling support, and mobile therapy. Other types of therapy being accessed by families included applied behavior analysis (ABA) or the Early Start Denver Model, which are interventions with substantial research to support their effectiveness (Autism Speaks, 2016b). These two programs utilize a behavioral approach that involves a professional who has specific training (CDC, 2015b).

Service expenditures. Along with the number of services being utilized comes significant costs for treatment and education of this population, with an estimated lifetime cost of $2.4 million for someone on the spectrum and $1.43 million for someone with ASD but without an intellectual disability (Buescher, Cidav, Knapp, & Mandell, 2014). This translates into an annual United States cost of approximately $236 to $262 billion for the treatment of children and adults on the spectrum, which includes all direct medical, direct non-medical, and productivity costs. These productivity costs specifically include costs associated with accommodation or residential care, special education, medical and non-medical services, parents’ productivity loss, and the individual with

ASD’s productivity loss (Buescher et al.). When looking at annual costs per family, a minimum of $17,000 is required to care for the child with ASD when compared to a child who does not have the diagnosis. These costs include care for the child’s health, education, and tailored therapy, not only for the child with ASD but also for family and caregiver (CDC, 2014b). Projected costs for the treatment of ASD have been forecasted as approximately $460 billion for the year 2025, an estimate that will likely outweigh projected costs for diabetes or ADHD, even with considering predicted prevalence rates for those populations (Leigh & Du, 2015).

In terms of functioning and severity, children on the spectrum range from low to high, which often dictates the types of services needed and typically received (e.g., a nonverbal child may need more speech intervention versus a child who has a mild verbal impairment and may not require those services). The *DSM-V* outlines three levels of severity for social communication and restricted, repetitive behaviors. Level 1 is “Requiring support” and Level 3 is “Requiring very substantial support.” A level 1 specifier shows the individual as having problems initiating social interactions as well as having problems transitioning from one activity to another. A level 3 specifier shows the individual as having very limited initiation of social interactions and may only respond to direct social approaches as well as experiencing great distress when a change in routine arises (APA, 2013). Given the severity from one child to the next, the need for services is still quite high for those who fall on the higher end of functioning or have a less severe form of impairment (Newschaffer & Curran, 2003).

State and National Level Standard Practice & Guidelines

Standards for ASD healthcare. "The world of the adult individual with autism is sorely underrepresented both at the policy level—federally and state—but most of all, in general" (Autism Speaks, 2016a). The statement comes from an individual whose brother is an adult with ASD. This type of qualitative information is vital in our understanding because it points out the lack of consistency in a standardized approach, comes directly from someone with a sibling on the spectrum, and shows his personal views in terms of necessary changes to public policy. Obtaining information from individuals who serve as care providers to those with ASD may provide insight into how services can and should be improved for this population.

History and evolving landscape of ASD healthcare. A number of initiatives, standards, guidelines, and recommendations have been proposed by federal agencies and organizations specific to ASD advocacy. Before 1981, autism was defined as a severe emotional disturbance. However, in 1981, the definition evolved to the category of other health impaired. This federal classification allowed for more program flexibility specific to the individual needs of the child, which was advantageous compared to the previous categorization that was more limited in its treatment population (Barlow, Raison, & Raison, 1981). Public Law 99-457, passed in 1986, supported the funding of preschool special education programs. Under this law, states receiving federal funding must provide free, multidisciplinary diagnosis, assessment, and appropriate public education to all three- to five-year-old children with disabilities. At that point in time, however, an agreed idea of what constitutes early intervention for children had not yet been achieved. Therefore currently, there is still a large need for effective early intervention programs, which has been a large responsibility of school systems and teachers (Congress of the United States, 1986).

Sperry et al. (1999) point out that, since the Individuals with Disabilities Education Act Amendments of 1997 (IDEA, 1997), Congress has highlighted the importance of more and effective collaboration between parents and providers in regard to service delivery systems. Based on IDEA, Public Law 105-17 defined autism as a developmental disability, with symptoms often apparent before age three (APA, 2013). In 2001, the No Child Left Behind (NCLB) Act was passed to ensure that all students would achieve proficiencies in reading and mathematics by the years 2013 to 2014. For those students with disabilities, including those on the autism spectrum, mainstreaming and including them in these assessments has placed accountability on teachers and school system administrators (Yell, Drasgow, & Lowrey, 2005). The Individuals with Disabilities Education Improvement Act (IDEIA) of 2004 was a reauthorization of IDEA of 1997, to ensure that infants, toddlers, children, and youths with disabilities receive services, with a focus on early intervention for those from birth to age two and special education and related services for those ages three to 21 (United States Department of Education, 2004). This includes a free and appropriate public education to meet the individual needs of children or adults and aids in their preparation for employment and independent living (CDC, 2014b).

The Interagency Autism Coordinating Committee (IACC) points out that the PubMed biomedical research literature exceeds over 11,000 journal articles on autism since January 2009. Since 2009, the number of published journal articles has more than doubled leading up to the year 2014. In addition, the IACC highlights the importance of how ASD research has evolved and where it currently stands, which accounts for increasing prevalence rates and updated *DSM* criteria (moving from version IV-TR to version 5). The IACC has also identified that ASD, along with other likely comorbidities and the resulting services needed, will require research studies in the areas of genetics, epidemiology, and neuroimaging (IACC, 2014). In one such study, the CDC is currently teamed up with the Study to Explore Development (SEED) to conduct research on environmental and genetic influences that may affect the causes and risk factors associated with ASD (CDC, 2014b).

Current policies for ASD. Over the last decade, federal acts have been proposed to address the increasing prevalence and associated costs of ASD, through research advocacy and monitoring efforts. These monitoring efforts include The Children's Health Act of 2000 (which established the National Center on Birth Defects and Developmental Disabilities at the CDC and authorized the establishment of Centers of Excellence at both CDC and the National Institutes of Health [NIH]) and the federal Combating Autism Act enacted in 2006, which enacted the IACC (NCSL, 2016). These federal acts frequently focus on and assess for areas including etiology, diagnosis, early detection, prevention, and treatment of autism.

CDC recommendations. The CDC provides current guidelines and recommendations for the ASD population that include standard developmental surveillance and screening practices and clinical practice recommendations for diagnosis and evaluation (CDC, 2015a). However, many states for which these guidelines have been proposed are still following their own practices at the state level, which may result in inconsistencies in care delivery. A number of states have proposed and implemented their own interventions to meet the needs of this population. For example, a majority of states have established a task force or commission, approximately half of the states have an active legislative standing committee to address autism needs and policies, and at least a dozen states have created a bureau or agency to administer or coordinate autism services. Some states, such as Arkansas, New Hampshire, New Jersey, and Utah, have developed registries for tracking diagnosis frequency and identifying where autism-related treatments are occurring (Easter Seals, 2016).

It is important to understand why differences among states are present. For example, the CDC created the Autism and Developmental Disabilities Monitoring (ADDM) Network as a collaborative effort among several states for the tracking and documentation of children on the spectrum throughout various communities, including prevalence rates. When looking at state-specific prevalence rates, Alabama, as an example, reported a much lower prevalence rate than the national rate (1 out of 125), whereas Arizona reported a higher prevalence rate (i.e., 1 out of 64) versus than the national rate, which was 1 out of 68 individuals at that time (CDC, 2014b).

Implementation and monitoring oversight. For society at large to understand and become educated about ASD, policy changes have been proposed to assess for improved and more effective interventions and services (Mereoiu et al., 2015). Doehring and Volkmar (2016) highlight the current gaps that exist between research and policy, which they mention are often overlooked, recommending that programs formally document service integration, research, and training techniques to further drive establishment of the broader policy changes. The strategic plan the IACC sets forth surrounds seven key questions, using a consumer approach that involves input from a variety of professionals (e.g., federal officials, researchers), caregivers, advocates and general community members, and those on the spectrum. These questions include: 1) When should I be concerned?; 2) How can I understand what is happening?; 3) What caused this to happen and can it be prevented?; 4) Which treatments and interventions will help?; 5) Where can I turn for services?; 6) What does the future hold, particularly for adults?; and 7) What other infrastructure and surveillance needs must be met? (IACC, 2014).

The questions also include affiliated aspirational goals, corresponding to each question: 1) Children at risk for ASD will be identified through reliable methods before ASD behavioral characteristics fully manifest; 2) Discover how ASD affects development, which will lead to targeted and personalized interventions; 3) Causes of ASD will be discovered that inform prognosis and treatments and lead to prevention/preemption of the challenges and disabilities of ASD; 4) Interventions will be developed that are effective for reducing both core and associated symptoms, for building adaptive skills, and for maximizing quality of life and health for people with ASD; 5) Communities will access and implement necessary high-quality, evidence-based services and supports that maximize quality of life and health across the lifespan for all people with ASD; 6) All people with ASD will have the opportunity to lead self-determined lives in the community of their choice through school, work, community participation, meaningful relationships, and access to necessary and individualized services and supports; and 7) Develop and support infrastructure and surveillance systems that advance the speed, efficacy, and dissemination of ASD research (IACC, 2014).

For its 2013 strategic plan update, the IACC additionally considered adults on the spectrum, as the previous plan's focus was limited to infants and children.

Current Gaps in Research

The need for education and training. Stakeholders are those who are the ones primarily invested in the child's care and well-being, which include the child's caregivers, professionals involved in his or her care, and even advocates (Sperry et al., 1999). It is important that these individuals are educated in the diagnosis, prognosis, and treatment of autism (Nissenbaum, Tollesfon, & Reese, 2002). In addition, educating the community is crucial in terms of planning health and educational services for this population through collaborative surveillance efforts (Rice et al., 2007). For example, The Treatment and Education of Autistic and Related Communication-Handicapped Children (TEACCH) program provides training opportunities on assessment, diagnosis, and evaluation (TEACCH, 2016). Other efforts, such as the CDC's "Learn the Signs. Act Early" program, provide resources to assist professionals in educating parents about ASD (CDC, 2014b).

The need for comprehensive care. Even with the effectiveness of early intervention for this population, finding one approach that could be applied to all on the spectrum remains to be determined (Baker & Abbott Feinfeld, 2003). Addressing every area of need for the child with ASD has been a continuing challenge among health professionals. Types of services specific to addressing the needs of this population include, but are not limited to, medical (e.g., pharmacological), behavioral (e.g., therapeutic, occupational therapy), communication (e.g., speech) and social (e.g., social skills training) needs (Autism Speaks, 2018b). In addition, there are many reasons why not all needs are being met, including issues accessing healthcare due to financial limitations or lack of available resources (Sharpe & Baker, 2007). For example, while some techniques demonstrate significant success with the child's social and behavioral adjustments in terms of positive outcomes, these interventions can be quite costly to implement (Buschbacher & Fox, 2003). System barriers may also constitute reasons for unmet needs, such as lack of administrative supports and essential resources and inconsistency in care delivery and perspectives (Bailey, Buysee, Edmondson, & Smith, 1992). Currently, much of early intervention programming is still conducted at the state level (CDC, 2015b), as the need for evidence-based early intervention continues to remain crucial to this population, in part due to rising prevalence rates. As a result, state-specific approaches have led professionals and organizations to apply their own processes to treat and address autism across the United States (Akshoomoff & Stahmer, 2006), which can be problematic, as there are no standardized methods at present.

The need for collaboration and communication. Currently, effective collaboration between families and health care providers overall is lacking (Kohler, 1999; Mereoiu et al., 2015). Changes to IDE now include a type of collaboration that involves parents and providers teaming up to determine the best practices and standards of care for ASD (Sperry et al., 1999). There is a significant educational process for someone who does not understand ASD, and it is often parents with a child on the spectrum who initiates much of their own education about the disorder. This likely involves spending countless hours researching information about the disorder, treatment options, and other considerations (Organization for Autism Research, 2018). Already having this information centralized will expedite the time families must spend to receive their answers and understand how to proceed moving forward.

A number of studies utilize the concept of a team approach, which is mainly apparent in the intervention utilized in the study. For example, one study involved a collaboration between speech-language pathologists and behavior analysts, where the behavior analysts taught applied behavior analysis (ABA) techniques to the speech professionals who were not familiar with ABA-based intervention (Autism Speaks, 2016f). In terms of supporting children diagnosed with ASD and their families, the collaboration and communication between these two groups of professionals can help set the stage for positive outcomes in a number of areas for the child with ASD, including improved communication, applied skills, and decreases in problematic behavior (Donaldson & Stahmer, 2014).

The need for continuation of services. Typically, after receiving the autism diagnosis for their children, parents find themselves unsure as to the next steps to take. It is vital to understand that simply delivering a diagnosis does not mean that the problem has been solved; rather, it has only begun due to the lifelong nature of the disorder. So, what happens after diagnosis? The parent is likely feeling overwhelmed after receiving the diagnosis news for his or her child, which in and of itself can be problematic (e.g., increased stress after hearing the diagnosis, uncertainty about how to best help the child); parents who receive the diagnosis news also immediately begin searching for ways to educate themselves about which services their children need (Sperry et al., 1999). Therefore, it is ideal for health professionals who deliver the news to then proactively work with the family, while aiding in the transitionary plans over the course of the child's life (Nissenbaum et al., 2002).

The need for transition planning. Providing a continual stream of services throughout the child's life, including into adulthood, is another of focus among health providers and families. The continuation of services is essential for this population, and transition planning is another area of focus both in terms of importance and the challenges presented. One example of this is demonstrated in Shogren and Plotner's (2012) study, where parents reported that post-graduation goals had not been established for the child upon graduation, which suggests issues with communication and collaboration for the transition planning teams. Therefore, recommendations for students and their families to collaborate with school and adult-oriented services early on in the transition process is essential (Shogren & Plotner, 2012).

Family perceptions of current services. Engaging families in the child's care is not only important, but also effective in terms of improved child outcomes (Bitsko et al., 2016). Although family education has been widely implemented and recommended and significant strides have been made in this area, caregivers still report the lack of collaboration with professionals who directly work with or care for the child (Kohler, 1999; Mereoiu et al., 2015). Additionally, families have reported experiencing difficulty in accessing services and having limited involvement in the child's treatment plan (Kohler, 1999). To examine parent perceptions, Kohler (1999) interviewed family caregivers to better understand the nature of early intervention services received by families of young children (i.e., aged 3 to 9 years of age). Kohler's study also sought to understand the nature and degree of family involvement in services, the methods providers have used with the families to ensure continuity of services, and they asked parents about the nature of their family problems and concerns with existing services. Following data collection, Kohler discussed that families required a number of different services and that families are involved with multiple providers for addressing various child issues. Data also revealed that families reported several issues, including services being ineffective in addressing what they were intended to treat, leading to parent dissatisfaction with services. Additionally, parents indicated accessibility issues when experiencing delays or difficulties getting their children an initial ASD diagnosis. In terms of collaboration, parents reported having little involvement with providers to meet and discuss intervention services or to observe providers conducting services with their children; also, parents reported very minimal interagency collaboration among providers.

Understanding the caregiver's perspective has been shown to provide vital information that should not be ignored. In addition to obtaining the care provider's opinion, incorporating what the caregiver has to say is undeniably crucial for gaining a sense of effective care. In their study, Sperry et al. (1999) introduced areas of convergent and divergent themes between parents and providers. While parents and providers tended to agree on a number of areas, including family support, early identification, and collaborative efforts, the areas of focus between the groups differed (i.e., families were more child-focused and providers were more service delivery-focused). It is also important to note areas of divergence among parents, which revealed issues relating to access, home-based programming, and law. Whereas, providers' divergence areas included quality programs/best practices and transition. These gaps in perception, while important to recognize, demonstrate that differences exist between parents and providers, which only strengthens an argument for collaborative efforts on the children's behalf as far as positive outcomes are concerned. As a result, understanding the satisfaction level of caregivers may help drive future policy changes (Kohler, 1999).

Approaches Implemented in Recent Years

One approach to effective collaborative care is the concept of a wraparound approach, which is family-centered and involves the family as well as other members, with the process typically facilitated by a resource coordinator (Becker-Cottrill et al., 2003). Team driven models have been strongly embraced as being effective for children with ASD, as the shift from a medical model has now progressed to a family focus process versus an expert-driven model. Similar to the idea of wrap-around services, it may be advantageous to integrate both types of techniques to add even more to the positive outcomes in families (Kohler, 1999).

Autism spectrum program centers and autism-related services have been increasing over recent years, due to the demands for care specific to the population (CDC, 2014b). While some centers are more comprehensive than others in terms of types of services provided, understanding what makes the program truly effective is important for demonstrating evidence-based practice (Crimmons, Durand, Theurer-Kaufman, & Everett, 2001). It is essential to understand that autism centers and those institutions providing autism-related care can vary in terms of types of services provided, in addition to determining which of those services are effective and which services could be improved (Kohler, 1999). Understanding the consistencies, as well as inconsistences, from one program to the next, may help fill in the gaps for service delivery, client satisfaction, and positive client outcomes.

Assessment of Existing Programs & Interventions

Types of current, comprehensive interventions. A number of facilities and programs exist for the treatment of the autism spectrum population. These include, but are not limited or inclusive to, medical centers that provide a diagnosis and medical care, ABA and other specialized therapy centers, specialty autism schools, and other autism service and support agencies. Several types of models and program interventions aim to provide a comprehensive concept in support of those individuals with ASD. The Autism Treatment Network currently has 14 established centers across the United States and Canada, consisting of physicians, researchers, families, and other medical professionals. This network strives to establish comprehensive care using a multidisciplinary approach driven by research and the resulting clinical, evidence-based practices, all while supporting and educating families through effective communication (Autism Speaks, 2016e).

Program quality indicators. Broadly speaking, the need to conduct program evaluation on autism centers is a vital process for improving service delivery in terms of making delivery mechanisms more efficient and less costly. This type of evaluation also captures whether the program is delivering what it initially intended to deliver. Additionally, program evaluation can present the community's, as well as providers', perceptions of the center, which may dictate future goal setting and direction for service delivery. As such, program and school models often differ from one center to another; however, overlapping areas are quite common (Crimmons et al., 2001).

Recommendations & Future Directions

The trend towards patient-centered treatment. The idea of using a patient-centered medical model has been established only in recent years. This model emphasizes identifying the individual needs of the patient by all involved in care, including caregivers, which shapes primary care in a comprehensive way. While there are challenges in terms of the level of care coordination for a patient-centered medical home, focusing on a unique model for autism that centers on care coordination and reimbursement may be the most effective approach (Golnick, Ireland, & Wagman Borowsky, 2009).

Current program initiatives. While a number of programs have been proposed to aid problems associated with ASD, the continuous improvement process of ascertaining the most comprehensive and effective care remains to be a central focus for this population. To date, there is no one program that has been able to address or meet all the needs of this population (CDC, 2014b); however, strides towards the most comprehensive care utilizing a collaborative approach continue to form over time. Moving away from the traditional medical model and placing an emphasis on patient- or client-centered treatment may also prove advantageous and beneficial, as it involves direct collaboration among various professionals and can help streamline the process for the continual receiving of care (Golnick et al., 2009).

A family focus model shows great promise in demonstrating positive outcomes, not just for children with ASD, but also for the family unit as a whole. Similarly, CDC researchers have reinforced this idea of a family focus model but in addition to a focus on the child's healthcare, in order to best promote that child's development (Autism Speaks, 2016d). In addition to understanding which approaches are effective, gathering information and data points from other areas is just as important. Among these are patient satisfaction, quality of life assessments, and family experience (Kincaid, Knoster, Harrower, Shannon, & Bustamante, 2002).

An additional step in gathering data on satisfaction is to directly query the source, the individual diagnosed with ASD. This will give that individual more of a say in his or her care, plus it will allow that person to be more directly involved in treatment plans, goals, etc. A consideration, however, is understanding when this may or may not be possible depending on the severity level and cognitive capacity of that person, which would then point to the caregiver or family as being the representative for those cases (Nys, Welie, Garanis-Papadatos, & Ploumpidis, 2004). Obtaining multiple perspectives, including the child’s family but also the professionals who may oversee the child’s care, is essential for a more comprehensive understanding of effective care for the ASD population (Mereoui et al., 2015; Sperry et al., 1999). Considering all possible sources of data pertaining to the child will fall in line with a patient-centered model driven by a team approach.

Purpose

With the prevalence of children being diagnosed with ASD, there are increasing expectations for autism-service agencies to provide effective and comprehensive services. Additionally, it is vital that service providers and families are well-equipped with the knowledge of appropriate evidence-based practices for meeting the needs of this challenging population (Mereoiu et al., 2015). The lack of research addressing consistent, current practices for service provision of ASD as well as actual versus perceived gaps in care heightens the need for this research. It is also important to understand that services geared towards the ASD population have changed over the years, making it vital to understand how these changes have impacted service delivery and perceptions of care.

A collaborative approach. For the current study, the researcher implemented a collaborative perspectives approach by obtaining perceptions of the family caregivers and service providers surrounding the care of individuals with ASD. The goal was to gather an accurate, in-depth, and comprehensive perspective on how to effectively address and meet the individual's needs. This will fill a gap in the literature, as parents often report a lack of collaboration with professionals (Kohler, 1999). In addition to the questions outlined in Kohler's (1999) *Survey for Family Services*, two additional areas of emphasis for the present study centered on communication and collaboration. Therefore, these two constructs were also included in the modified open-ended survey, as additional areas of interest when considering what constitutes effective and comprehensive care for autism service delivery.

Defining collaboration and communication. Collaboration has been defined in a number of ways. From a general viewpoint, collaboration can be classified as a partnership between parents and professionals and among professionals from different agencies who work together with mutual respect (Sperry et al., 1999). In looking specifically at service delivery, collaboration is often viewed in terms of care coordination, which is "a process that facilitates the linkage of children and their families with appropriate services and resources in a coordinated effort to achieve good health" (American Academy of Pediatrics, 2005, p. 1238). Because the purpose of the present study examined perceptions of service delivery, collaboration was investigated in terms of care coordination and was labeled as such in this way. When defining communication, it is often included as a goal (e.g., effective communication among health professionals and organizations involved in the child's care) in a successful care coordination model, but communication can also pose as a barrier when it is not present (American Academy of Pediatrics, 2005).

Research Questions

This qualitative research study explored the perceptions and experiences of both family caregivers and service providers regarding service delivery for individuals with ASD. In addition to examining experiences and perceptions of service delivery for both groups, the following research questions were also examined in detail:

1) What are the components of effective care coordination as perceived by family caregivers and service providers?
2) What are the elements of care coordination and communication that affect family caregivers' degree of satisfaction with services?
3) In the areas of care coordination and communication, what are the recommendations of family caregivers and service providers?

Chapter Three: Methodology

This chapter consists of eleven sections: a) rationale for the qualitative approach, b) research design, c) method, d) framework for the study, e) research questions examined, f) study procedure, g) participant recruitment and enrollment process, h) instruments utilized, i) data analysis conducted, j) trustworthiness measures employed, and k) the researcher's position. The research method and the rationale for using a qualitative approach are explained. The framework used to conduct the qualitative research interviews is provided, along with the research questions of interest. The participants and the methods for data collection in which they were interviewed are described. The procedures used to collect the data and the method used to analyze the data are also described. Lastly, because the study is a qualitative research project, trustworthiness measures that were employed and the researcher's position are also presented.

Rationale for the Qualitative Approach

A qualitative research approach was well-suited for the purposes of this study, as it allowed participants to share their experiences in service delivery, express areas of dissatisfaction, as well as areas of satisfaction, and offer recommendations for improving services. When conducting qualitative research, the researcher does not manipulate the areas of interest; rather the researcher attempts to understand how perceptions naturally occur (Merriam & Tisdell, 2016). The overall purpose for using a qualitative approach is to gain an understanding of natural experiences, which may include perceptions, beliefs, and opinions. Therefore, qualitative research does not derive its findings through the same statistical procedures or quantification used in quantitative analysis (Golafshani, 2003). Instead, qualitative data are quantified into concepts and relationships as a way to organize and present findings (Strauss & Corbin, 2007).

To capture data in a qualitative manner, the use of an open-ended survey for the present study allowed participants to express their personal experiences with service delivery. Information coming directly from the source follows the concept of the *voices of parents and providers* (Sperry et al., 1999) by understanding how families are affected personally and how service providers are affected professionally. By gathering the perceptions of those who are directly involved with individuals with ASD, it was envisioned that the data collected and the interventions identified would provide valuable information when developing and implementing effective and comprehensive service delivery for the future.

Design

The basic qualitative approach. The researcher conducted a basic qualitative research design for the purposes of this study. Basic qualitative research designs are common to applied fields of practice, including administration, health, and psychology through use of interviews, observations, and documents (Merriam & Tisdell, 2016). The basic qualitative design allows the researcher to ask participants to share in-depth descriptions of their experiences, with goals of understanding: a) how people interpret their experiences, b) how they construct their worlds, and 3) how meaning is attributed to their experiences (Creswell, 2007). Because the researcher seeks to understand how participants make meaning of their experiences, the rich and thick descriptions provide the necessary information to search for reoccurring themes within the data. The overall goal of using a basic qualitative approach is to understand how people make sense of their lives and experiences (Merriam & Tisdell). A basic qualitative design is also known as descriptive qualitative research, because it allows the researcher to present findings through detailed and descriptive summarizations of information gleaned from the data collected (Merriam, 2002).

Method

In line with a basic qualitative approach, the method utilized was an open-ended survey technique. Research questions are generally open-ended to gain an understanding of the specific experiences of participants (Merriam & Tisdell, 2016) and to ascertain commonalities of individual experiences under a thematic approach. A standardized open-ended survey aims to elicit as much detailed information from participants as possible, but it also allows the researcher to probe further during follow up as the researcher deems is needed. Since all participants were administered the same sequence of questions, the open-ended survey also allowed for a wide range of responses while minimizing bias (Turner, 2010).

The basic qualitative method followed these five concrete steps: a) collection of verbal data, b) reading of the data, c) breaking of the data into some kind of parts, d) organization and expression of the data from a disciplinary perspective, and e) synthesis or summary of the data for purposes of communication to the scholarly community (Giorgi, 1997) and is the generally accepted method for capturing data for all types of qualitative studies (Merriam & Tisdell, 2016). The researcher verbally asked the survey questions to participants using the open-ended interview, and participants provided verbal responses for each question administered. During administration, the interviews were audio recorded to be transcribed at a later date.

Following all interview administrations, participant responses to the questions were transcribed from the saved audio recordings. Then, the researcher attempted to make global sense of the data by reviewing the interview as a whole for each participant. After this, participant responses were divided into parts, also known as significant statements, where the researcher isolated the meaning of verbatim responses to extract the essence of what was being conveyed. Once the responses were assigned significant statements, the significant statements were transformed into themes for reporting purposes of this study (Creswell, 2007).

Framework for the Study

In Kohler's (1999) study, a number of parents reported a lack of collaboration with professionals. Centers and services devoted to ASD have significantly changed since the time of that study, so a reexamination of responses from participants whose families currently utilize services geared toward ASD is imperative. As a qualitative measure, Kohler's survey was created based on a review of the literature to examine the structure and quality of intervention services received by children with ASD and their families. A number of studies show the importance and benefit of obtaining qualitative data from individuals. For example, interviews with parents and service providers (Sperry et al., 1999) may serve as a way to demonstrate the importance of conducting qualitative analyses, suggesting that parents and service coordinators can each provide valuable information on the underlying factors that influence collaboration (Dinnebeil, Hale, & Rule, 1996).

Adapting and extending a previous study. Kohler's (1999) survey, *The Survey for Family Services* (see Appendix A), was created specifically for families of children with ASD and pervasive developmental disorder (PDD). Borrowing from Kohler's survey, the present study sought to administer similar survey questions to participants and to extend the data collection into the area of autism-related services; thus, service providers were also recruited as participants to aid in a more comprehensive understanding of service delivery. Therefore, the survey employed in Kohler's study was adapted to include questions specific to service providers, in addition to those questions already structured for family caregivers. Involving service providers was a recommendation set forth by Kohler for understanding service provider collaborations and relationships with family members. The questions administered in Kohler's study remained the same for family caregivers, but additional questions were tailored specifically to service providers to elicit information about how services were provided and delivered, rather than received.

Participants

Unlike Kohler's (1999) study that recruited parents of children from both preschool and school-age groups, the current study focused only on an age group that does not typically involve early intervention services. The age group of 7 to 21 years of age was chosen to investigate a common set of services received, which would likely be different in a younger age group (i.e., children under 7 years of age); in fact, Kohler presented data for the preschool and school age groups specifically to demonstrate a significant difference in total hours of intervention received on a weekly basis. Because of the difference in the services delivered to preschool age versus school-age children, the researcher sought to recruit participants of children who likely received similar types of services. Therefore, to ensure consistency, the age range of 7-to 21-year-old individuals with ASD was chosen. To be included in the study, family caregivers were required to have a child with ASD in this age range, and service providers were required to deliver services to individuals in this age range. In addition to family caregiver participants self-identifying as having a child with ASD, their child also needed to be receiving ASD-related services within six months of the study interview occurring.

Purposeful sampling (Creswell & Clark, 2007) was utilized, as the study specifically targeted service providers and family caregivers of individuals with ASD associated with autism-service agencies. Recruitment of participants involved working primarily with autism agencies that informed service providers and family caregivers about the study being conducted. These agencies provided contact information of interested participants to the researcher. Once contact information was provided, the researcher directly contacted potential participants through either a phone call or email to gauge participation interest.

The sample size of a basic qualitative study typically ranges from 6 to 10 participants (Haase, 1987), with a target goal of 10 participants for the current study. For the study, 10 service providers and 12 family caregivers were recruited, and of those individuals, five service providers and five family caregivers agreed to participate and were subsequently enrolled. Family caregivers included a variety of individuals who primarily raise and care for the individuals with ASD in their home environments. Service providers included a variety of professionals who directly work with individuals with ASD at their professional place of employment (e.g., psychologist, applied behavior analysis (ABA) therapist, occupational therapist, mental health counselor). Service provider and family caregiver demographic information is presented in the Results section, which provides a more detailed description of the participant sample.

Ethical considerations. To address concerns about participant confidentiality, all identifying information was masked and all participants received a unique study identification number. A consent form was given to the participants to detail the confidentiality of the study. The audio recordings from the phone interviews were saved digitally and secured in an encrypted computer program file. Audio recordings and transcripts were identified by study numbers only to maintain confidentiality. The data will be destroyed seven years after data collection.

Instruments

Two main instruments were used for the research study: a demographic survey and an open-ended interview survey. The first instrument was a demographic survey that contained a set of questions specific to either a family caregiver or a service provider. The second instrument was an open-ended survey tailored to either a family caregiver or service provider and aided in guiding participants through a series of questions for data collection purposes. The majority of questions for the open-ended interview were the same for each participant group but were tailored to either a family caregiver or a service provider. Therefore, the main open-ended survey was separated to acknowledge each participant group. Survey versions used for family caregivers and service providers can be found in Appendices B and C, respectively. The open-ended survey instrument allowed the researcher to ascertain experiences and perceptions of both groups of participants and is a procedure consistent with the application of qualitative research (Creswell, 2007).

Demographic survey. The demographic survey contained questions specific to participant group (e.g., service provider or family caregiver) and was completed by all participants recruited for the study. Questions for the family caregiver included items such as gender, age, ethnicity, household annual income, education level in years, and marital status. The demographics survey also assessed information about the participant's child, including the age of diagnosis, the individual who made the diagnosis (e.g., psychologist, school faculty or professional, medical professional), and the child's current age in years. Questions for the service provider included items such as gender, age, ethnicity, professional title, years of experience, and involvement level at the agency where autism-related services are delivered (e.g., areas of specialty, duties). The demographic questions were administered and are described in more detail in the results section. The demographic surveys for family caregivers and service providers can be found in Appendices D and E, respectively.

The surveys of family services for family caregivers and service providers. Permission to use and modify *The Survey for Family Services* was granted for this study (F. Kohler, personal communication, May 17, 2016). All questions from *The Survey for Family Services* were administered to family caregivers in the current study. These same questions were modified and tailored to also include service providers who deliver services to individuals with ASD between 7 to 21 years of age. Additional survey questions regarding communication and care coordination outside of *The Survey for Family Services* were also asked to both participant groups. Specifically, these additional questions focused on participants' perceptions of: a) relationships and care coordination (e.g., importance and frequency of working with the family caregiver or service provider, working together to meet the needs of the child), and b) communication methods and their effectiveness (e.g., how information is delivered, satisfaction with communication, preferred methods). This type of information has been used in other studies to demonstrate what comprises effective collaboration and communication between family caregivers and service providers (e.g., Dinnebeil et al., 1996). For the current study, Kohler's *Survey for Family Services* was retitled to encompass two separate surveys based on participant group: *The Survey of Family Services for Family Caregivers* and *The Survey of Family Services for Service Providers*. These separate surveys acknowledge the question modifications tailored to service providers, as well as the questions of communication and care coordination added to both surveys.

The Survey of Family Services for Family Caregivers, which targeted family caregivers, contained a total of 21 items that encompassed six categories: 1) Type and amount of services received (e.g., What is the nature of autism-related services received by families of children with ASD? How much and what type of services are received?); 2) Accessibility of services (e.g., What is the nature and degree of families' involvement in their services?); 3) Nature and degree of family involvement (e.g., What methods do providers use to ensure that their individual services have continuity or are organized around a common set of child needs and capabilities?); 4) Continuity of services received from different providers; 5) General satisfaction and concerns (e.g., What is the nature of families' problems and concerns with existing services?); and 6) Communication and care coordination recommendations and experiences with service providers.

The Survey of Family Services for Service Providers, tailored to service providers, contained a total of 20 items that encompassed six categories: 1) Type and amount of services delivered (e.g., What is the nature of autism-related services delivered by service providers of children with ASD? How much and what type of services are delivered?); 2) Accessibility of services (e.g., What is the nature and degree of the service provider’s involvement in the services?); 3) Nature and degree of family involvement (e.g., What methods do service providers use to ensure that their individual services have continuity or are organized around a common set of child needs and capabilities?); 4) Continuity of services received from different providers (e.g., As a service provider do you ever ask family caregivers about the services that they receive from other agencies?); 5) General satisfaction and concerns of family caregivers (e.g., What is the nature of your perception on family caregiver problems and concerns with existing services?); and 6) Communication and care coordination recommendations and experiences with family caregivers.

Procedure

After obtaining Institutional Review Board (IRB) approval from WKU (see Appendix F), a list of autism-related centers was identified from which to recruit potential participants. Agencies that provide autism-related services, as opposed to other facilities such as schools and hospitals, were specifically chosen, as they provide services tailored to ASD, which likely provides more comprehensive services for meeting the needs of this population. Specifically, agencies that provide more than one autism-related service and organizations that serve the ASD population were identified. Potential participants were also identified through verbal referrals of colleagues and supervisors. At first contact, agency directors, supervisors, and colleagues were provided with an introduction to the project’s intended efforts and goals. After they approved the recruitment process and discussed the study with service providers and family caregivers, potential participants were then contacted for participation. The recruitment strategy did not follow random sampling of the population, and instead, participants were self-selected through their interest in the study. Additionally, for the purposes of this study, the researcher did not attempt to match up service providers and family caregivers; rather, participants were chosen based on their interests in participating and sharing viewpoints of service delivery.

After the researcher personally discussed the study purpose and procedures with potential participants, and before any data collection occurred, individuals who agreed to participate reviewed and signed the informed consent document (see Appendices G & H). This document included instructions, an explanation of the study, the benefits of participation, information regarding limits of confidentiality and freedom to withdraw from the study, and the study instruments to be completed. In this document, the researcher also sought participant permission to audio record the session by having participants signing their initials on the informed consent document to indicate their agreement. To protect confidentiality, the only document that contained participant names was the informed consent form, and other documents utilized a study code for confidentiality purposes. Any questions that arose either during the informed consent process or the study procedure were addressed by contacting the researcher.

After collecting the signed informed consent document, participants completed the demographics survey so that the researcher could better understand the recruited population at hand. These questions were asked of participants through an online Qualtrics survey through the researcher’s university. For inclusion purposes, all participants were over the age of 18 years old, which was verified through completion of the demographic survey. Phone meetings to conduct the interviews were also scheduled at this time. Once the meetings were scheduled and prior to conducting the interviews, participants were sent the interview questions ahead of time so that they could review and consider the survey questions beforehand.

During their scheduled phone interviews, all participants were administered the open-ended survey with the researcher. The open-ended survey for each group took approximately 30 to 60 minutes to complete. Each survey was conducted with one family caregiver or service provider. The responses were audio recorded and documented during the interview and then transcribed and coded after the interview had concluded. In addition to telephone surveying as the method for data collection, notetaking to capture the survey responses also occurred.

Data Analysis

The purpose of a basic qualitative analysis is to identify and explore subjectively a concept, idea, or experience of each participant and then compare similar themes to other participant responses (Merriam & Tisdell, 2016). Consistent with the basic qualitative approach, the researcher analyzed participant responses and specific statements from the survey to provide an understanding of how service delivery was experienced. Analysis was conducted by organizing the data, coding the data, and then presenting the findings in a discussion format. The data analyses followed these steps set forth by Creswell (2007).

First, bracketing was employed, which helped the researcher set aside any personal bias that could have interfered with study results. The bracketing of experiences, including potential biases about autism-related service delivery, can be found at the end of this chapter. Second, after responses were transcribed, significant statements were created, which pulled the core meaning from individual verbatim responses. This step is also known as horizontalization to allow the researcher to create a data set of non-repetitive and non-overlapping statements (Creswell, 2007). Third, clustered themes were created based on the significant statements, and as themes emerged from the analysis of the data, they were coded (Creswell, 2013). Following this, themes were finalized with the researcher's committee. Finally, a summarized description of each theme to capture the meaning and essence of participant experiences was provided (Creswell, 2007), which included an operational definition for understanding what comprised the theme category. Additionally, descriptive statistics and frequencies from the demographic survey data were reviewed and presented to identify the study population at hand. Demographic information and survey data that involved frequency counts were calculated.

Trustworthiness Measures

Qualitative research designs must include validity and reliability measures for ensuring that empirical nature of the research is credible and trustworthy (Brantlinger, Jimenez, Klingner, Pugach, & Richardson, 2005). Quality criteria for establishing trustworthiness include these four methods: a) credibility (e.g., conducting appropriate and well-recognized research methods) to support internal validity, b) transferability (e.g., providing context through background information and detailed descriptions of the research areas studied for comparison purposes) to support external validity or generalizability, c) dependability (e.g., in-depth methodology description for easily repeating the study) to support reliability, and d) confirmability (e.g., triangulation methods to reduce researcher bias, admission of researcher's beliefs and assumptions) to support objectivity (Shenton, 2004). Strategies within each of these four trustworthiness areas were employed and are described in further detail below.

Credibility. For the study, several credibility measures were employed, including adoption of appropriate, well-recognized research methods; data triangulation; strategies to help ensure participant accuracy of responses; disconfirming evidence; peer scrutiny of the project; and background, qualifications, and experiences of the researcher.

Adoption of appropriate, well-recognized research methods. The researcher employed credibility measures by following an open-ended survey method, which is a common, appropriate approach in qualitative research (Merriam & Tisdell, 2016). The questions administered in the study were borrowed from a previous study (Kohler, 1999), and questions regarding communication and care coordination that were added to the study survey arose from existing research and operational definitions found in the literature (Shenton, 2004).

Data triangulation**.** An audit trail containing all participant responses was documented, which included field notes, the saved audio recordings, as well as transcriptions of each phone interview. Reliability was enhanced by obtaining detailed field notes that included writing down participant responses as they were occurring, using a good-quality recording device, and transcribing the recording to ensure accuracy of responses. Also, the audio recording was transcribed to indicate the pauses and overlaps during the survey (Creswell, 2007).

Strategies to help ensure participant accuracy of responses. Another credibility measure employed was to promote participant accuracy of responses. The researcher discussed the voluntary nature of the research to allow participants an opportunity to refuse participation at any point in the project and be able to withdraw from the study if desired. This helped ensure that participants were genuinely willing to participate of their own will. Participants were also encouraged by the researcher before the interviews were conducted to provide accurate responses about their experiences during the phone interview. Additionally, the researcher made attempts to establish meaningful rapport and provided information, which included disclosing professional status. This was done to aid in participants being able to speak freely and without fear of losing credibility in the eyes of an authority figure (Shenton, 2004).

Disconfirming evidence. After themes were created based on significant statements, the researcher reviewed potential outliers in the data, also known as negative or discrepant case analysis. Some outlier statements are also presented in the Results section, along with the common statements from the analysis, for explaining areas where there may have not been complete consensus in a given area (Brantlinger et al., 2015).

Peer scrutiny of the project. A peer research team was employed to help build credibility into the study. Committee members participated in the data analysis conclusions to help reduce biases and idiosyncrasies regarding the analyses and interpretations. This included the members working together by rechecking data and discussing data and theme coding in order to achieve reliable results (Brantlinger et al., 2015). The peer research team consisted of the primary researcher and three other members. As the primary researcher, I am a graduate student in my sixth year of a Psy.D.

program in Clinical Psychology at Western Kentucky University. Three additional peer research team members are active faculty members at universities who represent fields of Psychology, Teacher Education, and Counseling, with one member having knowledge in policy and practice and the other two members having experiences working with the ASD population. The peer research team assisted in the analysis of themes using intercoder agreement once all interviews were transcribed (Creswell, 2007).

Background, qualifications, and experience of the researcher. The researcher has received a number and variety of professional experiences working with the ASD population, including various professional work settings (university, autism center, hospital, private practice), collaborations with different service providers (e.g., clinical psychologists, directors, researchers, neuropsychologists) and families, and with a diverse range of individuals with ASD (e.g., children as young as 7 years old to college age, mild to severe impairment).

Transferability. The use of thick, detailed descriptions of the phenomenon studied was also employed. Detailed descriptions of participant responses were included as part of the results for the study. Even though generalizability is not a goal of qualitative research, the researcher attempted to generalize, or make conclusions about the findings by connecting the information to existing literature. Specific cases were also documented for particularizability, which determines the degree of transferability to other situations (Brantlinger et al., 2015).

Dependability. The researcher maintained a detailed and complete audit trail of each step of the research process to help confirm the findings and to strengthen dependability of the study, which also included field notes during data analysis. This process allows for replicability for future studies (Shenton, 2004).

Confirmability. Measures of confirmability were also employed in the study, including investigator triangulation for reducing potential investigator bias. This involved attempts to be neutral when analyzing responses and not be affected by researcher bias, motivation, or interest, in addition to two team members participating in coding the transcribed interviews. Additionally, no conflicts of interest were present. Two reviewers also coded the data for reliability purposes, with the goal of achieving at least 80% interrater reliability agreement. A percentage at or above 80% reflects good percentage agreement among raters (Bradley, Curry, & Devers, 2007). To doublecheck accuracy, each transcription was reread while listening to the corresponding recorded interview. Additionally, member checking was employed for verification of the data, whereby the research committee members were consulted throughout the data collection and analysis procedures for ensuring data accuracy, reliability, and identifying any potential bias in the data analysis (Brantlinger et al., 2015).

Researcher's Position

Creswell (2007) discussed the importance of bracketing to help the researcher set aside any personal bias that may interfere with the study results. To bracket or set aside personal biases, the following narrative is included.

As the primary researcher, I have had many professional experiences working with individuals diagnosed with ASD, their families, and a variety of service providers working with this population. My first professional experience was working with a 12-year-old boy diagnosed with ASD in his home environment. The experience took place as part of course credit during my junior and senior year as an undergraduate college student when I majored in Psychology. During this experience, as a tutor, mentor, and social skills trainer to him, I gained firsthand knowledge and exposure of what ASD meant to the affected child and the family unit, how the diagnosis impacted the family, and the resulting requirement for a number and variety of services the child and his family utilized on a weekly basis. While this child and his family utilized many different types of services, these services may or may not apply to other children on their spectrum who may require an entirely different set of services.

From my experience working with this child, other opportunities to work with the ASD population followed, including working at an autism center while completing a master's degree in Clinical Psychology, working in a hospital setting as a research coordinator, completing a therapy practicum at an autism center while enrolled in my current doctoral program, and my current work as a certified psychological assistant in a private practice setting. During all of these professional experiences, discussions about service delivery implications with the ASD population, including service provider and family caregiver perceptions, were common. While these discussions, encounters, and interactions have provided me with an idea about service delivery, they may not reflect all ideas about services, as there could be other viewpoints and experiences to consider.

Conflict of interest assessment. While the majority of service provider and family caregiver participants were recruited around the area where the researcher worked professionally, the researcher did not concurrently work with any participants and was not familiar with any potential participants on a more personal level. Had the researcher have known any potential participants on a more personal level, those potential participants would not have qualified for the study, in an attempt to minimize bias. Additionally, the researcher attempted to maintain neutrality by adhering to the role of observer as much as possible, allowing only for participant beliefs, perceptions, and experiences to come across during the interviews.

Chapter Four: Results

The analysis was completed using a basic qualitative design. As stated by Merriam and Tisdell (2016), in-depth interviews allow a researcher to understand participant experiences based on a targeted topic area. In this study, the focus was on service delivery experiences with the ASD population. Qualitative research uses the concept of collecting detailed interview information to understand participant experiences and perceptions (Moustakas, 1994). All participant semi-structured interviews occurred by phone, during which the conversations were documented through audio recordings, and were then transcribed after the interviews had concluded. After reviewing each transcript as a whole and in parts, verbatim statements and/or segments were identified, upon which significant statements were created to grasp the essence or main point of each data point.

Following the creation of significant statements, each statement was assigned to a thematic category that appeared to best represent the concept being conveyed from life description, which follows a common approach across qualitative research (van Manen, 1990). After thematic statements were assigned, a committee member, in addition to the researcher, reviewed both the significant statements and thematic statements that were created to serve as an initial reliability check. Following the reliability check, the verbatim information, significant statements, and thematic statements were again reread within the context of the whole interview to uncover essential themes. The research team then convened to discuss the proposed essential themes to again employ reliability checks and data validity, during which the themes were finalized for the study.

Description of the Participant Sample

For the basic qualitative design, 10 participants (five service providers and five family caregivers) were recruited and enrolled in the study through purposeful sampling based on existing relationships, relevant experiences, and willingness to share ideas, beliefs, and important information. After signing the informed consent form, all participants were provided an online link to complete the demographic survey using a university-based data collection interface, Qualtrics. Following completion of all participant responses, a report was run for each group for a review of their demographic results. All participants, (family caregivers and service providers) resided in the northern and southcentral areas of Kentucky. The service provider sampling included a variety of professions, with no one profession overlapping another. Of note, while a pediatric dentist profession is not typically associated with autism-related services, this participant was still included in the study sample, as this individual’s experiences centered on tailoring and delivering dentistry services specific to the ASD population.

All service providers were female, and most identified with a White/Caucasian ethnic background (N = 4), held a full-time (versus part-time) job position (N = 4), and provided services in the Southwestern region of Kentucky (N = 4). The age of providers ranged from 38 years to 67 years old. Years of experience in their current role ranged from 1 to 43 years, and years of working specifically with the ASD population ranged from 5 to 43 years. Typical work week percentage of direct service involvement with the ASD population ranged from 10 percent (pediatric dentist) to 95 percent (psychologist), and the weekly number of individuals with ASD provided with direct services ranged from 4 (occupational therapist) to 40 (pediatric dentist) individuals. Table 1 displays some selected demographic information for this group.

Table 1

Service Provider Demographics

Service Provider	Profession	Years of Experience in Current Role	Years of Work with ASD Population
1	Occupational Therapist	43	43
2	Psychologist	4	18
3	Administrator	1	22
4	Pediatric Dentist	4	11
5	Applied Behavior Therapist	5	5

Family caregiver participants consisted of mostly females (N = 4), who reported being married (N = 5), and ranged in age from 38 to 47 years old at the time of the interview. The children for whom the interview surrounded and for whom family caregivers shared their experiences regarding service delivery were mostly males (N = 4), and their ages at the time of interview ranged from 11 to 18 years old. The age at which the child was diagnosed with ASD ranged from 28 months to 96 months, and the professional who made the diagnosis included medical professionals (N = 2), psychologists (N = 2), and a public health professional (N = 1). Table 2 displays some selected demographic information for this group.

Table 2

Family Caregiver Demographics

Family Caregiver				Child	
ID	Gender	Age	Ethnicity	Gender	Age
1	F	42	White/Caucasian	M	13
2	F	42	Two or more races	M	18
3	M	47	White/Caucasian	F	13
4	F	47	White/Caucasian	M	11
5	F	38	White/Caucasian	M	16

A question not used in the theme analysis and asked to family caregivers to determine types of services utilized was: "What services has your child received during the past six months?" When posing this question, family caregivers reported on the type of service, the providing agency, frequency for which the service was provided, and where the service occurred (e.g., home, a clinic setting, school environment). This question allowed the researcher to better understand the number of services each family required, in addition to the frequency of each service (e.g., 1 hour per week vs. as needed) and the method by which services were generally paid. Family caregivers reported a variety of services used by their children (e.g., counseling, special education service, in-home care, speech and occupational therapy), which also resulted in differences in the amount of services they received (e.g., weekly, monthly, as needed).

In addition, family caregivers were asked how they generally paid for service their family utilized. Most family caregivers responded with insurance as the primary payment method for the services their child receives; in addition, some services were free due to state funding (e.g., educational services, Michelle P. Waiver) coverage. Table 3 lists the types of services, service frequency, and payment method reported by family caregivers.

Table 3

Types of Services Accessed, Frequency, & Payment Method

Family Caregiver	Services Child Received Over the Past 6 Months	Service Frequency	Payment Method
1	Occupational Therapy	1 Hour Per Week	Insurance
	Applied Behavior Analysis	1 Hour Per Week	Insurance
	Mental Health Counseling	1 Hour Per Week	Insurance
	Special Education Services	1 Hour Per Week	State Funded
2	Speech Therapy	1 Hour Per Week	State Funded
	Occupational Therapy	1 Hour Per week	State Funded
	Medical Care (i.e., endocrinology, pulmonology)	As Needed Basis	Insurance
3	Mental Health Therapy	Once Per Month	Insurance
	Psychiatry (i.e., medication)	Once Every 3 Months	Insurance
	Behavior Therapy	Every Other Week	Insurance (Medicaid)
	Case Worker Services	Once Per Month	Insurance (Medicaid)
4	In-Home Support Services	2.5 Hours Per Day	Michelle P. Waiver
5	School Accommodation Services	Every Day (Hours Vary Based Upon Need)	State Funded

Regarding payment method for services delivered, service providers were asked how services they provide are generally paid for by families (e.g., insurance vs. out-of-pocket). Depending on the service provided, payment methods the service provider received ranged from mainly insurance (N= 3) to a monthly membership to free in cost. Table 4 below presents the types of payment methods utilized by each service provider.

Table 4

Service Provider Payment Method for Delivered Services

Service Provider	Profession	Payment Method
1	Occupational Therapist	Insurance Out-of-Pocket
2	Psychologist	Free Out-of-Pocket
3	Administrator	Monthly Membership
4	Pediatric Dentist	Insurance
5	Applied Behavior Analysis Therapist	Insurance Out-of-Pocket

Summary of the Qualitative Results

Themes were determined after looking at the frequency of thematic statements belonging to a broader, more over-arching concept, which resulted in five top themes, in addition to other less-occurring, smaller theme groups. After the top five themes were identified, additional members of the committee reviewed all themes and their corresponding thematic statements for reliability checking and agreement purposes. Once agreement was established among all committee members and the researcher, the themes for each participant group (i.e., service providers and family caregivers) were finalized. Only the top five themes will be reviewed in detail for reporting purposes to meet dissertation requirements, and frequency counts of theme passages are presented below.

It is important to note that, even though some of the interview questions were set up to target a particular area (e.g., accessibility of services, education) within service delivery, the theme analysis was conducted across *almost all* questions for determining the common themes that emerged overall. Upon conducting the analysis, a variety of themes within each of the questions tended to emerge. In other words, multiple themes were present within answers to a given question. For example, questions geared towards accessibility of services included responses surrounding barriers to accessibility as expected, but other themes such as collaboration, education, and family support also tended to emerge. Additionally, elements of care coordination, which was the overarching research area examined for the study, are evident not just in questions pertaining to that area but are also found within participant responses for other questions.

Each essential theme and the thematic statements that compose the themes are presented with specific descriptives from individual participants. The interviews consisted of 20 open-ended questions to service providers and 21 open-ended questions to family caregivers to provide a consistent structure of questions asked across all participants, in addition to be able to review responses at the group level. The themes that emerged within each group are discussed below, with additional specific examples and quotes to best represent, capture, and portray the main message and actual dialogue of participants. Actual statements from participant responses lend to establishing credibility in the data collection and analysis process and are also presented as part of the findings. For the purposes of the study, two of the three research questions (i.e., effective communication and recommendations) were included in the thematic analysis but are also separately and specifically highlighted below under the Collaboration theme for both groups. Additionally, other questions were not included in the thematic analysis (see Appendix I) due to their dichotomous response nature or were better presented in a table format. Positive experience statements were included in the thematic analysis but are highlighted and presented separately, as they did not necessarily fit the theme operational definitions.

Service Provider Themes

Across the questions asked to service providers, the following essential themes emerged based on most frequent responses, and each theme was evident within each participant to some degree. These themes included: a) Collaboration, b) Accessibility and Availability, c) Education, d) Child-Centered Care, and e) Family Support. To provide a visual reference, Table 5 identifies each essential theme and the operational definition that composed the essential theme. The number of passages refers to the number of specific verbatim passages from the interviews across all service provider participants. Specific quotes relating to particular themes, as well as summaries of common service provider experiences, are also shared below.

Table 5

Service Provider Themes

Essential Theme	Abbreviated Operational Definition	Number of Passages
Collaboration	Communication and care coordination	112
Accessibility & Availability	Barriers to service delivery	106
Education	Need to train and teach family caregivers specific processes and procedures	44
Child-Centered Care	Approach or program model in assessing, delivering, analyzing, and monitoring child’s individual needs	38
Family Support	Identifying unique and challenging needs for families and how these needs impact the family unit	30

These themes were the top five identified areas that most frequently occurred within this group, and each theme is explored in further detail below, along with an operational definition to effectively define how the theme was comprised.

Collaboration. This theme was operationally defined as: The service provider's collaboration style, involving communication (i.e., method, frequency, opportunity, resources, initiation) and care coordination considerations. This theme was the most frequently occurring theme across the sample, with 112 significant statements identified. Of these statements, communication (N = 80) and care coordination (N = 32) were reported by service providers. Communication statements involved the method in which communication commonly occurs with families (e.g., in-person meetings, phone calls, email, texting) and with other providers (e.g., networking, providing referrals), the frequency with which communication occurs, and the resources used to communicate information to and with families, as well as with other providers. Method of communication was reported most frequently (N = 44), with service providers most frequently providing statements on networking, communicating, and connecting with other providers. In-person meetings were also frequently reported, including meeting with parents during an initial assessment or orientation and discussing and explaining information face-to-face with families.

Regarding resources used as a communication tool, service providers reported a variety of examples, including website resources and social media and resources/information provided during meetings, such as home instructions. While not reported as frequently as communication, care coordination considerations also arose among service providers. Statements involving the importance of parents establishing trust with the service provider were common, as was sharing of information for care coordination purposes, participating on a multidisciplinary team and involving team members in care planning, and having a one-stop shop for services as an ideal option for families.

Components of effective care coordination. Regarding communication and collaboration, service providers were also asked the question, “What are the most common methods of communication you use when discussing autism services with family caregivers?” Service providers reported a variety of communication methods, including in-person meetings, emails, texts, online health portal access, phone calls, and progress reports. There was overlap among service providers in the types of methods used, with all service providers reporting that in-person meetings are utilized at some point. Service provider preference on the type of communication method was also shared. For example, one service provider (Service Provider 1) discussed that the amount of necessary paperwork is best to be reviewed in-person rather than through text: “I don’t want texting…[ ] … I need to talk. Texting is only for if you need to change an appointment, a good time to call me, text me. I will see that before I see an email.” Another service provider (Service Provider 5) indicated: “Well, the only one of those that’s billable is the in-person meeting. We have that time, so we try to steer things toward that because we are still running a business.”

Elements of care coordination that affect satisfaction with services. In terms of communication and collaboration, service providers were also asked the question, “What does effective communication with family caregivers look like? This is in regard to the autism services you provide to individuals with autism.” Overall, service providers had varied responses and experiences on what they deemed to be effective communication. One service provider (Service Provider 1) discussed communicating to parents as the session was occurring with them, observing the provider working with the child:

> We talk a whole lot. And I talk through my therapy session, *This is why we're doing this, and this is why I am not stopping*, when the child starts crying and the parents are on the edge of their seat.

Another service provider (Service Provider 3), who is also a parent of a child with ASD, stated:

> That's one that's really easy for me, I think, because I'm a parent and they trust me, and I think that's huge because I think a lot of families have been burned, and they don't trust organizations. They don't really trust agencies. And so, as soon as they find out that I've been there and I get it, then they completely open up to me. And when they talk to me about things they've felt misunderstood about, and I get it, then they really open up.

Another service provider (Service Provider 4) discussed an educational approach to communication and collaboration:

> I think taking a three-prong approach, actually verbally saying it, and then having written materials, and then our treatment coordinator verbally says it again. So, that way they've heard it from me, they've seen it in writing, and then they've heard it again from the care coordinator. And that seems to get the information across really well.

Recommendations for care coordination. Regarding communication and collaboration, service providers were specifically asked the question, "When you are thinking about working with family caregivers, what things do you find most helpful for the autism services you deliver?" One service provider (Service Provider 2) discussed the approach used in her practice and stated:

> Probably the K.I.S. method, which is *keep it simple*. I find that parents need to see it in how it works, so it's not just enough to tell you about it. They actually need to get their hands on it and practice it. So, many times in the parent trainings that we do, we bring materials, and we have them practice with each other, because it looks really simple when someone models it for you, but when you try to implement it, it's a lot different.

Another provider (Service Provider 5) discussed her experiences in working with families and stated:

> I think first and foremost, helping them understand and buy-in to what we're doing. I think that is the baseline. If they don't understand what we're doing and why we're doing our methods, then it tends to be a really difficult road, and the services are much less likely to be successful in my experience.

Positive statements of collaboration. While a large majority of statements for collaboration within service delivery focused on identifying gaps or areas for improvement in how service providers communicate and coordinate care, service providers also addressed some positive aspects of how they effectively collaborate or what they believed to be important when determining helpful collaborative efforts. For example, service providers reported being active in their encouragement for parents to communicate with them, discussed their involvement in coordinating with families, and shared their approaches in collaboration that have worked most effectively. One service provider (Service Provider 3), who also has a child with ASD, discussed the importance of being receptive to and understanding of parents in terms of effectively coordinating care. This individual also discussed her attempts in providing alternative options to families when traditional services are deemed ineffective, further discussing her involvement in the planning of the child's services at the request of the family:

> With them, I can tell when they start talking about their kid, like I can recognize it. They're my tribe, so I get it when they start talking to me and that I think when they recognize I get it. I can tell they need somebody to understand.

Accessibility and Availability. This theme was operationally defined as: Barriers to service delivery that include financial costs, time (e.g., scheduling), distance/travel, provider specific training, appropriateness (types of services offered: individual, groups), siloed services, operational (space), availability, too few professionals, and staff turnover. This theme was the second most frequently occurring theme across the sample, with 106 significant statements identified. Service providers identified a variety of barriers to service delivery for families, which most frequently included financial costs (N = 27) as a recurring barrier, followed by specific training required to work with the ASD population (N = 22), siloed services (N = 13), appropriateness of the service in meeting needs (N = 10), too few professionals (N = 9), time (N = 8), lack of program availability (N= 8), operational issues (N= 7), staff turnover (N = 1), and distance/travel concerns (N = 1). Close to half of the statements regarding financial cost barriers (N= 12) arose from the question, "[With regard to service delivery], do you have any unresolved problems or concerns at this time?" Service providers responded to this question with statements concerning out-of-pocket programs and the resulting financial burden for families, limitations with insurance plans (e.g., caps and limits to services, lack of coverage), and funding issues in carrying out or sustaining services and programs.

Regarding specific training required to work with the ASD population, service providers discussed difficulty for families to find providers who have been trained in evidence-based practices or have extensive experience working specifically with children on the spectrum and treating their unique, individual needs. Regarding siloed services, service providers often responded with concerns of disjointed or fragmented services, issues with inconsistencies between services, and problems generalizing skills from one service to other settings, which can be overwhelming and daunting for families. Regarding appropriateness of the service in meeting needs, service providers discussed the need to better tailoring services to ASD requirements, such as the opportunity for a peer group, but also to provide services that are more age-appropriate. Additionally, issues with aging clients were addressed, as well as the need to provide services that foster more responsibility and independence in clients. Regarding too few professionals, service providers acknowledged a need to have more professionals available, indicating issues such as a low provider to client ratio and low staff availability, which can impact obtaining an initial ASD diagnosis. They additionally responded with statements for improving services with additional staff on board.

Regarding barriers with time, service providers discussed a variety of issues, including scheduling constraints, which can impact communication and properly prioritizing care, as well as the time-consuming nature of required services for children of this population. Regarding lack of program availability, service providers indicated that services themselves can be limiting and not adequately meet the child’s needs and that there can be a first-come, first-served mentality. Service providers also spoke about their hopes in starting up new programs and expressed continued efforts toward improvement of services, even stating that parents are requesting new programs for their children. Regarding operational issues, service providers discussed having more space to allow for other service opportunities and improving services in general. Both staff turnover and issues with traveling to the service location were also reported by a few service providers.

Positive statements of accessibility and availability. While barriers on service delivery comprised most of the statements reported by service providers, positive aspects of service delivery were also shared with regard to accessibility and availability. For example, one service provider (Service Provider 4) discussed having a role to specifically help reduce barriers in care:

> I think we've done a lot to help reduce the barriers to care. We flag kids that have autism spectrum and other special healthcare needs with a different color, so that when we're booking those appointments, it would be very difficult for us to have eight kids with special needs all at the same hour. We try to space them out during the day, so that we know that we can spend more time with the family, and we know they're not going to be disturbed by another kid that may have their condition and is not having a great day.

Another service provider (Service Provider 5) indicated that the nature of services provided lend well to making services easily accessible for parents to use in the home environment:

> I would say with ABA and specifically the approach that we use, which is the verbal behavior approach, it definitely lends itself to being able to carry that

> through. And one of the reasons I say that is because we do use the tiered model approach, our direct service providers are paraprofessionals.

Lastly, another provider (Service Provider 3) discussed providing a variety of service options for families (e.g., social skills groups in addition to regularly provided services) and not placing restrictions on those services, unlike what may occur in a clinic or hospital.

Education. This theme was operationally defined as: How service providers identify the need to train and teach family caregivers specific processes and procedures through observation, modeling, and direct instruction. This also includes their process for training, education, and coaching of family caregivers. This theme was the third most frequently occurring theme across the sample, with 44 significant statements identified. Of these statements, service providers most frequently reported on providing direct instruction (N = 22), the importance of education in general (N = 13), modeling with parents (N = 4), observation (N = 3), and coaching parents (N = 2). Examples of direct instruction included providing hands on learning experiences for parents, formally educating and training them on the service (whether in-person or online), and training them on how to collect data or assess and reinforce behaviors in the home environment.

Knowledge about services provided. As part of the interview, this question was also asked to service providers: “Do you believe that family caregivers are knowledgeable about the agency’s method for monitoring their child’s progress in the services you provide?” Because of the dichotomous nature of this interview question, the responses for this question were reviewed separately from the theme analysis. The question responses are presented under the education theme, as both the question and responses were geared towards this area. Service provider responses regarding this question were mixed, with some responses indicating that family caregivers are not knowledgeable about the service they provide, while others said that it depends, and other responses indicating that caregivers are knowledgeable. One service provider (Service Provider 3) stated:

> That is a very varied answer. There are some, and honestly, from the other professionals I know, this tends to be the case for them as well. There are some families that want to know every detail about what's going on. They really know what they're talking about. Then, there are other families that just want to drop them off and you handle it, and they don't really seem to care to be involved.

Another provider (Service Provider 5) stated, "Yes, I do think that they're knowledgeable. I think families that come to us, and of course this is a generalization, but I would say they usually come in with some knowledge of ABA, and they've done their homework."

Child-centered care. This theme was operationally defined as: The service provider's approach or program model in assessing, delivering, analyzing, and monitoring the child's individual needs. This theme was the fourth most frequently occurring theme across the sample, with 38 significant statements identified. Of these statements, service providers often spoke to catering and assessing for the individual traits and needs of clients, continual monitoring and modifying of goals, and outlining of their specific program or service model to meet the child's needs.

Family support. This theme was operationally defined as: Service providers identify the unique and challenging needs for families (e.g., lack of support, stressors, emotional unmet needs) and how these needs impact the family unit (e.g., resulting in service needs of respite care, counseling, stress management). This theme was the fifth most frequently occurring theme across the sample, with 30 significant statements identified. Service providers addressed areas relating to family stressors (N = 13), the importance of respite care (N = 5), the lack of support families experience (N = 5), addressing family's emotional needs (N = 3), concerns expressed by parents (N = 2), and the importance of family counseling (N = 2). When reporting about stressors, service providers discussed coping difficulties (i.e., feeling overwhelmed or emotional), which can impact marriage and the family as a whole. The importance of respite care was also discussed, with service providers indicating that a lack of respite care can contribute to stress and that parents may choose their own respite care over being involved in observing the child's session. A lack of support was also revealed, with service providers speaking to the importance of providing positive aspects with families and coming up with realistic and feasible solutions for the family.

Positive statements of family support. While most frequently reported comments surrounded the need or importance for family support, some positive statements for family support were also reported by service providers. For example, one service provider indicated that her services provide benefits, not just to the child with ASD, but for the child's family as well. In regard to the services provided, this provider (Service Provider 5) stated:

> It's just absolutely transformative for the child but also for the entire family unit. They're learning how to be able to function as a quote-unquote *normal* family. They can maybe go to the store without having to worry about the child flopping

> down in the middle of the aisle and everybody staring. I mean, just imagine not having to worry about that at some point. So, just the anxiety and stress factor alone…and I think it just helps families be able to have a happier life at home, which is what everybody wants.

Family Caregiver Themes

Across the questions asked to family caregivers, the following essential themes emerged based on most frequently occurring responses, and each theme was evident within each of the participant's responses to some degree. These themes included: a) Collaboration, b) Family Support & Involvement, c) Accessibility & Availability, d) Child-Centered Care, and e) Education. Table 6 identifies each essential theme and the operational definition that composed the essential theme. The number of passages refers to the number of specific verbatim passages from the interviews across all family caregiver participants. Specific quotes relating to particular themes, as well as summaries of common family caregiver experiences are also shared below.

Table 6

Family Caregiver Themes

Essential Theme	Abbreviated Operational Definition	Number of Passages
Collaboration	Communication and care coordination	95
Family Support & Involvement	Family need for support and involvement and/or decision-making process in child's care	35
Accessibility & Availability	Barriers to service delivery	31
Child-Centered Care	Perceptions and understanding in effectively monitoring the child's individual needs for ensuring success and independence	28
Education	Need to train and educate service providers and family caregivers	27

Similar to the service provider data, these themes were the top five identified areas that occurred most frequently within this group, and each theme is explored in further detail below, along with the full operational definition to effectively define how the theme was comprised.

Collaboration. This theme was operationally defined as: The family caregiver's collaboration style, involving communication (i.e., method, frequency, opportunity, resources, initiation) and care coordination. This theme was the most frequently occurring theme across the sample, with 95 significant statements identified. Care coordination statements were most frequently occurring (N = 37), followed by method of communication (N = 33) with providers (e.g., in-person meetings, phone calls, email, texting), communication process in general (N = 12), frequency of communication (N = 8), and the resources that are shared with the family (N = 5). Overall regarding care coordination, family caregivers expressed the importance of effective care coordination, instances when they believed care coordination was ideally occurring or not occurring, and the process for which care coordination occurs for and within the families with whom they worked. The method in which communication was most commonly reported was through referrals. Family caregivers shared that service providers were often either recommended or referred to them for services, or the providers did the referring to other providers. Other methods for services being communicated to family caregivers occurred through insurance companies and waiver programs (i.e., Michelle P. Waiver), online searches, or by communicating with other family caregivers.

Components of effective care coordination. Regarding communication and collaboration, family caregivers were also asked the question, "What are the most common methods of communication you use when discussing your child's autism services with service providers?" Family caregivers provided a variety of communication methods, including in-person meetings, emails, texts, online health portal access, phone calls, and progress reports. There was overlap among family caregivers in the types of methods used, with all caregivers reporting that in-person meetings are utilized at some point. Family caregiver preference on the type of communication method was also shared. For example, one family caregiver (Family Caregiver 4) stated:

> Between parents and the individual caregivers, we text regularly throughout the day and say, *This is coming up at school*. And they text us with any questions they have about specific things, you know, what [the child] is and isn't allowed to do if something comes up. I think our caregivers and support broker, we communicate pretty well in a lot of different ways.

Another caregiver (Family Caregiver 3) shared information about communication methods on a more irregular basis:

> With phone calls, I will occasionally get phone calls from our behavior specialist, and that is also more in a reactionary mode. That's her response to make me aware of certain things. That's how I get information from her. I'll send the email out to just make sure I say the same thing to multiple service providers, so that's a different thing.

Elements of care coordination that affect satisfaction with services. In terms of communication and collaboration, family caregivers were additionally asked the question, "What does effective communication with service providers look like? This is in regard to the services your child with autism receives." One family caregiver (Family Caregiver 2) stated:

> I think effective would mean being able to, again, address the patient as a whole. Address the client as a whole. That means developmental delays, along with the medical concerns. We have to treat each patient holistically, medically as a whole entire entity, not just as a disease process. Effective care would give the patient the ability to coordinate their care to get the best overall care. That means you interact with every person who provided care to that patient in a way that is one unit, one patient, one-on-one care to advance the patient.

Another family caregiver (Family Caregiver 4) spoke to the education and training needed and stated:

> I think that gets back to the training bit, if everybody spoke the same language, because it’s hard to communicate when you’re not all using the same terms. Education would be very helpful in being able to communicate with each other.

Another family caregiver (Family Caregiver 5) discussed the open communication concept that has been made available to her family and stated:

> I would say in our situation, I feel like nothing is off the table. I feel like they can say anything to me, and I can say anything to them. And we’ve always been respectful and get along, but if I have a question, I am never talked down to or pushed aside, and same thing for them. I see them as *mom* and they see them as *students*. We’re coming from different viewpoints as well. I would say it’s effective because we all listen. We all keep [the child] the main focus.

Recommendations for effective care coordination. Regarding communication and collaboration, family caregivers were specifically asked the question, “When you are thinking about working with service providers, what things do you find most helpful for the autism services your family uses?” One family caregiver (Family Caregiver 1) stated:

> Accessibility. I like to know that I can get a hold of providers if I need them, especially if you have behavior-type issues come up, it’s really good to know that people are available if you need them, and then they can give you some ideas of like, if an emergency happens, here’s what you could do. That, I think is really helpful, just to know they’re available, and if they’re not available then there’s someone else you can talk to.

Another family caregiver (Family Caregiver 4) stated: “We try to spend a decent amount of time with someone if they are somebody we are considering hiring, and of course if we know someone who's worked with them before that goes a long way, too." Another family caregiver (Family Caregiver 2) expressed dissatisfaction with current communication and collaboration methods for her son:

> A lot, a lot of advocation. Me constantly getting in their face at the face-to-face meetings and saying, *This is what I need for you to do for us, for my son. I need you to talk to him. I need you to care about what's developmentally going on with him*. I can't state that enough that they really do not try enough to coordinate developmental delays into their actual care of patients.

Family support & involvement. This theme was operationally defined as: Family caregivers identify a family need for support, including their involvement and/or decision-making process in determining effective care for their children with ASD but also for the family as a whole. This theme was the second most frequently occurring theme across the sample, with 35 significant statements identified. This theme contained a variety of ways in which families identified supportive ways to address family needs, as well as how they involved themselves in their children's care through their family decision-making process; these areas tended to widely differ from one family caregiver to the next. For example, one family (Family Caregiver 1) had recently begun ABA therapy with their child and expressed still needing more time to determine the effectiveness of the therapy, additionally indicating that her family would make the determination to continue the child in the service depending on progress.

Another family (Family Caregiver 4) made the decision to hire individuals they knew personally to deliver services to their child: "We hired folks we knew and trusted. We still had to go through all the background checks with them, but we know them. We get to choose who they are instead of having someone sent to us.” This same family caregiver also shared experiences about being trained on the service and able to provide that service to the child: “I’m one of the care providers in this situation, and I think you’ll find with most Michelle P. Waiver folks have one parent, at least one who is going to be involved in the care.” Other family caregivers expressed that only one parent is involved in the child’s direct care, while other families involve both parents to make decisions related to the child’s service delivery.

Positive statements of family decision and involvement. When asked about whether family caregivers had any unresolved problems or concerns at this time, in regard to service delivery, most caregivers (N = 3) reported having no issues. One family caregiver (Family caregiver 4), whose child receives in-home support, reported that the family as a whole is happier when the child’s needs are met, saying, “It makes for him being happier. It makes everybody happier. It’s just a much better fit for what he needs.” This same family caregiver also discussed having personal needs addressed when initially going through the diagnosis process with her child, saying:

> I needed someone to talk to, to let me know I’m not completely nuts because it was so stressful, and she actually said, *I think there’s something else going on with him*, and *Why don’t you go see the doctor? It sounds like there’s a possibility he has autism*.

Positive aspects were also shared about both immediate family members, and outside family members supporting the child and the family as a whole. One family caregiver (Family Caregiver 1) stated: “My family has been very supportive, so that’s been really helpful. In that regard, that’s been very good.” Another caregiver (Family Caregiver 2) discussed having a family member outside of her immediate family who has assisted in the child's care:

> My twin sister… [ ] …brings a multitude of knowledge and skills, as she was a special needs teacher, and she often gives me things to do to help support me and giving care and reaffirming some of those goals in the IEP set by the occupational and speech therapist.

Accessibility & availability. This theme was operationally defined as: Barriers to service delivery include financial costs, time (e.g., scheduling), appropriateness (e.g., types of services offered; targeted age group), siloed services, availability, and too few professionals. This theme was the third most frequently occurring theme across the sample, with 31 significant statements identified. Family caregivers identified a variety of barriers regarding service delivery to their family, which most frequently included availability (N = 8) as a recurring barrier, followed by appropriateness of the service in meeting needs (N = 7), siloed services (N = 5), too few professionals (N = 4), financial costs (N = 3), and time (N = 2) and accessibility (N = 2).

Regarding availability, family caregivers expressed difficulty in locating available services for their children, suggesting that services are not always accessible or available and that it is helpful to be aware of all available services. Regarding appropriateness of the service in meeting their children's needs, family caregivers most frequently discussed the need for age-appropriate services, as well as a variety of service options. Regarding siloed services, family caregivers discussed experiencing difficulty with locating and securing services, which affected obtaining the initial ASD diagnosis for the child. Regarding too few professionals, family caregivers reported statements on a lack of professionals and further expressed that having a registry of professionals would be helpful. Regarding financial costs, family caregivers reported that costly resources were involved in getting their children the necessary services (e.g., paying out-of-pocket for social skills classes), while another family caregiver (Family Caregiver 4) shared that their family was given a budget for community living services. Regarding issues with time and accessibility of services, long waiting lists were reported, and accessibility of providers was difficult for one particular family caregiver’s experiences.

Positive statements of accessibility and availability. While most statements reported by family caregivers focused on barriers to accessibility and availability, some positive statements also emerged. For example, family caregivers discussed that some of the services their children access (or accessed within the last six months) were relatively easy to access and secure, which was due to factors such as continued and required availability (e.g., public school mandates, availability of general counselors), the service being handled through insurance, and the child being eligible to receive the service because of the ASD diagnosis.

Child-centered care. This theme was operationally defined as: The family caregiver's perceptions and understanding in effectively monitoring the child's individual needs for ensuring success and independence. This theme was the fourth most frequently occurring theme across the sample, with 28 significant statements identified. Like the family decision and involvement theme, statements by family caregivers suggest a wide variability in terms of the children’s specific needs to be addressed. Overall, family caregivers addressed several concepts, including what works best for the children, what would help the children receive more effectiveness within the service, and the ongoing nature of required services for the children.

Education. This theme was operationally defined as: How family caregivers identify the need to train and educate service providers and family caregivers in caring for and working with the ASD population. This theme was the fifth most frequently occurring theme across the sample, with 27 significant statements identified. Of these statements, family caregivers reported on the importance of family caregiver education (N = 7), a need for service provider education (N = 7), a lack of education in general (N = 7), and instances when the family caregiver need to initiate his or her own education regarding the child's care (N = 7). Regarding the importance of family caregivers being educated, family caregivers discussed being actively involved in their children's meetings for educational purposes, as well as having effective, basic autism training for family caregivers.

Family caregivers also reported the need for service provider education and training in terms of better knowing how to work with children on the spectrum and for improving the service delivery process. Family caregivers additionally expressed a lack of education in general by sharing experiences when initially going through the process to get their children diagnosed or finding out information along the way. Family caregivers also shared experiences of when they have had to initiate their own educational process to better understand how to effectively address and treat their children's needs. For example, one family caregiver (Family Caregiver 5) described going back to school, in part, to further educate herself about the ASD population and how she can better understand her child and how to be more effective in her caregiving role.

Knowledge about services received. As part of the interview, this question was also asked to family caregivers: “As a family caregiver, are parents knowledgeable about the agency’s method for monitoring their child’s progress in these services?” Because of the dichotomous response nature of this interview question, the responses for this question were reviewed separately from the theme analysis. The question responses are presented under the education theme, as both the question and responses were generally geared towards this area. Similar to service provider responses regarding this question, family caregiver responses were also mixed, with responses indicating variability in knowledge of services for themselves and also for other family caregivers. One family caregiver (Family Caregiver 1) stated:

> I’ve talked to different parents, and it seems like people know a little bit. They’ll say, *Oh, I went to this specialist*, and I would say, *Well, I went to this specialist*. And some of them go to a different specialist. I don’t feel like there really is a collective bucket where everybody pulls the information from. I feel like there are information silos.

Another family caregiver (Family Caregiver 5) who is also a behavior specialist and is currently working on becoming a board-certified behavior analysist said, “With good intention, parents can sometimes be a little too trusting and think, ‘Oh, that’s the professional. They know what they are doing.’ And then they just stop, and I think some parents don’t get as invested.”

Positive statements of education. Many of the statements shared on education focused on the need to better train professionals and parents for achieving more knowledge, competency, and experience overall. However, one family caregiver (Family Caregiver 3) expressed having a positive experience with competent professionals involved in the child's care, saying, "We've just been lucky with our initial diagnosis and our initial team of professionals that have all been very competent. Luckily, good, competent personnel make wonders of difference."

Overlap of Themes Between Groups

In terms of theme overlap between the service provider and family caregiver groups, these themes were found to contain a similar overarching idea even though operational definitions slightly differed for several of them: a) Accessibility & Availability, b) Child-Centered Care, c) Collaboration, and d) Education. Regarding Accessibility & Availability, both service providers and family caregivers reported on barriers affecting existing services, and each group also identified areas in which barriers should be addressed. The theme Child-Centered Care was also addressed by both groups, with a focus on identifying the child's needs to promote positive change. Service providers and family caregivers also discussed Collaboration as a theme, each reporting on methods and frequency of communication, as well as issues pertaining to care coordination. Lastly, Education as a theme was also an area of overlap between the groups, with service providers indicating a need for more education and training for parents, while family caregivers addressed the need for education and training for both parents and service providers. The theme Family Support that emerged with service providers and the theme Family Support & Involvement that emerged with family caregivers shared overlap in terms of the support concept and how each group identified the need to provide families support to some degree. Between these two themes, service providers indicated what they have witnessed in terms of perceived necessary support for families, while family caregivers provided direct examples of when they are in need of support and/or supportive services.

Divergence of Themes Between Groups

While there was overlap in how service providers and family caregivers identified the need for family support, family caregivers additionally responded with their need to be involved and make decisions together as a family unit in regard to their children's ASD-related services. While there is a difference between these groups in terms of how they were operationally defined, both themes relate to the family system in some capacity. Therefore, the divergence between these themes relates more to how exactly the family system is to be involved in the child's care, which was most apparent from the perspective of family caregivers. When comparing themes between service providers and family caregivers, the operational definitions differed because of the respective group's role. For example, the Child-Centered Care theme for service providers targeted specific approaches for meeting the children's needs, while family caregivers provided perceptions and experiences for when their individual children's needs are (or are not) effectively met.

Chapter Five: Discussion

This study sought to understand experiences of family caregivers and service providers of children with ASD in their views of effective care coordination and what they perceive regarding improvements within service delivery for this population. An emphasis on collaboration, which includes care coordination and communication, allowed the researcher to assess this area in more detail with participants. A basic qualitative research design was chosen as the methodology for this study, as it allowed the researcher to uncover a deeper understanding of the subjective experience of family caregivers and service providers with the ASD population. The depth of information that came from this study may assist current and future direction of service delivery for children with ASD. The following chapter will discuss highlights and implications from the findings, the research questions investigated for the study, how the findings relate to the literature, limitations of the study, and recommendations for future research.

Summary of the Findings

Consistent with the literature, service delivery for families often requires a variety of interventions and treatments with differing service professionals (Autism Speaks, 2018b), which was evident among the family caregiver group, as varying services were received, with some overlap of services reported by participants. The service providers recruited for the study also represented varying professions in the services they deliver to the ASD population. Additionally, service delivery is multi-faceted, as acknowledged in the literature (Entwistle, Firnigl, Ryan, Francis, & Kinghorn, 2012), with a number of themes emerging for both service providers and family caregivers in the current study. Even for questions targeting specific areas in service delivery (e.g., family involvement, collaboration), various themes emerged within a given question for both participant groups, further illustrating the complex nature of this research area. The findings of this study expand the existing literature by providing additional information regarding service delivery experience and perceptions for the ASD population. When comparing the themes that emerged from participant groups to the literature, the results of this study are supported through previous literature as described in Chapter 2. For example, similar to Sperry and colleagues' (1999) focus group study that included family caregivers and service providers, findings from the current study also found similar themes of collaboration, training, family support, and barriers (e.g., finances) between the two groups, as well as areas of divergence.

Collaboration was a major theme identified and most frequently occurring between both groups, which is an area of need previously addressed through research (Kohler, 1999; Mereoiu et al., 2015). The present study allowed for a deeper understanding of this concept, as several questions specifically targeted experiences of service providers and family caregivers but also gathered perceptions of effective elements and recommendations for improving service delivery. As a collaborative effort, the concept of a parent-professional model is one method currently being piloted but not yet fully implemented (Murray, Ackerman-Spain, Williams, & Ryley, 2011); however, of note, there is a robust literature base on how to effectively train parents on the principles and skills professionals bring (e.g., parent-child interaction therapy, parent management training; Parent-Child Interaction Therapy International, 2018). Regarding a parent-professional model, this approach aims to empower both family caregivers and service providers in their training and education about ASD, and when family caregivers and service providers are able to effectively collaborate, better family outcomes, including those for the child with ASD, tend to occur (Murray et al.). Applying a parent-professional training model and then assessing experiences with service delivery could be an effective step forward in ascertaining the outcomes of this type of collaborative process among family caregivers and service providers.

One unique facet that arose from the study in relation to a parent-professional collaboration model is the possibility of individuals doubling as service providers and family caregivers for children with ASD. These individuals carry firsthand knowledge and experience of caring for a child on the spectrum and could seamlessly relate to other family caregivers on that level; in addition, they may have an “insider’s view” on what it means to be an effective service provider to other families of children with ASD. Therefore, the concept of creating a strong working alliance between parent and professional might take on an enhanced dynamic with the service provider already having direct experience caring for a child with ASD; this facet may be especially enlightening through additional research efforts in determining whether satisfaction with services, for example, is positively impacted with a more relatable provider.

Summary of the Research Question Findings

For the purposes of the project, only the research questions will be discussed in detail in this chapter even though additional areas and findings emerged from the data. As part of the overarching research inquiry, this study attempted to better understand service delivery experiences and perceptions of family caregivers and service providers, which included answering the following research questions surrounding collaboration:

1) What are the components of effective care coordination as perceived by family caregivers and service providers?,
2) What are the elements of care coordination and communication that affect family caregivers' degree of satisfaction with services?, and
3) In the areas of care coordination and communication, what are the recommendations of family caregivers and service providers?

Across all themes for family caregivers and service providers, the theme of collaboration (which encompasses care coordination and communication) presented the highest frequency of responses for both groups. This high frequency could be related to collaboration and communication as identified gaps in the literature (Kohler, 1999; Mereoiu et al., 2015), providing further evidence of their undoubtable importance, consideration, and necessity within service delivery.

Elements of Effective Care Coordination

In reference to the question about components of effective care coordination, both family caregivers and service providers discussed a variety of methods they use to communicate about the child's services, as well as their own communication preferences. There was no identification of using only a single method for communication for any individual participant or either participant group, suggesting that communication occurs across a range of modalities (e.g., face-to-face, email, phone) and among all participants. This is an important point, considering the current technological advances that allow individuals to communicate with one another, not only for service delivery purposes. However, even with multiple communication modalities set in place, the process through which communication occurs continues to be an issue within service delivery (e.g., Mereoiu et al., 2015). For example, one family caregiver discussed how communication regarding her child can sometimes occur in a reactive (versus proactive) manner and then require her to inform the child's other service providers of the situation. Recommendations from other studies for determining more effective communication have been proposed. For example, in their thematic analysis study, Nancarrow and colleagues (2013) presented characteristics of a good interdisciplinary team according to service providers. As a main theme of their study, communication was described as individuals possessing effective communication skills and ensuring that appropriate systems are set in place for promoting communication within the team. Based on this theme, as well as others presented, the researchers proposed that these themes should serve as a competencies framework for further investigating good interdisciplinary team work.

The evolving technology landscape will continue dictating how communication methods occur in regard to service delivery and will be an important concept for future research to consider. For example, telehealth and telemedicine care models for the ASD population are currently being assessed for feasibility and efficacy; a pilot study using a new distance-learning program called Extension for Community Healthcare Outcomes (ECHO) was employed to train primary care providers in best practices for ASD (e.g., diagnosis, screening, treatment protocols, care management), and those participating in the program showed significant improvements in screening and managing ASD (Mazurek, Curran, Burnette, & Sohl, 2018). Programs such as these show promise in addressing timely diagnoses—an area of particular concern due to increased prevalence rates and current delays in obtaining initial diagnosis (Autism Speaks, 2018a)—as well as potential to reduce overall healthcare costs (e.g., Kvedar, Coye, & Everett, 2014; Lindgren et al., 2016).

Service provider communication preference was another facet that arose during the interviews, with some providers indicating their own preferred methods and frequency when working with families and other service providers; other provider statements on communication were guided by whether the method could be billed to insurance. Even with the variety of communication methods that exist, limitations in utilizing these methods may be occurring between service providers and family caregivers as a result of insurance stipulations. Understanding that communication methods may be dictated by insurance companies is an important policy consideration for how future service delivery may be impacted. For example, inadequate insurance coverage can be associated with difficulty in accessing and using services, as well as lack of shared decision making and care coordination, which can impact satisfaction with services (Vohra, Madhavan, Sambamoorthi, & St. Peter, 2014). A future study to examine service delivery experiences without barriers to communication (i.e., insurance limitations) could help researchers better understand when effective communication is occurring versus not.

Elements of Care Coordination & Family Satisfaction with Services

With regard to the question about the elements of care coordination that affect family caregiver degree of satisfaction with services, both family caregivers and service providers offered a variety of elements, including frequent and regular communication between parties, education and training on the services provided, focus on patient-centered models, and the level of comfort and familiarity between caregiver and provider.

In addition, there was a unique perspective of a service provider who is also a family caregiver of a child with ASD. Having roles as both a provider and caregiver allowed the individual to address the interview questions from a service provider perspective, but with considerations as a family caregiver, when responding to experiences with service delivery. Information from these types of individuals, like the participants interviewed in the current study, may be beneficial to future service delivery, as they may be able to offer their expertise from perspectives of both a service provider and family caregiver.

While service providers most often focused on their own process or methods of care coordination with families and other service providers, family caregivers were more likely to provide statements surrounding their children with ASD, including explicit emphasis on a patient-centered model of care and incorporating a whole-child approach. A child-specific mentality makes sense for family caregivers because they have a single child in mind and tended to discuss their own child's individual needs in relation to the questions posed. Service providers, instead, talked more generally about care coordination, including methods they find effective and how these methods are integrated into their work with children and families. This finding is similar to Sperry and colleagues' (1999) findings in that families were more child-focused and providers were more service delivery-focused. Still, some service providers discussed particular case examples of their approaches and what their approaches looked like with specific families; this helps illustrate individual cases that require being handled differently from one family to the next. When connecting a child-focused concept to the literature, a patient-centered model has been emphasized in recent years, which places the child at the center of treatment (Golnick et al., 2009). The concept for determining service delivery on a personal level provides a rich array of patient experiences, including implications of feeling valued and having needs effectively addressed (Entwistle et al., 2012).

Recommendations for Better Care Coordination and Communication

When reviewing the recommendations for better care coordination and communication as proposed by family caregivers and service providers, a number of differing recommendations arose within and between each group. Service providers most often discussed recommendations involving their specific approaches when working with families, including making their services easily implementable by families, as well as providing education to family caregivers on the effectiveness of those services. Family caregivers frequently discussed recommendations surrounding accessibility to care, advocating for their children, and finding professionals with whom the family feels comfortable and familiar to be most effective to the children's care. The concept of seeking out service providers with whom families feel comfortable interacting speaks to the importance of developing rapport and trust with their children, which, in some cases, may supersede the provider's knowledge and experiences; this principle is supported by the literature, suggesting that health care relationships beyond communication are important to patients and their families (Entwistle et al., 2012).

Further exploring factors such as emotional competence, or bedside manner, in addition to being effective and knowledgeable in one's given specialization, may be helpful for families who are seeking a meaningful connection with a service provider but would also benefit from the necessary expertise of that provider. For example, initiatives such as the Standardized Patient Program were designed for improving service delivery by training medical students on empathy and communication skills prior to engaging in clinical practice; this initiative is meant to begin teaching and mastering these skills early on in the provider’s career, which has been lacking in patient care (Peregrin, 2014). Implications point to an ideal situation in which a service provider would be able to fulfill a dual role in providing their expertise while connecting to the family on a deeper, personal level with regard to their children’s ASD care.

Limitations

While a small sample size is recommended for qualitative research, the findings of the study may not generalize to all service provider and family caregiver experience and perceptions. Another limitation to address is that the participant sample was recruited from a mainly semi-rural location, which could have implications on factors such as barriers to service delivery. Participants who have greater accessibility to services may have differing viewpoints and experiences. Another limitation is that the study did not match up service provider to family caregiver (i.e., those individuals who directly work with each other as part of the child’s care), which may have allowed for a better, more direct comparison of services being delivered and received. A suggestion for future research is to match participants to allow for more of a “true” collaborative approach than how this was conducted in the current study. Also, because ASD is a spectrum disorder, the types and amount of services may significantly differ from one family to the next, which could make for quite different experiences and perceptions regarding service delivery.

Differences in service delivery experiences could also be evident when considering factors such as age of the child, severity of the disorder, and other co-occurring disorders with ASD that could further dictate service delivery and resulting experiences and perceptions. For example, the current study only examined services received or delivered for children with ASD from ages 7 to 21 years old; assessing service delivery for younger ages would likely present differing experiences for participant groups. The same idea holds true for service providers depending on the type of service provided, their educational and training background, and their level of involvement with children on the spectrum.

Trustworthiness measures that were not employed in the current study, such as participant checking, may have been additionally beneficial to include. Participant checking involves participants checking over their responses upon transcription to determine accuracy and ensure their intended responses have been captured appropriately (Shenton, 2004); this may also have allowed participants to further expand upon or clarify their original responses for more effective reporting. Similar studies conducted in the future may want to consider this measure, along with other potential trustworthiness measures to be employed.

While specific questions, like the ones administered in the current study, can be advantageous for pinpointing specific experiences within service delivery, targeted (or too specific) questions may have limited participants from sharing other experiences and perceptions. Broader questions may have allowed participants to present additional details and experiences they also found to be important and relevant for sharing. An approach to help accomplish this could be implementing a phenomenological study design, whereby the researcher creates themes by uncovering the meaning of participant responses (Merriam & Tisdell, 2016) rather than having the questions guide the theme, which was applied in the current study.

Recommendations for Future Research

There are several recommendations for future research that may extend this study and the findings that emerged. Based on participant responses from the current study, gathering additional, valuable information through a follow-up study could lend to an even more in-depth understanding of specific or targeted areas within service delivery. This could include asking participants to expand upon their ideas, having participants prioritize areas of importance within service delivery, and assessing for new types of information and experiences that were not included in the current study. For example, some of the family caregivers had children who were at or close to the transitionary period following high school. Questions specific to transition within service delivery could provide additional, valuable information for this age group, as transition planning and continuation of care concerns are current gap areas in the literature (Nissenbaum et al., 2002).

Similarly, another recommendation is to conduct follow up qualitative studies to better understand particular subsets of ASD or how specific services are tailored to this population, which could continue advancing the research in this area. When developing future studies with similar goals, one recommendation is to pool additional participants, with the intent of recruiting a larger and/or more diversified sample to allow for better generalizability of findings. Additionally, a follow up quantitative study can aid in generalizability, as these types of studies can be done with greater number of participants. For example, use of a Likert scale for program evaluation or future survey development might also be employed as a means to track service delivery experiences over time, with the ability to quantify data and obtain a large sample size.

Conclusion

In summary, the research questions were answered for this study, which examined service delivery experiences, perceptions, and recommendations for service providers and family caregivers. By examining these questions and the themes that emerged, results from both participant group data presented a number and variety of barriers to accessibility and availability of services, considerations for the children and resulting service requirements, the need for collaboration (which includes communication and care coordination), the importance of family support, and the importance and need for education and training.

Overall, while service providers and family caregivers shared various examples of positive experiences and perceptions with service delivery, both groups expressed important considerations for what constitutes effective service delivery, along with proposed recommendations for continual improvement in best meeting the children’s ongoing and unique needs associated with ASD. Additionally, some family caregivers expressed areas of dissatisfaction with current services for their children. Cumulatively, these shared experiences are consistent with current and past efforts in both research and practice for ascertaining and providing the most comprehensive, effective care possible to children with ASD. The variability of responses among participants and between groups reflects the importance of considering and better understanding the unique experiences of individuals who deliver services and those who directly care for children with ASD.

References

Akshoomoff, N. A., & Stahmer, A. (2006). Early intervention programs and policies for children with autism spectrum disorders. Retrieved from http://www.rchsd.org/documents/ 2014/02/early-intervention-programs-policies-for-children-with-autism-spectrum-disorders.pdf

American Academy of Pediatrics. (2005). Care coordination in the medical home: Integrating health and related systems of care for children with special health care needs. *Pediatrics, 116*, 1238-1244. doi: 10.1542/peds.2005-2070

American Psychiatric Association (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). Washington, DC: Author.

Autism Speaks (2018d). What is autism? Retrieved from https://www.autismspeaks.org/ what-autism

Autism Speaks (2018c). What causes autism? Retrieved from https://www.autismspeaks.org/what-autism/learn-more-autism/ what-causes-autism

Autism Speaks (2018b). Treatments. Retrieved from https://www.autismspeaks.org/treatments

Autism Speaks (2018a). Distance training improves autism care, shortens diagnosis time. Retrieved from https://www.autismspeaks.org/science-news/distance-training improves-autism-care-shortens-diagnosis-time

Autism Speaks (2016f). What is applied behavior analysis? Retrieved from https://www.autismspeaks.org/applied-behavior-analysis-aba-0

Autism Speaks (2016e). What is the ATN? Retrieved from https://www.autismspeaks.org/science/resources-programs/autism-treatment-network/what-atn

Autism Speaks (2016d). Study finds high rate of developmental disabilities among struggling families. Retrieved from https://www.autismspeaks.org/science/science-news/study-finds-high-rate-developmental-disabilities-among-struggling-families

Autism Speaks (2016c). Learn the signs of autism. Retrieved from https://www.autismspeaks.org/what-autism/learn-signs

Autism Speaks (2016b). How is autism treated? Retrieved from https://www.autismspeaks.org/what-autism/treatment

Autism Speaks (2016a). Aging with autism: A brother's story. Retrieved from https://www.autismspeaks.org/news/news-item/aging-autism-brother%E2%80%99s-story

Bailey, D. B., Buysee, V., Edmondson, R., & Smith, T. M. (1992). Building family centered practices in early intervention: A team-based model for change. *Infants and Young Children, 5*, 73–82. doi:10.1097/00001163-199207000-00010

Baio, J. B., Wiggins, L., Christensen, D. L., Meanner, M. J., Daniels, K., Warren, Z., … Dowling, N. (2018). Prevalence of autism spectrum disorder among children aged 8 years—Autism developmental disabilities monitoring network. *Morbidity and Mortality Weekly Report*, 67, 1-23. doi: http://dx.doi.org/10.15585/mmwr.ss6706a1

Baker, B. L., & Abbott-Feinfield, K. (2003). Early intervention for autism. *Current Opinion in Psychiatry*, *16*, 503-509. doi: 10.1097/01.yco.0000087255.35258.d6

Barlow, B., Raison, S., & Raison, J. (1981). Policy options for serving autistic-like children in rural areas. Retrieved from http://files.eric.ed.gov/fulltext/ED218820.pdf

Becker-Cottrill, B., McFarland, J., & Anderson, V. (2003). A model of positive behavioral support for individuals with autism and their families: The family focus process. *Focus on Autism and Other Developmental Disabilities*, *18*, 113-123. doi: https://doi.org/10.1177/108835760301800205

Bitsko, R. H., Holbrook, J. R., Robinson, L. R., Kaminski, J. W., Ghandour, R., Smith, C., & Peacock, G. (2016). Health care, family, and community factors associated with mental, behavioral, and developmental disorders in early childhood—United States, 2011-2012. *Morbidity and Mortality Weekly Report*, *65*, 221-226. doi: http://dx.doi.org/ 10.15585/mmwr.mm6509a1

Bradley, E. H., Curry, L. A., & Devers, K. J. (2007). Qualitative data analysis for health services research: Developing taxonomy, themes, and theory. *Health Research and Educational Trust*, *42*, 1758-1172. doi: 10.1111/j.1475-6773.2006.00684.x

Brantlinger, E., Jimenez, R., Klingner, J., Pugach, M., & Richardson, V. (2005). Qualitative studies in special education. *Council for Exceptional Children*, *71*, 195-207. doi: https://doi.org/10.1177/001440290507100205

Buescher, A. V. S., Cidav, Z., Knapp, M., & Mandell, D. S. (2014). Costs of autism spectrum disorders in the United Kingdom and the United States. *JAMA Pediatrics*, *168*, 721-728. doi: 10.1001/jamapediatrics.2014.210

Buschbacher, P. W., & Fox, L. (2003). Understanding and intervening with the challenging behavior of young children with autism spectrum disorder. *Language, Speech, and Hearing Services in Schools*, *34*, 217-227. doi: 10.1044/0161-1461(2003/018)

Centers for Disease Control and Prevention (2014b). Community report on autism. Retrieved from http://www.cdc.gov/ncbddd/autism/ states/comm_report_autism_2014.pdf

Centers for Disease Control and Prevention (2014a). CDC Features: 10 things to Know about new autism data. Retrieved from http://www.cdc.gov/features/ dsautismdata/ index.html

Centers for Disease Control and Prevention (2015b). Autism spectrum disorder (ASD): Treatment. Retrieved from http://www.cdc.gov/ncbddd/ autism/treatment.html

Centers for Disease Control and Prevention (2015a). Autism spectrum disorder (ASD): Recommendations and guidelines. Retrieved from http://www.cdc.gov/ncbddd/ autism/hcp-recommendations.html

Centers for Disease Control and Prevention (2018). Autism spectrum disorder (ASD): Signs and symptoms. Retrieved from https://www.cdc.gov/ncbddd/ autism/signs.html

Congress of the United States (1986). Education of the handicapped act amendments of 1986. Retrieved from http://files.eric.ed.gov/fulltext/ED276165.pdf

Creswell, J. W. (2007). *Qualitative inquiry and research design: Choosing among five traditions* (2nd ed.). Thousand Oaks, CA: Sage.

Creswell, J. W. (2013). Qualitative, quantitative, and research design: Choosing among five approaches (3rd ed.). Thousand Oaks, CA: Sage.

Creswell, J. W. & Clark, V. L. P. (2007). *Designing and conducting mixed methods research*. Thousand Oaks, CA: Sage Publications. Retrieved from http://www.sagepub.com/sites/ default/files/upm-binaries/10982_Chapter_4.pdf; http://www.sagepub.com/sites/default/ files/upm-binaries/10983_Chapter_6.pdf

Crimmins, D. B., Durand, V. M., Theurer-Kaufman, K., & Everett, J. (2001). Autism program quality indicators: A self-review and quality improvement guide for schools and programs serving students with autism spectrum disorders [Guide]. New York State Education Department.

Dinnebeil, L. A., Hale, L. M., & Rule, S. (1996). A qualitative analysis of parents' and service coordinators' descriptions of variables that influence collaborative relationships. *Topics in Early Childhood Special Education*, *16*, 322-347. doi: 10.1177/027112149601600305

Doehring, P., & Volkmar, F. R. (2016). Knowledge gaps in ASD research: Short and long term implications for policy. *Journal of Autism and Developmental Disorders*, *46*, 733-736. doi: https://doi.org/10.1007/s10803-015-2683-3

Donaldson, A. L., & Stahmer, A. C. (2014). Team collaboration: The use of behavior principles for serving students with ASD. *Language, Speech, and Hearing Services in Schools, 45*, 261-276. doi: 10.1044/2014_LSHSS-14-0038

Easter Seals (2016). State autism profiles. Retrieved from http://www.easterseals.com/explore resources/living-with-autism/state-autism-profiles.html

Entwistle, V., Firnigl, D., Ryan, M., Francis, J., & Kinghorn, P. (2012). Which experiences of health care delivery matter to service users and why? A critical interpretive synthesis and conceptual map. *Journal of Health Services Research & Policy*, *17*, 70-78. doi: https://doi.org/10.1258/jhsrp.2011.011029

Filipek, P. A. (2005). Medical aspects of autism. In F. R. Volkmar, R. Paul, A. Klin, & D. Cohen, (Eds.), *Handbook of autism and pervasive developmental disorders* (pp. 534-578). Hoboken, NJ: John Wiley & Sons, Inc.

Giorgi, A. (1997). The theory, practice, and evaluation of the phenomenological method as a qualitative research method. *Journal of Phenomenological Psychology*, *28*, 235-260. doi: 10.1163/156916297X00103

Golafshani, N. (2003). Understanding reliability and validity in qualitative research. *The Qualitative Report*, *8*, 597-606. Retrieved from http://nsuworks.nova.edu/tqr/vol8/iss4/6

Golnick, A., Ireland, M., & Wagman Borowsky, I. (2009). Medical homes for children with autism: A physician survey. *Pediatrics*, *123*, 966-971 doi:10.1542/peds.2008-1321

Haase, J. E. (1987). Components of courage in chronically ill adolescents: A phenomenological study. *Advances in Nursing Science*, *9*, 64-80. doi: 10.1097/00012272-198701000-00010

Hutton, A. M., & Caron, S. L. (2005). Experiences of families with children with autism in rural New England. *Focus on Autism and Other Developmental Disabilities*, *20*, 180-189. doi: https://doi.org/10.1177/10883576050200030601

Individuals with Disability Education Act Amendments of 1997 [IDEA]. (1997). Retrieved from http://www2.ed.gov/policy/speced/leg/idea/idea.pdf

Interagency Autism Coordinating Committee [IACC] (2014, April). *IACC Strategic plan For autism spectrum disorder (ASD) research —2013 update.* Retrieved from the U.S. Department of Health and Human Services Interagency Autism Coordinating Committee website: http://iacc.hhs.gov/strategic-plan/2013/index.shtml

Kincaid, D., Knoster, T., Harrower, J., Shannon, P., & Bustamante, S. (2002). Measuring the impact of positive behavior support. *Journal of Positive Behavior Interventions*, *4,* 109-117. doi: 10.1177/109830070200400206

Klin, A., McPartland, J., & Volkmar, F. R. (2005). Asperger syndrome. In F. R. Volkmar, R. Paul, A. Klin, & D. Cohen, (Eds.), *Handbook of autism and pervasive developmental disorders,* (pp. 88-125). Hoboken, NJ: John Wiley & Sons, Inc.

Kohler, F. W. (1999). Examining the services received by young children with autism and their families: A survey of parent responses. *Focus on Autism and Other Developmental Disabilities*, *14*, 150-158. doi: https://doi.org/ 10.1177/108835769901400304

Kvedar, J., Coye, M. J., & Everett, M. (2014). Connected health: A review of technologies and strategies to improve patient care with telemedicine and telehealth. *Health Affairs*, *33*, 194-199. doi: 10.1377/hlthaff.2013.0992

Leigh, J. P., & Du, J. (2015). Brief report: Forecasting the economic burden of autism in 2015 and 2025 in the United States. *Journal of Autism and Developmental Disorders, 45*, 4135-4139. doi: 10.1007/s10803-015-2521-7

Lindgren, S., Wacker, D., Suess, A., Schieltz, K., Pelzel, K., Kopelman, T., …Waldron, D. (2016). Telehealth and autism: Treating challenging behavior at lower cost. *Pediatrics*, *137*, 168-175. doi: 10.1542/peds.2015-2851O

Mazurek, M. O., Curran, A., Burnette, C., & Sohl, K. (2018). ECHO autism STAT: Accelerating early access to autism diagnosis. *Journal of Autism and Developmental Disorders*, *49*, 127. doi: https://doi.org/10.1007/s10803-018-3696-5

Mereoiu, M., Bland, C., Dobbins, N., & Niemeyer, J. A. (2015). Exploring perspectives on child care with families of children with autism. Retrieved from http://ecrp.uiuc.edu/v17n1/mereoiu.html

Merriam, S. B. (2002). *Qualitative research in practice: Examples for discussion and analysis.* San Francisco, CA: Jossey-Bass.

Merriam, S. B., & Tisdell, E. (2016). *Qualitative research: A guide to design and implementation*. San Francisco, CA: Jossey-Bass.

Moustakas, C. (1994). *Phenomenological research methods*. Thousand Oaks, CA: Sage.

Murray, M. M., Ackerman-Spain, K., Williams, E. U., & Ryley, A. T. (2011). Knowledge is power: Empowering the autism community through parent-professional training. *The School Community Journal*, *21*, 19-36. Retrieved from https://files.eric.ed.gov/fulltext/EJ932198.pdf

Nancarrow, S. A., Booth, A., Ariss, S., Smith, T., Enderby, P., & Roots, A. (2013). Ten principles of good interdisciplinary team work. *Human Resources for Health*, *11*, 1-11. Retrieved from http://www.human-resources-health.com/content/11/1/19

National Conference of State Legislatures [NCSL] (2016, February). Autism. Retrieved from http://www.ncsl.org/research/health/autism-policy-issues-overview.aspx

Newschaffer, C. J., & Curran, L. K. (2003). Autism: An emerging health problem. *Public Health Reports*, *118*, 393-399. doi: 10.1093/phr/118.5.393

Nissenbaum, M. S., Tollesfson, N., & Reese, R. M. (2002). The interpretative conference: Sharing a diagnosis of autism with families. *Focus on Autism and Other Developmental Disabilities*, *17*, 30-42. doi: 10.1177/108835760201700103

No Child Left Behind Act of 2001 [§] 110, 32 U.S.C. [§] 3229 (2002).

Nys, H., Welie, S., Garanis-Papadatos, T., & Ploumpidis, D. (2004). Patient capacity in mental health care. *Health Care Analysis*, *12*, 329-337. doi: https://doi.org/10.1007/s10728-004-6640-0

Organization for Autism Research (2018). A parent's guide to research. Retrieved from https://researchautism.org/resources/a-parents-guide-to-research/

Parent-Child Interaction Therapy International (2018). Parent-child interaction therapy (PCIT). Retrieved from http://www.pcit.org/

Peregrin, T. (2014). Enhanced bedside manner heals patient-practitioner communication. *Journal of the Academy of Nutrition and Dietetics*, *114*, 529-532. doi: 10.1016/j.jand.2014.02.005

Rice, C. E., Baio, J., Van Naarden Braun, K., Doernberg, N., Meaney, F. J., & Kirby, R. S. (2007). A public health collaboration for the surveillance of autism spectrum disorders. *Pediatric and Perinatal Epidemiology, 21*, 179-190. doi: https://doi.org/10.1111/j.1365-3016.2007.00801.x

Rogers, S. J. (1996). Brief report: Early intervention in autism. *Journal of Autism and Developmental Disorders*, *26,* 243-246. doi: 10.1007/BF02172020

Ruble, L. A., & Dalrymple, N. J. (2002). COMPASS: A parent-teacher collaborative model for students with autism. *Focus on Autism and Other Developmental Disabilities*, *17*, 76-83. Retrieved from http://autismservicesresearchgroup.weebly.com/uploads/1/3/9/2/13923263/compass.pdf

Sharpe, D. L., & Baker, D. L. (2007). Financial issues associated with having a child with autism. *Journal of Family and Economic Issues*, *28*, 247-264. doi: 10.1007/s10834-007-9059-6

Shenton, A. K. (2004). Strategies for ensuring trustworthiness in qualitative research projects. *Education for Information*, *22*, 63-75. Retrieved from http://www.crec.co.uk/ docs/ Trustworthypaper.pdf

Shogren, K. A., & Plotner, A. J. (2012). Transition planning for students with intellectual disability, autism, or other disabilities: Data from the national longitudinal transition study-2. *Intellectual and Developmental Disabilities*, *50*, 16-30. doi: 10.1352/1934-9556-50.1.16

Sperry, L. A., Whaley, K. T, Shaw, E., & Brame, K. (1999). Services for young children With autism spectrum disorder: Voices of parents and providers. *Infants and Young Children*, *11*, 17-33.

Strauss, A., & Corbin, J. (2007). *Basics of qualitative research: Techniques and procedures* (2nd ed.). Retrieved from http://www.li.suu.edu/library/ circulation/Stein/Comm%206020ksStraussCorbinBasicsQualitativeFall07.pdf

Treating Autism (2013). Medical comorbidities in autism spectrum disorders: A primer for health care professionals and policy makers. Retrieved from http://nationalautismassociation.org/pdf/MedicalComorbiditiesinASD2013.pdf

Treatment and Education of Autistic and Related Communication Handicapped Children (TEACCH) (2016). TEACCH autism program. Retrieved from http://www.teacch.com

Turner, D. W. (2010). Qualitative interview design: A practical guide for novice investigators. *The Qualitative Report*, *15*, 754-760. Retrieved from http://www.nova.edu/ ssss/QR/QR15-3/qid.pdf

United States Department of Education (2004). Individuals with disabilities education improvement act. Retrieved from http://idea.ed.gov/

van Manen, M. (1990). *Researching lived experience: Human science for an action sensitive pedagogy*. London, Ontario: Althouse Press.

Vohra, R., Madhavan, S., Sambamoorthi, U., & St. Peter, C. (2014). Access to services, quality of care, and family impact for children with autism, other developmental disabilities, and other mental health conditions. *Autism: The International Journal of Research and Practice*, *18*, 815-826. doi:https://doi.org/10.1177/ 1362361313512902

Volkmar, F. R., & Klin, A. (2005). Issues in the classification of autism and related conditions. In F. R. Volkmar, R. Paul, A. Klin, & D. Cohen, (Eds.), *Handbook of Autism and pervasive developmental disorders* (pp. 5-41). Hoboken, NJ: John Wiley & Sons, Inc.

Xu, G., Strathearn, L., Liu, B., & Bao, W. (2018). Prevalence of autism spectrum disorder in children and adolescents, 2014-2016. *The Journal of the American Medical Association*, *319*, 81-82. doi: 10.1001/jama.2017.17812

Yell, M., Drasgow, E., & Lowrey, K. A. (2005). No child left behind and students with autism spectrum disorders. *Remedial and Special Education*, *34*, 195-204. doi: 10.1177/ 10883576050200030101

Appendix A: Kohler's (1999) *The Survey of Family Services*

Type and Amount of Services Received: Parents were asked to (1) identify each service that their child/family had received during the past 6 months (i.e., preschool, speech therapy, respite care, therapeutic support staff, parent classes, etc.).

For each service, parents stated the (1) providing agency, (2) beginning and ending (if applicable) dates of delivery, (3) the number of days and hours the service was provided each week, and (4) where the service occurred (home, clinic, etc.).

Accessibility of Services: Parents provided (1) information about the accessibility of each service they had received during the 6-month period (e.g., how they learned about the service, whether it was easy or difficult to find/secure, and (2) how the service was paid for—insurance, medical access, or out-of-pocket funds).

The PI specifically asked whether parents experienced any difficulties accessing their services (e.g., lack of information or assistance from professionals, long waiting lists, etc.).

Nature and Degree of Family Involvement: Parents were asked the following five questions related to their involvement in each individual service:

(1) Do any family members participate in developing or planning this service?

(2) Do family members ever observe the agency person work with your child?

(3) Do parents or other family members participate in the implementing/conducting the service *with* the agency representative?

(4) Are family members able to continue or carry through the service in the absence of the agency person?

(5) Are parents knowledgeable about the agency's method for monitoring their child's progress in this service? (Parents were asked to elaborate on these questions).

Continuity of Services Received from Different Providers: Parents were asked about the methods that different providers used to ensure that their separate services were linked around a common set of child needs and skills:

(1) Do individual providers ever ask you about the services that you receive from other agencies?

(2) Do any providers ever recommend that you inform other agencies of the services that they provide?

(3) Do the different providers ever talk to one another about the services they provide to your child or family?

(4) Do individual providers ever observe one another implementing services with your child?

(5) Do any of the providers collaborate with one another in planning or evaluating services? (For each question, parents indicated whether none, some, or all participating agencies utilized this method to ensure continuity of services).

General Satisfaction and Concerns: Parents were asked to report their overall satisfaction with existing services. Three questions were asked:

(1) Do these services provide important benefits to your child or family? How could these services be improved?

(2) Does your child or family have any additional needs that are not being met by existing services?

(3) Do you have any unresolved problems or concerns at this time?

Appendix B: The Survey of Family Services for Family Caregivers

To the family caregiver: **"Today, I am going to ask you some questions about the autism services your child with autism has received in the last 6 months. These questions will be from your viewpoint as a family caregiver for your child with autism."**

Type and Amount of Services Received

Asked to the family caregiver:

(1) Identify each service that their child/family had received during the past 6 months (i.e., preschool, speech therapy, respite care, therapeutic support staff, parent classes, etc.).

Question: **"What services has your child received during the past 6 months?"**

Services child received during the past 6 months (List each service below)

Asked to the family caregiver:

For each service: (1) providing agency, (2) beginning and ending (if applicable) dates of delivery, (3) the number of days and hours the service was provided each week, and (4) where the service occurred (home, clinic, etc.).

Providing Agency	**Beginning & Ending (if applicable) Dates of delivery**	**Number of days and hours the service was provided**	**Where the service occurred (home, clinic, etc.)**

Accessibility of Services

Asked to the family caregiver:

(1) Information about the accessibility of each service they had received during the 6-month period (e.g., how they learned about the service, whether it was easy or difficult to find/secure).

(2) How the service was paid for (insurance, medical access, or out-of-pocket funds).

“How did you learn about the service?”	**“Was it easy or difficult to find/secure the service?”**	**“What aspects made this easy or difficult to secure?”**	**“How was the service paid for (insurance, medical access, out-of-pocket)?”**

The PI specifically asked whether parents experienced any difficulties accessing their services (e.g., lack of information or assistance from professionals, long waiting lists, etc.).

(3) **“Overall, did you experience any difficulties in accessing services for your child?”**

(3a) If so, **“What aspects made it difficult to secure the service?”**
-or-
(3a) If not, **“What aspects made it easy to secure the service?”**

Nature and Degree of Family Involvement

Asked to the family caregiver:

(1) **“Do any family members participate in developing or planning this service?” “**
  (1a) If yes, **“How often does this happen? (weekly, monthly annually?)”**

(2) **“Do family members ever observe the agency person work with your child?”**
  (2a) If yes, **“How often does this occur? (weekly, monthly annually?)”**

(3) **“Do parents or other family members participate in the implementing/conducting the service *with* the agency representative?”**
  (3a) If yes, **“How often (weekly, monthly annually?)”**

(4) **“Are family members able to continue or carry out the service in the absence of the agency person?”**

(5) **“As a family caregiver, are parents knowledgeable about the agency’s method for monitoring their child’s progress in these services? Please elaborate.”**

Continuity of Services Received from Different Providers

Asked to the family caregiver:

They were asked about the methods that different providers used to ensure that their separate services were linked around a common set of child needs and skills:

(1) **“Do individual providers ever ask you about the services that you receive from other
agencies?”**
  (1a) If yes, **“How often (weekly, monthly annually?)”**

(1) **“Do any providers ever recommend that you inform other agencies of the services that they provide?”**
  (2a) If yes, **“How often (weekly, monthly annually?)”**

(2) **“Do the different providers ever talk to one another about the services they provide to your child or family?”**
  (3a) If yes, **“How often (weekly, monthly annually?)”**

(3) **“Do individual providers ever observe one another implementing services with your child?”**
    (4a) If yes, **“How often (weekly, monthly annually?)”**

(4) **“Do any of the providers collaborate with one another in planning or evaluating services?”**
    (5a) If yes, **“How often (weekly, monthly annually?)”**

General Satisfaction and Concerns

Asked to the family caregiver:

Asked to report their overall satisfaction with existing services. Three questions were asked:

(1) **“Do these services provide important benefits to your child or family?”**
(1a) If so, **“What are these benefits”**
(1b) **“How could these services be improved?”**

(2) **“Does your child or family have any additional needs that are not being met by existing services?”**

(3) **“Do you have any unresolved problems or concerns at this time?”**

Communication and Collaboration

Asked to the family caregiver:

(1) **“What does effective communication with service providers look like? This is in regard to the services your child with autism receives.”**

(2) **“What are the most common methods of communication (Email, text, progress notes, in-person meetings, phone calls, etc.) you use when discussing your child’s autism services with service providers?”**

(3) **“When you are thinking about working with service providers, what things do you find**
most helpful for the autism services your family uses?”

Appendix C: The Survey of Family Services for Service Providers

To the service provider: **"Today, I am going to ask you some questions about the autism services you provide to individuals with autism between the ages of 7 and 21 years old. These questions will be from your viewpoint as a service provider who delivers autism services to individuals with autism for this age group."**

Type and Amount of Services Delivered

Asked to the service provider:

Question: **"What services have you delivered to individuals with ASD ages 7 to 21 during the past 6 months?"**

Services delivered during the past 6 months (List each service below)

Asked to the service provider: **“What services have you delivered to individuals with ASD ages 7 to 21 during the past 6 months?”**

Beginning & Ending (if applicable) dates of delivery	**Number of days and hours the service was provided**	**Where the service occurred (home, clinic, etc.)**

Accessibility of Services

Asked to the service provider:

(5) **“In your experience as a service provider, within the last 6 months how do you ensure that family caregivers learn about the services you provide?”**

(6) **“How are services you provide generally paid for (insurance, medical access, out-of-pocket) by families?”**

(3) **“Do you believe family caregivers experience difficulty in accessing the types of services you provide? Please elaborate.”**

Nature and Degree of Family Involvement

Asked to the service provider:

(1) **"Do you as a service provider participate in developing or planning of services? Please discuss this in detail."**

(2) **"Do family caregivers ever observe you as a service provider working with their children who have ASD?"**
(2a) If yes, **"How often (weekly, monthly annually)?"**

(3) **"Do family caregivers participate in the implementing/conducting of services *with* you as the service provider?"**
(3a) If yes, **"How often (weekly, monthly annually)?"**

(4) **"From your perspective, are family members able to continue or carry through the service in the absence of the agency person?"**
(4a) If no, **"What are some barriers?"**

(5) **"Do you believe that family caregivers are knowledgeable about the agency's method for monitoring their child's progress in the services you provide? Please elaborate."**

Continuity of Services Received from Different Providers

Asked to the service provider:

(1) **"As a service provider do you ever ask family caregivers about the services that they receive from other agencies?"**
(1a) If yes, **"How often (weekly, monthly annually)?"**

(2) **"As a service provider do you ever recommend that family caregivers inform other agencies of the services that they provide?"**
(2a) If yes, **"How often (weekly, monthly annually)?"**

(3) **"As a service provider do you ever talk to other service providers about the services you provide to those with ASD and their families?"**
(3a) If yes, **"How often (weekly, monthly annually)?"**

(4) **"As a service provider do you ever observe other service providers implementing services with individuals with ASD and their families?"**
(4a) If yes, **"How often (weekly, monthly annually)?"**

(5) **“As a service provider do you collaborate with other service providers in planning or evaluating services?”**
    (5a) If yes, **“How often (weekly, monthly annually)?”**

General Satisfaction and Concerns

Asked to the service provider:

(1) **“Do these services provide important benefits to families?”**

(1a) If so, **“What are these benefits?”**

(1b) **“How could these services be improved?”**

(2) **“Do you believe that children and their families have any additional needs that are not being met by existing services?”**

(3) **“Do you have any unresolved problems or concerns at this time?”**

Communication and Collaboration

Asked to the service provider:

(1) **“What does effective communication with family caregivers look like? This is in regard to the autism services you provide to individuals with autism.”**

(2) **“What are the most common methods of communication (Email, text, progress notes, in-person meetings, phone calls, etc.) you use when discussing autism services with family caregivers?”**

(3) **“When you are thinking about working with family caregivers, what things do you find most helpful for the autism services that you deliver?”**

Appendix D: Family Caregiver Demographic Questions

Please read each question carefully and select the appropriate response. The first set of questions applies to you, as the family caregiver. Also, you will answer questions on behalf of your child/adolescent/young adult who was diagnosed with autism/autism spectrum disorder.

Questions about you (the family caregiver):

1. What is your gender?

   ☐ Male
   ☐ Female
   ☐ Other: ___________________

2. What is your current age?

   ___________ (age in years)

3. Which of the following best describes your racial or ethnic background?
   ☐ American Indian/Alaska Native
   ☐ Asian
   ☐ Black/African American
   ☐ Hispanic/Latino
   ☐ Native Hawaiian/Other Pacific Islander
   ☐ White/Caucasian
   ☐ Two or more races
   ☐ Prefer not to respond

4. What is your marital status?
   ☐ Single
   ☐ Married
   ☐ Living with a Partner
   ☐ Divorced/Separated
   ☐ Prefer not to say

5. How many individuals currently live in your household, including yourself?
   __________ (number of individuals)

6. Of these individuals, how many extended family members currently live in your home?
   _______ (number of extended family members)

7. Indicate the members who serve as a support for your family (check all that apply):
   - ☐ Husband/Wife
   - ☐ Boyfriend/Girlfriend
   - ☐ A family member outside of your immediate family (i.e., your mother/father, your sister/brother, etc.)
   - ☐ Family friend
   - ☐ Neighbor
   - ☐ Other (specify): ____________________

8. What is the highest educational level you have completed?
   - ☐ Some high school or less
   - ☐ High school graduate (includes equivalency)
   - ☐ Some college, no degree
   - ☐ Associate's degree
   - ☐ Bachelor's degree
   - ☐ Graduate or professional degree

9. Please indicate your gross annual salary income:
   - ☐ Less than $25,000
   - ☐ $25,000 to $49,999
   - ☐ $50,000 to $74,999
   - ☐ $75,000 to $99,999
   - ☐ $100,000 or more

10. In addition to your child with ASD (who we are asking about for this study), how many other children in your immediate family have a diagnosis of autism or have special needs?

    ________ (number of children)

Questions about your child with autism/autism spectrum disorder:

11. Indicate the age your child was diagnosed with autism/ASD:

______ (years)

12. Indicate who made the diagnosis of autism for your child:
    - ☐ Medical professional (i.e., pediatrician, physician)
    - ☐ Psychologist
    - ☐ Psychiatrist
    - ☐ School/educational professional
    - ☐ Other: ____________________

13. Indicate the current age of your child:

    ______ (years)

14. Does your child receive free or reduced lunch at school?

    - ☐ Yes
    - ☐ No

15. What age was your child when you first became concerned about

    him/her? _________ (months)

16. How many blood-related siblings does your child have? ________

17. How many other siblings does your child have? ________

Appendix E: Service Provider Demographic Questions

Please read each question carefully and select the appropriate response.

Questions about you (the service provider):

1. What is your gender?

   ☐ Male
   ☐ Female
   ☐ Other: _______________

2. What is your current age?

   ___________ (age in years)

3. Which of the following best describes your racial or ethnic background?
   ☐ American Indian/Alaska Native
   ☐ Asian
   ☐ Black/African American
   ☐ Hispanic/Latino
   ☐ Native Hawaiian/Other Pacific Islander
   ☐ White/Caucasian
   ☐ Two or more races
   ☐ Prefer not to respond

4. What is the highest educational level you have completed?

   ☐ Some high school or less
   ☐ High school graduate (includes equivalency)
   ☐ Some college, no degree
   ☐ Associate's degree
   ☐ Bachelor's degree
   ☐ Graduate or professional degree

5. Are you currently a full-time or part-time employee?

   ☐ Full-time (at least 32 hours of work per week)
   ☐ Part-time (less than 32 hours of work per week)

6. In a typical work week, what percentage of your work involves direct, clinical services to individuals with ASD?

   ______________ (%)

7. In a typical work week, how many individuals with ASD do you provide services with each week?

______________ (number of individuals with ASD)

8. How many years have you been working in your current role?

____________ (years)

9. Which area best fits your current professional position? Select one.

☐ Administrator
☐ Consultant
☐ Counselor
☐ Educator
☐ Nurse Practitioner/Physician Assistant
☐ Physician
☐ Psychologist (Clinical, School)
☐ Project Coordinator
☐ Social Worker
☐ Special Education Coordinator
☐ Speech/Language Pathologist
☐ Technical Assistant
☐ Therapist
☐ Other (specify): ___________________

10. How many years have you been working with the ASD population?

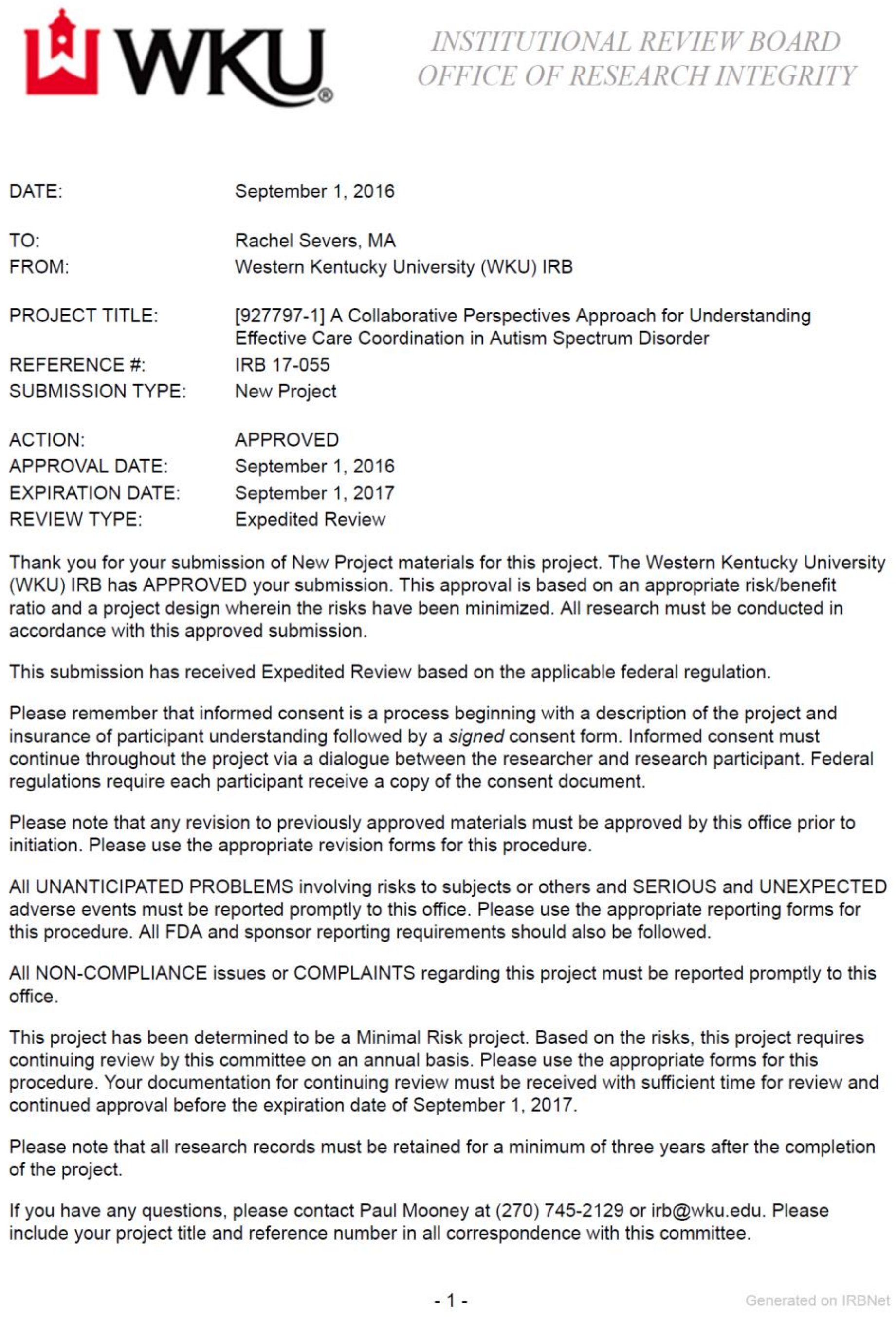
____________ (years)

11. What is the name and location of the company where you work?

___________ (Name of company)

_____________ (City, State)

Appendix F: Human Subjects Review Board Approval Letter



WKU

INSTITUTIONAL REVIEW BOARD
OFFICE OF RESEARCH INTEGRITY

DATE: September 1, 2016

TO: Rachel Severs, MA
FROM: Western Kentucky University (WKU) IRB

PROJECT TITLE: [927797-1] A Collaborative Perspectives Approach for Understanding Effective Care Coordination in Autism Spectrum Disorder
REFERENCE #: IRB 17-055
SUBMISSION TYPE: New Project

ACTION: APPROVED
APPROVAL DATE: September 1, 2016
EXPIRATION DATE: September 1, 2017
REVIEW TYPE: Expedited Review

Thank you for your submission of New Project materials for this project. The Western Kentucky University (WKU) IRB has APPROVED your submission. This approval is based on an appropriate risk/benefit ratio and a project design wherein the risks have been minimized. All research must be conducted in accordance with this approved submission.

This submission has received Expedited Review based on the applicable federal regulation.

Please remember that informed consent is a process beginning with a description of the project and insurance of participant understanding followed by a *signed* consent form. Informed consent must continue throughout the project via a dialogue between the researcher and research participant. Federal regulations require each participant receive a copy of the consent document.

Please note that any revision to previously approved materials must be approved by this office prior to initiation. Please use the appropriate revision forms for this procedure.

All UNANTICIPATED PROBLEMS involving risks to subjects or others and SERIOUS and UNEXPECTED adverse events must be reported promptly to this office. Please use the appropriate reporting forms for this procedure. All FDA and sponsor reporting requirements should also be followed.

All NON-COMPLIANCE issues or COMPLAINTS regarding this project must be reported promptly to this office.

This project has been determined to be a Minimal Risk project. Based on the risks, this project requires continuing review by this committee on an annual basis. Please use the appropriate forms for this procedure. Your documentation for continuing review must be received with sufficient time for review and continued approval before the expiration date of September 1, 2017.

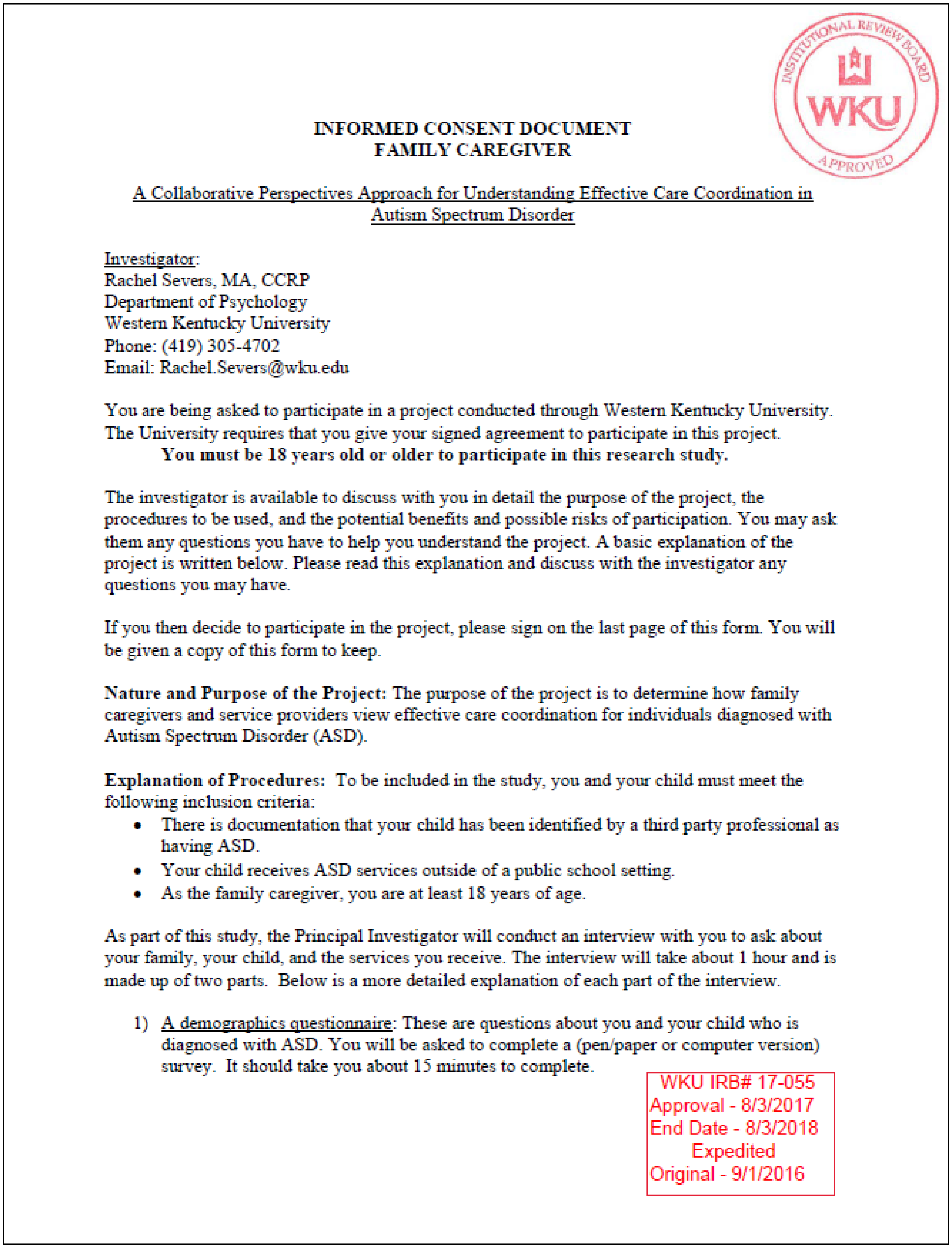
Please note that all research records must be retained for a minimum of three years after the completion of the project.

If you have any questions, please contact Paul Mooney at (270) 745-2129 or irb@wku.edu. Please include your project title and reference number in all correspondence with this committee.

- 1 -

Generated on IRBNet

Appendix G: Informed Consent Form: Family Caregiver



INFORMED CONSENT DOCUMENT
FAMILY CAREGIVER

A Collaborative Perspectives Approach for Understanding Effective Care Coordination in Autism Spectrum Disorder

Investigator:
Rachel Severs, MA, CCRP
Department of Psychology
Western Kentucky University
Phone: (419) 305-4702
Email: Rachel.Severs@wku.edu

You are being asked to participate in a project conducted through Western Kentucky University. The University requires that you give your signed agreement to participate in this project.

You must be 18 years old or older to participate in this research study.

The investigator is available to discuss with you in detail the purpose of the project, the procedures to be used, and the potential benefits and possible risks of participation. You may ask them any questions you have to help you understand the project. A basic explanation of the project is written below. Please read this explanation and discuss with the investigator any questions you may have.

If you then decide to participate in the project, please sign on the last page of this form. You will be given a copy of this form to keep.

Nature and Purpose of the Project: The purpose of the project is to determine how family caregivers and service providers view effective care coordination for individuals diagnosed with Autism Spectrum Disorder (ASD).

Explanation of Procedures: To be included in the study, you and your child must meet the following inclusion criteria:

- There is documentation that your child has been identified by a third party professional as having ASD.
- Your child receives ASD services outside of a public school setting.
- As the family caregiver, you are at least 18 years of age.

As part of this study, the Principal Investigator will conduct an interview with you to ask about your family, your child, and the services you receive. The interview will take about 1 hour and is made up of two parts. Below is a more detailed explanation of each part of the interview.

1) A demographics questionnaire: These are questions about you and your child who is diagnosed with ASD. You will be asked to complete a (pen/paper or computer version) survey. It should take you about 15 minutes to complete.

WKU IRB# 17-055
Approval - 8/3/2017
End Date - 8/3/2018
Expedited
Original - 9/1/2016

2) The Survey for Family Caregivers & Service Providers: The Principal Investigator will ask you some questions and record and/or write down your answers. These are questions that will investigate the types of services your child with ASD receives. Other questions will look at your interactions with service providers, including how you may work together to address your child's needs, your overall satisfaction with services, and any recommendations you might have for improving these services for your child.

Discomfort and Risks: There is no anticipated discomfort while completing the survey questions. Although we will take multiple precautionary steps to protect and safeguard confidentiality, there is still a very small chance that confidentiality will be breached.

Benefits: The results of the study will increase the understanding of how family caregivers and service providers view effective care coordination and communication in regards to service delivery for the ASD population.

Confidentiality: Your name and any other identifiable information will not be released or used in any of the study findings. Your data will be numerically coded for confidentiality and stored in a locked office at Western Kentucky University in Bowling Green, KY. Any data collected will be kept in a password-protected document on a password-protected computer. Any data collected and recorded on hard copy will also be locked and stored securely. The data will be kept secure for a minimum of three years after project completion. Please be aware that the research team may discuss the group results in general terms in a public forum, and you may request a copy of this report. Specific individual information will never be revealed.

Refusal/Withdrawal: Refusal to participate in this study will have no effect on any future services you may be entitled to from the University. Anyone who agrees to participate in this study is free to withdraw from the study at any time with no penalty.

You understand also that it is not possible to identify all potential risks in an experimental procedure, and you believe that reasonable safeguards have been taken to minimize both the known and potential but unknown risks.

____ ________________

Signature of Participant Date

____ ________________

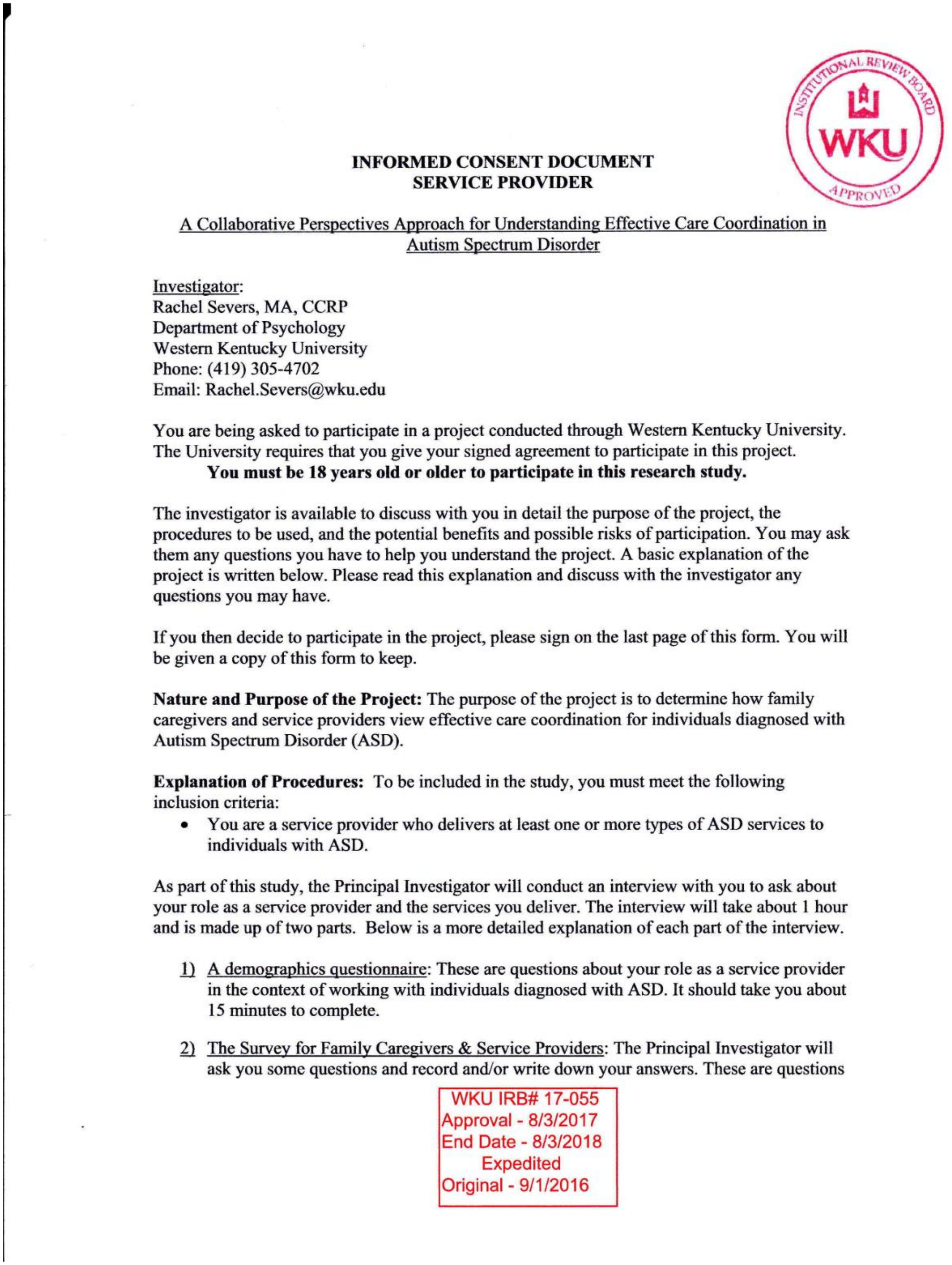
Witness Date

- I agree to the audio/video recording of the research. ***(Initial here)*** __________

THE DATED APPROVAL ON THIS CONSENT FORM INDICATES THAT
THIS PROJECT HAS BEEN REVIEWED AND APPROVED BY
THE WESTERN KENTUCKY UNIVERSITY INSTITUTIONAL REVIEW BOARD
Paul Mooney, Human Protections Administrator
TELEPHONE: (270) 745-2129

WKU IRB# 17-055
Approval - 8/3/2017
End Date - 8/3/2018
Expedited
Original - 9/1/2016

Appendix H: Informed Consent Form: Service Provider



INFORMED CONSENT DOCUMENT
SERVICE PROVIDER

A Collaborative Perspectives Approach for Understanding Effective Care Coordination in Autism Spectrum Disorder

Investigator:
Rachel Severs, MA, CCRP
Department of Psychology
Western Kentucky University
Phone: (419) 305-4702
Email: Rachel.Severs@wku.edu

You are being asked to participate in a project conducted through Western Kentucky University. The University requires that you give your signed agreement to participate in this project.

You must be 18 years old or older to participate in this research study.

The investigator is available to discuss with you in detail the purpose of the project, the procedures to be used, and the potential benefits and possible risks of participation. You may ask them any questions you have to help you understand the project. A basic explanation of the project is written below. Please read this explanation and discuss with the investigator any questions you may have.

If you then decide to participate in the project, please sign on the last page of this form. You will be given a copy of this form to keep.

Nature and Purpose of the Project: The purpose of the project is to determine how family caregivers and service providers view effective care coordination for individuals diagnosed with Autism Spectrum Disorder (ASD).

Explanation of Procedures: To be included in the study, you must meet the following inclusion criteria:

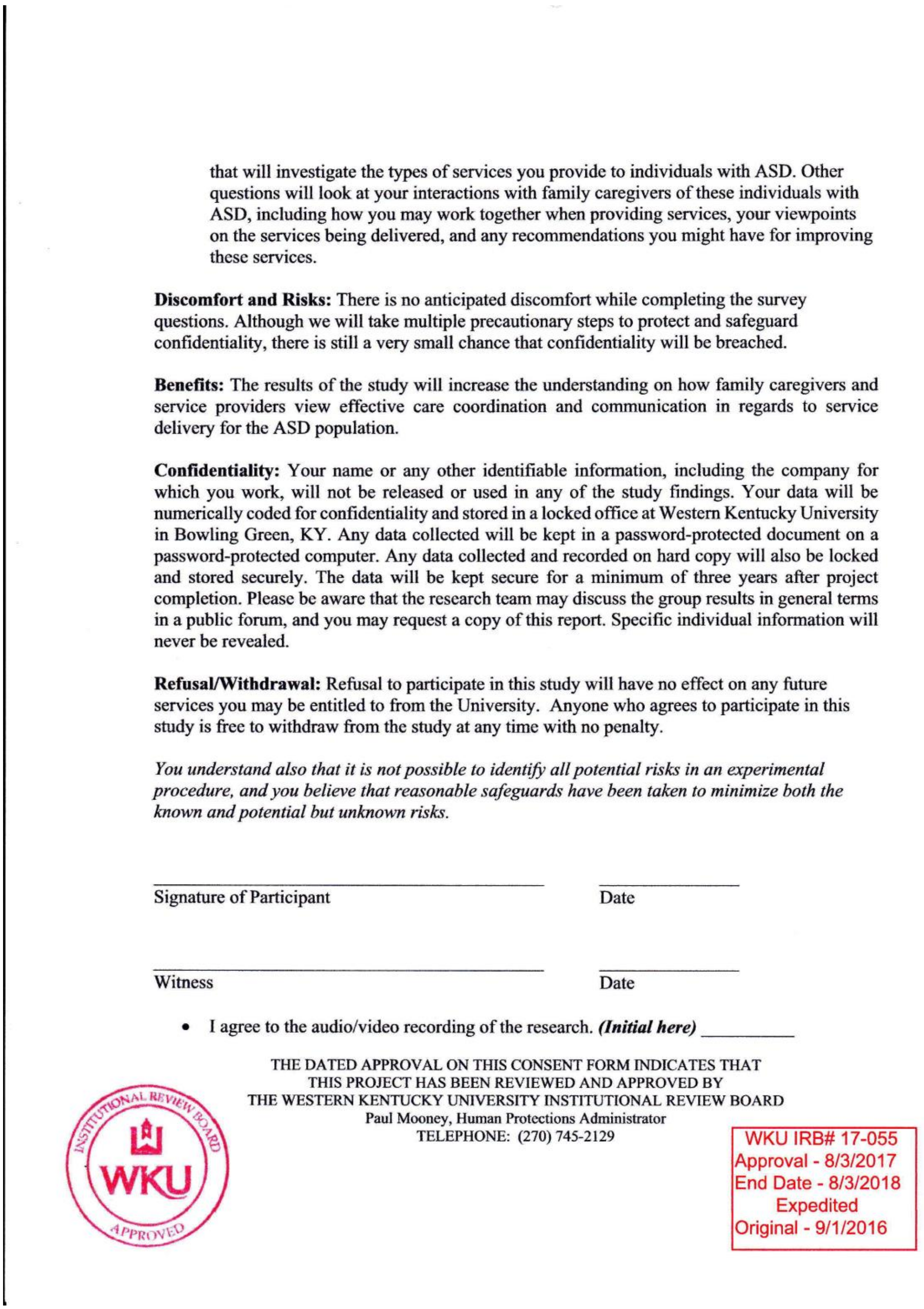
- You are a service provider who delivers at least one or more types of ASD services to individuals with ASD.

As part of this study, the Principal Investigator will conduct an interview with you to ask about your role as a service provider and the services you deliver. The interview will take about 1 hour and is made up of two parts. Below is a more detailed explanation of each part of the interview.

1) A demographics questionnaire: These are questions about your role as a service provider in the context of working with individuals diagnosed with ASD. It should take you about 15 minutes to complete.

2) The Survey for Family Caregivers & Service Providers: The Principal Investigator will ask you some questions and record and/or write down your answers. These are questions

WKU IRB# 17-055
Approval - 8/3/2017
End Date - 8/3/2018
Expedited
Original - 9/1/2016



that will investigate the types of services you provide to individuals with ASD. Other questions will look at your interactions with family caregivers of these individuals with ASD, including how you may work together when providing services, your viewpoints on the services being delivered, and any recommendations you might have for improving these services.

Discomfort and Risks: There is no anticipated discomfort while completing the survey questions. Although we will take multiple precautionary steps to protect and safeguard confidentiality, there is still a very small chance that confidentiality will be breached.

Benefits: The results of the study will increase the understanding on how family caregivers and service providers view effective care coordination and communication in regards to service delivery for the ASD population.

Confidentiality: Your name or any other identifiable information, including the company for which you work, will not be released or used in any of the study findings. Your data will be numerically coded for confidentiality and stored in a locked office at Western Kentucky University in Bowling Green, KY. Any data collected will be kept in a password-protected document on a password-protected computer. Any data collected and recorded on hard copy will also be locked and stored securely. The data will be kept secure for a minimum of three years after project completion. Please be aware that the research team may discuss the group results in general terms in a public forum, and you may request a copy of this report. Specific individual information will never be revealed.

Refusal/Withdrawal: Refusal to participate in this study will have no effect on any future services you may be entitled to from the University. Anyone who agrees to participate in this study is free to withdraw from the study at any time with no penalty.

You understand also that it is not possible to identify all potential risks in an experimental procedure, and you believe that reasonable safeguards have been taken to minimize both the known and potential but unknown risks.

____ ______________

Signature of Participant Date

____ ______________

Witness Date

- I agree to the audio/video recording of the research. ***(Initial here)*** __________

THE DATED APPROVAL ON THIS CONSENT FORM INDICATES THAT
THIS PROJECT HAS BEEN REVIEWED AND APPROVED BY
THE WESTERN KENTUCKY UNIVERSITY INSTITUTIONAL REVIEW BOARD
Paul Mooney, Human Protections Administrator
TELEPHONE: (270) 745-2129

WKU IRB# 17-055
Approval - 8/3/2017
End Date - 8/3/2018
Expedited
Original - 9/1/2016

Appendix I: Questions Not Included in Thematic Analysis

Service Providers

- <u>Type and Amount of Services Received</u>: What services have you delivered to individuals with ASD ages 7 to 21 during the past six months?
- <u>Accessibility of Services</u>: How are services you provide generally paid for by families, whether it's through insurance, medical access, out-of-pocket?
- <u>Nature and Degree of Family Involvement</u>: Do you believe that family caregivers are knowledgeable about the agency's method for monitoring their child's progress in this service? Please elaborate.
- <u>Continuity of Services Received from Different Providers</u>: As a service provider do you ever observe other service providers implementing services with individuals with ASD and their families? How often?
- <u>Continuity of Services Received from Different Providers</u>: As a service provider do you collaborate with other service providers in planning or evaluating services? How often?
- <u>Communication and Collaboration</u>: What are the most common methods of communication (Email, text, progress notes, in-person meetings, phone calls, etc.) you use when discussing autism services with family caregivers?

Family Caregivers

- <u>Type and Amount of Services Received</u>: What services has your child received during the past 6 months?
- <u>Accessibility of Services</u>: How was the service paid for (insurance, medical access, out-of-pocket)?
- <u>Nature and Degree of Family Involvement</u>: As a family caregiver, are parents knowledgeable about the agency's method for monitoring their child's progress in this service? Please elaborate.
- <u>Continuity of Services from Different Providers</u>: Do individual providers ever observe one another implementing services with your child? If yes, How often (weekly, monthly annually?)
- <u>Continuity of Services from Different Providers</u>: Do any of the providers collaborate with one another in planning or evaluating services? If yes, How often (weekly, monthly annually?)
- <u>Communication and Collaboration</u>: What are the most common methods of communication (Email, text, progress notes, in-person meetings, phone calls, etc.) you use when discussing your child's autism services with service providers?