EXPERIENCES OF COLLABORATIVE SERVICE DELIVERY FOR TRANSITION-AGE YOUNG ADULTS WITH ASD

By

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As autism spectrum disorder (ASD) diagnoses increase, demands are placed on families and service providers to coordinate and deliver services aligned with the multi-faceted needs of individuals with ASD. As a result, there is a critical need to understand practices that might facilitate efficient and responsive delivery of care. One such practice is the focus of this study: collaboration. Current research outlines models for and practices comprising collaboration. Yet, practice often falls short of these recommendations, resulting in heightened stress and unmet needs for stakeholders. This issue is particularly pronounced for postsecondary transition-age young adults with ASD, given additional stressors emerging within this period. Therefore, there is a critical need for research to explore the firsthand experiences of young adults with ASD, their caregivers, and their providers in collaborating to coordinate service delivery for the young adults. This study used a qualitative design guided by a phenomenological analytic framework to investigate lived experiences of participants with collaboration. Interviews were conducted with caregivers, providers, and young adults with ASD who are purposefully selected for their engagement in collaborative planning surrounding the transition-related needs of young adults. Data were analyzed for themes across participants and a description of the phenomenon of
collaboration was developed. Findings from the study highlighted roles stakeholders adopt, driving elements, and elements of time pervading across collaborative relationships, providing insight into key elements of successful collaboration shared across teams. Findings from the study contribute to theory, a body of research, and practice recommendations promoting collaboration as an achievable practice to improve postsecondary planning and outcomes for young adults with ASD, their families, and their providers.
CHAPTER 1
INTRODUCTION

Autism Spectrum Disorder (ASD) is a multi-faceted disorder impacting approximately 1 in 59 children and their estimated 6 to 10 million immediate family members in the United States today (Centers for Disease Control and Prevention [CDC], 2018; Organization for Autism Research [OAR], 2010). Individuals with ASD present with a variety of unique and lifelong needs, including those of a medical, psychological, and educational nature (Doshi-Velez, Ge, & Kohane, 2014; Pringle, Colpe, Blumberg, Avila, & Kogan, 2012; Simonoff et al., 2008). As a result, family members of individuals with ASD must work with service providers across multiple domains to meet the needs of the individual with ASD as well as the needs of the family members (Pringle et al., 2012; Shattuck, Wagner, Narendorf, Sterzing, & Hensley, 2011; Taylor & Henninger, 2015). Research and policy indicates that family members and service providers of individuals with ASD should collaborate to coordinate service delivery, in order to ensure efficient and responsive delivery of services (see e.g., Lubetsky, Handen, Lubetsky, & McGonigle, 2014). This issue is particularly salient for families of postsecondary transition-age young adults with ASD, given the increased needs of young adults with ASD, the stress placed on families and young adults during this time period, and the implications of service delivery for postsecondary outcomes of young adults with ASD (Chappel & Sommers, 2010; Lee & Carter, 2012; Westbrook et al., 2015).

Although collaboration among families, adolescents or young adults, and service providers has been identified as a key practice for effective postsecondary transition planning, empirical research remains limited (Noonan, Morningstar, & Erickson, 2008; Smith & Anderson, 2014). Specifically, researchers have pointed to the need for qualitative research to allow families, providers, and adolescents or young adults to articulate challenges and needed supports,
based on their own experiences (Cheak-Zamora, Teti, & First, 2015). In turn, this type of research might facilitate improved postsecondary outcomes for individuals with ASD, and might facilitate improved collaborative service delivery practices for providers and families (Dyke, Bourke, Llewellyn, & Leonard, 2013).

**Purpose and Research Questions**

The purpose of this qualitative study is to describe the lived experiences of caregivers of, service providers for, and young adults with ASD in collaborating to coordinate services to meet the postsecondary transition-related needs of the young adults. A phenomenological methodological approach was adopted, given the suitability of this approach for studying the lived experiences of a group of individuals surrounding a phenomenon (Creswell, 2013; Merriam, 2009; Van Manen, 1990; Van Manen, 2014). Specifically, the phenomenon under investigation is as follows: collaboration among caregivers, service providers, and young adults to coordinate service delivery to meet the postsecondary transition-related needs of the young adult with ASD. The following research question guides this line of inquiry: What are the lived experiences of caregivers of, service providers for, and young adults with ASD in collaborating to coordinate services to meet the transition-related needs of the young adult? Additional sub-questions further guide the inquiry: What factors influence collaboration? How do participants perceive their roles in collaboration? How do participants describe progress toward outcomes resulting from collaboration?

**Definition of Terms**

**Autism Spectrum Disorder**

A lifelong neurodevelopmental disorder characterized by impairments in social-communication and repetitive and restrictive behaviors (American Psychiatric Association)
(APA), 2013). For the purpose of this study, those individuals previously diagnosed with Asperger’s disorder, Rett’s disorder, childhood disintegrative disorder, or pervasive developmental disorder—not otherwise specified will also be included under this umbrella diagnosis.

**Caregivers**

The primary parents, caretakers, or guardians of the individual with ASD. Caregivers are conceptualized as belonging to a larger family unit, which also includes the individual with ASD.

**Collaboration**

This term is used to refer to all stakeholders actively working together to plan for, coordinate, and evaluate services provided to meet the needs of the individual with ASD and his or her family members (i.e., each caregiver and each service provider has a mutual working relationship with all other caregivers or service providers). When appropriate, this term might also refer to the young adult working with his or her caregivers and service providers to plan services. Notably, a variety of terms are used in research literature and policy to refer to this general concept: interdisciplinary collaboration, interprofessional collaboration, partnerships, service integration, multidisciplinary teams, multidisciplinary collaboration, interdisciplinary teams, interdisciplinary practice, collaborative practice, family or parent involvement, family-centered services, teamwork (Perreault & Careau, 2012; Petri, 2010; Summers et al., 2005). However, distinctions do exist between terms. For the purpose of this study, I sought to combine two conceptualizations of working relationships (i.e., partnerships and interdisciplinary/interprofessional collaboration) into one overarching concept (i.e., collaboration). For clarity, the definitions of the two distinct concepts are provided below:
Partnerships

In general, cited definitions for partnerships emphasize the working relationship between family members and service providers, rather than working relationships between providers. For instance, Summers and colleagues define partnerships as “mutually supportive interactions between families and professionals, focused on meeting the needs of children and families, and characterized by a sense of competence, commitment, equality, positive communication, respect, and trust” (2005; p. 66). In general, partnerships are characterized as caregivers and service providers working collaboratively together, with agreed-upon roles, and toward a common goal (Dunst & Paget, 1991). Caregivers and providers offer complementary expertise to one another, solve problems together, and share in decision-making (DeChillo, Koren, and Schultze, 1994; Lucyshyn, Horner, Dunlap, Albin, and Ben, 2002; Turnbull, Turbiville, & Turnbull, 2000).

Interdisciplinary/interprofessional collaboration

Literature on interdisciplinary/interprofessional collaboration generally emphasizes working relationships between various providers, rather than between caregivers and providers. For instance, researchers have defined interdisciplinary collaboration as a process by which providers from different disciplines work together to make decisions and achieve a common goal related to a client’s needs (Banach & Couse, 2012; Berg-Weger & Schneider, 1998; Bronstein, 2003; Petri, 2010). Similarly, researchers define interprofessional collaboration as a process by which different providers work together to take action to achieve a goal or improve service delivery (D’Amour et al., 2005; Zwarenstein, Goldman, & Reeves, 2009).

Service Providers

The term “providers” refers to those professionals providing individuals with ASD or their family members with medical, psychological, allied health, educational, or other support
services. Providers might include speech/language pathologists, occupational therapists, physical therapists, behavioral therapists, counselors, vocational rehabilitation providers, pediatricians, assistive technology specialists, personal care assistants, or other related providers.

Transition

Any reference to transition in this study (e.g., transition-age, transition-related needs) refers to the period of time in which the young adult with ASD, his or her caregivers, and his or her service providers are planning for the individual’s transition from high school to postsecondary settings. This period starts when transition planning starts, whether formally (i.e., by age 16 years per law) or informally (i.e., sooner than age 16 years), and ends when the individual graduates high school (i.e., age 22 years).
CHAPTER 2
LITERATURE REVIEW

The following chapter describes aspects of service delivery as they apply to children, adolescents, and young adults with ASD in order to 1) provide a frame of reference for general service delivery considerations; and 2) highlight the significant need for research surrounding postsecondary transitions. First, a brief description of current diagnostic and service use considerations surrounding individuals with ASD is provided. Second, an overview of service delivery for individuals with ASD and their families is described. This overview includes a review of the history of service delivery in the United States, current laws and policies guiding service delivery in the United States, available services, transition planning, and families roles’ in coordinating these services. Third, models of collaborative service delivery, including discussion of contributing factors, resulting outcomes, and ongoing need for research are reviewed. Fourth, current empirical literature regarding caregivers’ and service providers’ experiences with coordinating service delivery as part of collaborative relationships, including specifically in relation to meeting the transition-related needs of young adults with ASD is described. Fifth, a summary of the literature review, as related to the need for the current study is provided. Finally, the family systems theoretical framework that will guide the current study is outlined.

Individuals with Autism Spectrum Disorder

ASD is a complex, lifelong disorder characterized by social-communication impairments and repetitive and restrictive behaviors (APA, 2013). Recent estimates suggest that approximately 1 in 59 children are diagnosed with ASD in the United States (CDC, 2018), with estimates suggesting as many as 1 in 50 children are diagnosed with ASD in schools (Blumberg et al., 2013). Boys are diagnosed with ASD four times more often than girls, and the disorder is
prevalent across various cultural groups, although detection may be delayed among lower-SES and cultural minority groups. Current research suggests that ASD is genetically-linked, although the exact nature of this link has not been determined. Prognosis for individuals with ASD is typically more positive for those individuals with fewer intellectual or language impairments, although only a minority of adults with ASD currently live or work independently (APA, 2013).

Of individuals diagnosed with ASD, estimates suggest that 94% of these individuals have special healthcare needs that necessitate provision of healthcare or related services (Pringle et al., 2012). For instance, among one clinical sample of 13,740 individuals diagnosed with ASD, 87.8% experienced auditory disorders and infections, 77.5% experienced seizures, 33% experienced psychiatric disorders (e.g., anxiety, attention-deficit/hyperactivity disorder, depression, bipolar disorder, schizophrenia, conduct disorders), and 24.3% experienced gastrointestinal disorders (Doshi-Velez, et al., 2014). Among another population-derived cohort of 112 individuals diagnosed with ASD, 70% experienced at least one comorbid disorder (Simonoff et al., 2008). The most common comorbid disorders were social anxiety disorder, attention-deficit/hyperactivity disorder, and oppositional defiant disorder (Simonoff et al., 2008). In addition, research suggests that young adults with ASD are at particular risk for developing comorbid psychiatric disorders, as compared to young adults in the general population (Bellini, 2004). Thus, there is a critical for individuals with ASD to receive services aligned with their individualized needs.

Regarding service receipt, recent estimates suggest over half of school-age children with ASD require three or more services to meet their needs (Pringle et al., 2012). These services include behavioral interventions, occupational therapy, social skills trainings, and speech/language therapy (Pringle et al., 2012). In addition, over half of school-age children with
ASD use one or more psychotropic medications, requiring ongoing access to medical services and supports (Pringle et al., 2012). Likewise, estimates suggest adolescents who are still enrolled in school use an average of three services (Taylor & Henninger, 2015). These services most often include psychological or mental health services, speech/language services, career counseling or job skills training services, in-home or in-classroom aides, and medical services (Taylor & Henninger, 2015). Finally, estimates suggest that 23.5% of young adults with ASD use medical services, 35% use mental health services, 41.9% use case management services, and 9.1% use speech therapy services (Shattuck et al., 2011).

Despite the widespread service use among school-age individuals with ASD, estimates regarding post-school outcomes among young adults with ASD remain grim. For instance, Shattuck and colleagues (2012), examined post-school outcomes among 500 individuals with ASD, based on National Longitudinal Transition Study 2 (NLTS2) data. Their analyses indicated 34.7% of young adults with ASD had ever attended college and 55.1% had ever held paid employment since graduating high school. However, among individuals graduating high school in the past two years, the rate of disengagement from employment or education was over 50%. This rate was greater than that for individuals with a language impairment, learning disability, or intellectual disability. Furthermore, Shattuck and colleagues’ (2011) estimates suggest 39.1% of young adults with ASD report no service use since high school, despite a need for services. Researchers hypothesize that the sudden end of structured programs (e.g., educational programs, pediatric services), distances from programming, and a lack of knowledge by young adults with ASD regarding how to navigate adult systems of service delivery may account for adulthood disengagement (Shattuck et al., 2011).
In addition, estimates suggest that the lifetime cost associated with providing services to individuals with ASD averages around 3.2 million dollars per individual, placing significant financial demands on federal, state, community, and funding programs (Ganz, 2007; Shattuck et al., 2011). The greatest amount of this cost is incurred during the individual’s adulthood years, and this amount is greater than that for individuals who are not diagnosed with ASD (Ganz, 2007). Therefore, an understanding of factors that might contribute to efficient and effective delivery of services in a manner that addresses the pervasive, lifelong, and individualized needs of individuals with ASD and their families emerges as critical, particularly in relation to promoting post-school outcomes for the individuals with ASD.

**Overview of Service Delivery for Individuals with ASD**

Given the prevalence of ASD diagnoses, the multi-faceted needs of individuals with ASD, and the widespread use of services among individuals with ASD, the demands placed on current service delivery systems continue to increase (Moodie-Dyer, Joyce, Anderson-Butcher, & Hoffman, 2014). To best understand the factors that might lead to efficient and effective service delivery, an examination of the characteristics of current service delivery systems is necessary. This examination will be framed within historical reviews of services for individuals with disabilities in general, the rise of ASD as a diagnosis and related services, and laws and policies guiding service delivery. This examination also will delineate types of services commonly used by individuals with ASD and their families today, and the role of families and individuals with ASD in planning for services. This section will review broad considerations regarding service delivery for individuals with ASD, in addition to discussion of issues that apply specifically to transition-age individuals with ASD.
Historical Review of Service Delivery for Individuals with Disabilities

Within the United States, the conceptualization of services for individuals with disabilities has shifted dramatically since the beginning of the 20th century. This shift has included changing ideas in regard to theoretical conceptions of service delivery, the best location for service delivery, the role of families in service delivery, and the types of services provided (Wehman, 1998). As outlined by Caldwell (1973), the 20th century was governed by three major periods of disability service paradigms. The first major period spanned the first half of the 20th century and can be characterized as the ‘forget and hide’ period. During this period, individuals with disabilities were generally hidden from the public so as to ‘avoid embarrassing’ their families. The second major period spanned the 1950s to 1960s and can be characterized as the ‘screen and segregate’ period. During this period, individuals were tested, labeled, and placed within segregated institutions in order to ‘protect’ these individuals and aid in their functioning.

Finally, the third major period began in the 1970s and continues to exist today (Wehman, 1998). This period is founded on the efforts of parents of individuals with disabilities during the deinstitutionalization and disability rights movements of the 1950s and 1960s. During this time, parents advocated for and connected their children to community-based services, rather than those provided in segregated institutions (Jackson, Ryndak, & Wehmeyer, 2008). In turn, the ‘identify and help’ period emerged in the 1970s, characterized by efforts for early identification and interventions for individuals with disabilities. Families and service providers sought to, and continue to seek to, provide services as early as possible, address individuals’ disability symptomology, support families, and promote achievement of an individual’s full potential.
Historical Review of ASD Diagnoses and Services

Although individuals with ASD were undoubtedly subsumed among those individuals broadly defined as having disabilities and impacted by the aforementioned periods of disability service paradigms, ASD as a unique disability was not identified until the 1940s or officially recognized as a separate diagnosis until 1980. In 1943, Leo Kanner first described individuals displaying those patterns of social-communication deficits and restricted and repetitive behaviors characterizing ASD diagnoses today (Baker 2013; Thompson, 2013). Following Kanner’s initial descriptions and similar descriptions by Hans Asperger in 1944, various attempts were made at diagnosing ASD on a ‘catch-as-can’ basis (Thompson, 2013). In the 1960s and 1970s, attempts to intervene on ASD-type symptomology using psychoanalytic therapy techniques dominated, but outcomes were generally unsuccessful (Thompson, 2013). For instance, Langdell (1973) estimated that ‘best outcomes’ for individuals were obtained in an average of 14.8% of cases utilizing these techniques. Further, DeMyer and colleagues (1973) estimated that 1 to 2% of individuals diagnosed with ASD would recover to ‘normal’ functioning, 5 to 15% would recover to ‘borderline’ functioning, and 16 to 25% would recover to ‘fair’ functioning but the majority of individuals with ASD (60 to 75%) would remain at a ‘poor’ level of functioning despite intervention efforts. In general, the consensus existed among practitioners that prognosis of individuals with ASD symptoms was poor and little could be done to improve functioning (Thompson, 2013).

However, also during the 1960s and 1970s, research emerged that would serve as the foundation for efficacious intervention approaches today. As described by Thompson (2013), this research was generally founded within three theoretical traditions that continue to guide modern ASD diagnostic efforts and service conceptualization. First, foundational research
within clinical nosology and epidemiology traditions was conducted, informing modern diagnostic practices and instruments such as the Childhood Autism Rating Scale (CARS), the Autism Diagnostic Observation Schedule (ADOS), the Autism Diagnostic Interview (ADI), and the Modified Checklist for Autism in Toddlers (M-CHAT). Second, important research guided by developmental theory took place, laying the foundation for intervention practices today such as Relationship Development Intervention (RDI), Floortime, and the Treatment and Education of Autistic and Communication Handicapped Children (TEACCH) program. This research was grounded on the ideas of Piaget, Vygotsky, Bowlby, and Chomsky. Third, behavior analytic research flourished, particularly in relation to early intervention services for children with ASD. Seminal studies in this period included those by Ferster (1961), Wolf, Risley and Mees, (1964) and Løvaas, (1967) and were largely grounded in the work of Skinner. The influence of this work is seen in various intervention approaches today, such as Applied Behavior Analysis (ABA), Early Intensive Behavioral Intervention (EIBI), Positive Behavioral Supports (PBS), Verbal Behavior Intervention (VBI), and Pivotal Response Therapy (PRT).

Following this foundational work, strides were taken in both defining ASD as a diagnosis and developing instruments to aid in diagnostic decision-making. ‘Autistic disorder’ was officially recognized as a diagnosis for the first time in the 1980 publication of the Diagnostic and Statistical Manual of Mental Disorders, 3rd Edition (DSM-III; APA, 1980). In 1987, Pervasive Developmental Disorder–Not Otherwise Specified (PDD-NOS) was added to the Revised Edition of the DSM-III (DSM-III-R) as a related and subclinical version of Autistic disorder (APA, 1987). In 1994, Asperger’s disorder was added to the 4th Edition of the DSM (DSM-IV) as a related version of Autistic disorder characterizing individuals with lessened language and cognitive impairments (APA, 1994). In addition, Lord and colleagues published
the ADOS in 1989, aiding in systematic identification of autism diagnoses. Also during this time, a landmark study by Løvaas (1987) demonstrated that EIBI services could result in the long-term lessening of ASD symptoms for diagnosed children, laying the foundation for a plethora of intervention efforts in the coming decades.

Beginning in the 1990s and following the turn of the 21st century, services for individuals with ASD and their families began to improve dramatically (Baker, 2013). Prior to the 21st century, ‘best practice’ of service delivery was guided by the view that service providers should tell parents what was best for their children, given their knowledge and training. However, following a family-centered paradigm shift at the end of the 20th century, the conceptualization of ‘best practice’ of service delivery shifted. Service providers began to acknowledge that families and their needs should exist as the driving force behind service delivery, with families’ views shaping the types and range of services offered to individuals with ASD (Feinberg & Vacca, 2000). In 1994, ASD was first recognized as a disability classification under Individuals with Disabilities Education Act (IDEA) legislation, marking a shift from practices of the 1970s and 1980s of educating children with ASD in classrooms for students with severe intellectual disabilities or emotional disturbance (Thompson, 2013). In addition, there has been a surge of studies attempting to identify what constitutes ‘best practice’ and ‘evidence-based practice’ in service delivery for individuals with ASD and their families in recent decades (Thompson, 2013).

Although research and practice related to service delivery for individuals with ASD and their families has been marked with much success in the past 25 years, challenges continue to exist related to diagnoses and service delivery. For instance, numerous studies have identified potentially effective intervention methods for individuals with ASD, although challenges exist in
identifying the necessary intensity of services and in matching services to individuals’ needs and phenotypic characteristics (Thompson, 2013). In the 2013 publication of the DSM-5, the definition of ASD shifted from categorically different ASD diagnoses to an overall umbrella ASD (APA, 2013). This changing conceptualization was met with much uncertainty regarding which individuals would meet updated diagnostic criteria and which individuals would benefit from services supported by evidence obtained from individuals meeting old diagnostic criteria. In addition, challenges related to service delivery are more pronounced than ever due to increasing identification of individuals with ASD, differing theoretical perspectives regarding intervention efforts, insufficient ASD-related training of service providers, and limited political willingness to invest in treatments (Baker, 2013; Thompson, 2013). Overall, however, tremendous progress has been made in the history of ASD diagnostic and intervention services. For instance, children with ASD are now educated alongside their typically-developing peers, attend college, and hold jobs (Thompson, 2013). Although no ‘cure’ for ASD exists and ‘residual effects’ of the disorder will always exist in diagnosed individuals, much progress has been made to improve the lives of individuals with ASD and their families (Thompson, 2013).

**Review of Relevant Legislation and Policies**

A range of laws and policies at the federal, state, and local levels interact to govern provision of services to individuals with ASD and their families in the United States today. These laws vary considerably across states, differ across domains of service delivery, and have varying degrees of applicability to individuals and families depending on the individual’s age and the specific nature of the individual’s needs (Lubetsky et al., 2014). In general, these laws and policies necessitate varying degrees of family and child involvement in planning for service delivery, although each calls for the delivery and funding of high-quality services for individuals.
with ASD and their families (Lubetsky et al., 2014; Swiezy, Stuart, & Korzekwa, 2008). In addition, states are increasingly initiating policies to promote collaboration among service providers and between service providers and families in planning for services for individuals with ASD (Lubetsky et al., 2014).

At the federal level, laws and policies historically have governed provision of educational services and mental health services, with increasing calls for collaboration among families and service providers in establishing plans (Blue-Banning, Summers, Frankland, Nelson, & Beegle, 2004). For instance, children with disabilities, including those with ASD, first were afforded the right to a Free and Appropriate Public Education within the 1975 authorization of the Education for All Handicapped Children Act (Wehman, 1998). Although parents of children with disabilities were not guaranteed officially the right to provide input regarding their child’s educational evaluations and plans until the 1997 reauthorization of the Individuals with Disabilities Education Act (IDEA; formerly EHA) legislation, EHA acknowledged the importance of parental involvement in educational planning, particularly in constructing the child’s Individualized Educational Program (IEP) and monitoring progress toward goals (Bezdek, Summers, & Turnbull, 2010; Wehman, 1998). In regard to collaboration for transition planning specifically, collaboration among families, service providers, and individuals with disabilities was first mandated officially in the 1990 reauthorization of IDEA (Chappel & Somers, 2010). In 1990, families and individuals with ASD were afforded the right to 1) documentation of transition plans in the student’s IEP; 2) plans that included transition goals, services, and a course of study designed to meet the student’s individual needs; and 3) formal connection to outside agencies (e.g., vocational rehabilitation) to support the student’s transition out of school.
Current Individuals with Disabilities Education Improvement Act (IDEIA) legislation (most recently re-authorized in 2004) guarantees receipt of individualized services such as instructional modifications and accommodations, related services (e.g., speech/language therapy, occupational therapy, counseling services), and behavior supports and intervention plans to ensure educational progress of all students with disabilities alongside their typically-developing peers to the maximum extent possible (Lubetsky et al., 2014; Swiezy et al., 2008). Regarding transition services, aforementioned expectations continue to stand. Currently, transition planning must begin by age 16, and the plan should delineate students’ present level of performance, exposure to instruction, use of related services, accumulation of community experiences, and postsecondary employment, education, and living goals. The plan should outline necessary services and supports to achieve goals, state intended outcomes, and be based on students’ individual strengths. Both the student and his or her caregivers should participate fully in this planning, along with representations from outside service agencies to ensure coordination of services.

Similarly, Section 504 of the Rehabilitation Act of 1973, the No Child Left Behind Act of 2001, and the Every Student Succeeds Act of 2015 guarantee students with disabilities necessary supports and all students, including those with disabilities, access to high-quality instruction and expectations in educational settings (Lubetsky et al., 2014; Swiezy et al., 2008). In regard to transition services, the Act calls for collaboration among vocational rehabilitation and related organizations with school personnel to facilitate delivery of supports for an individual’s transition-related needs. Individuals with disabilities should receive an Individualized Program for Employment (IPE) to guide delivery of transition-related services and supports. In addition, federal laws such as the Communities’ and Children’s Mental Health Systems Improvement Act
point to the importance of partnerships between service providers and families for service provision for children with ASD (Blue-Banning et al., 2004).

At the state or local level, the following laws and policies might be applicable to a given individual with ASD and his or her family throughout the individual’s life: State Department of Education legislation, local education system policies, early intervention services, Medicaid or state waiver policies, services afforded through Departments of Development or Intellectual Disabilities/Autism, state agencies for technology assistance, services afforded through Offices of Vocational Rehabilitation, postsecondary education disability support services, community mental health services, independent living centers, medical care policies, and private insurance policies, among others (Lubetsky et al., 2014; Roberts, 2010). These laws and policies most often create funding streams to support provision of services related to screening, diagnostic assessment, information and referrals, early intervention, behavioral supports, in-home care, parent skill training and education, respite care, case management, supportive housing, and supported employment (Feinberg & Vacca, 2000; Lubetsky et al., 2014; Shattuck & Grosse, 2007). Regarding competitive employment for individuals with disabilities specifically, the Workforce Initiative Opportunity Act of 2014 and the Disability Employment Initiative seek to increase access to, training for, and support within competitive employment settings for individuals with disabilities (United States Department of Labor, 2017). In addition, Vocational Rehabilitation services seek to promote access to and maintenance of employment for individuals with disabilities by providing vocational assessments, counseling services, job search supports, job training, and on-the-job supports (Department on Disability Services, 2018).
Types of Services Utilized

Caregivers of individuals with ASD report using a variety of support services, including medical, psychological, allied health, educational, and family support services, among others (Lubetsky et al., 2014; Swiezy et al., 2008; Vohra, Madhavan, Sambamoorthi, & St Peter, 2014). These services might be dichotomized between those of a ‘formal’ nature (i.e., delivered from service providers, agencies, schools) and those of an ‘informal’ nature (i.e., supports from other individuals in a family’s life) (Symon, 2001). Use of services vary according to the needs of children and families, with selection of services informed by a child’s presenting symptomology and the match of services to a given family’s cultural values, economic supports, and social supports (Jensen & Spannagel, 2011). Further, the nature of service use by a family is likely to change over time, given the child’s reaction to and progress from previous services. For instance, Jensen and Spannagel proposed a model of service use in which a family’s use of services is related in a linear fashion to ‘cognitive resources,’ severity of symptoms, and skill deficits of the child with ASD. As the child develops skills and improves in functioning, service use decreases. The authors also delineate service philosophies for children with lower levels of skills versus those with higher levels of skills. That is, children with ‘lower’ levels of skills likely receive more ‘treatment’-focused services intended to target specific behaviors, teach skills, and increase functioning, whereas children with ‘higher’ levels of skills likely receive more ‘management’-focused services intended to put appropriate environmental supports in place and promote maintenance of skills across time. Overall, service use ranges from that of an intensive nature to that provided in an outpatient setting on a periodic basis and can span weeks to years (Jensen & Spannagel, 2011)
Given the wide range of presenting symptoms and concerns related to ASD, families of individuals with ASD often use a range of services from various providers throughout the individual’s life. Families might seek medical services from pediatricians, neurologists, dentists, nurses, social workers, and other medical specialists (Lubetsky et al., 2014; Symon, 2001). These medical providers might provide ‘routine’ health care and pharmacological management as well as specialized care related to seizures, hypotonia, sleep disorder, gastrointestinal complaints (e.g., toileting/bowel complaints), and allergies (Gurney, McPheeters, & Davis, 2006; Jensen & Spannagel, 2011; Lubetsky et al., 2014). Families might seek psychological services from psychologists or behavior analysts related to diagnostic services, parent support services, parent behavioral skills training, behavior analytic interventions, or other therapeutic interventions to teach coping skills, social skills, or cognitive restructuring (Jensen & Spannagel, 2011; Lubetsky et al., 2014). Regarding allied health needs, families might seek services from speech/language therapists, occupational therapists, physical therapists, music therapists, or recreational therapists related to the individual’s specific needs (Jensen & Spannagel, 2011; Lubetsky et al., 2014; Symon, 2001). Service use in this domain might also include providers of complementary and alternative medicine (CAM) techniques (Jensen & Spannagel, 2011).

To meet their educational needs, school-age children might be afforded services from special and general education teachers, speech/language therapists, occupational therapists, physical therapists, behavior specialists, and counselors, as determined by the impact of the child’s disability on his or her educational progress and the child’s need in a given year (Jensen & Spannagel, 2011; Lubetsky et al., 2014; Symon, 2001). In addition, families might seek ‘formal’ sources of support such as support groups, advocacy groups, and respite care providers or ‘informal’ sources of support such as support from other parents of children with disabilities,
other family members, friends, or participation in recreational activities (Lubetsky et al., 2014; Symon, 2001). Finally, for postsecondary transition-age individuals with ASD, school-based transition facilitators (i.e., a designated individual or school psychologists, special education teachers, school counselors, vocational counselors, social workers), vocational counselors, job coaches, postsecondary education support personnel, and independent living support personnel might provide supports (Hendricks & Wehman, 2009; Lee & Carter, 2012).

**Overview of Transition Planning**

In relation to the present study, a specific overview of ‘best practice’ delivery of services to promote transition planning is provided. Transition planning is a multi-faceted process that is guided by aforementioned laws and policies and includes delivery of a range of services such as those previously discussed. Several researchers offer a number of suggestions regarding components and strategies to include when developing transition plans for an individual with ASD. For instance, transition plans must be appropriately individualized and guided by the individual student’s strengths, aspirations, and needs (Chappel & Somers, 2010; Lee & Carter, 2012). To do so, support personnel should assess, interview, and observe the student and his or her family members (Chapel & Sommers, 2010). Goals for transition-age individuals should include development of self-advocacy skills, social skills, vocational skills, and independent living skills (Chappel & Sommers, 2010; Lee & Carter, 2012). Support personnel should facilitate on-the-job experiences for the individual before he or she graduates, discuss necessary job supports, discuss living arrangements for the individual, and plan for the individual’s involvement in community activities (Chappel & Sommers, 2010; Hendricks & Wehman, 2009; Lee & Carter, 2012). This planning should begin at least 3 to 4 years before the individual graduates from high school, and the individual, his or her family members, school-based
providers, and agency-based or community-based providers should collaborate actively as part of the transition planning team (Chappel & Sommers, 2010; Lee & Carter, 2012).

**Role of Families in Service Delivery**

Given the multitude of service providers with whom an individual with ASD might interact in his or her lifetime, significant demands are placed on the estimated 6 to 10 million immediate family members of and service delivery providers for individuals with ASD (Moodie-Dyer et al., 2014; OAR, 2010). Demands in navigating service delivery systems increase for families after a child turns three years old, at which time families must transition from more coordinated IDEA Part C services to separate systems of care governed by a range of laws and policies (Feinberg & Vacca, 2000). For school-age children, families most often must take the lead in researching and identifying available services and applicable laws and policies, locating services for which they qualify, and paying for services for their child with ASD (Jensen & Spannagel, 2011; Lubetsky et al., 2014). In general, no centralized source of information exists for these families, making navigation an extremely daunting task for families (Lubetsky et al., 2014). For transition-age individuals with ASD, families serve an important role in informing necessary supports and appropriate plans for the child with ASD, often taking the lead in coordinating efforts (Cai & Richdale, 2016; Hendricks & Wehman, 2009; Lee & Carter, 2012).

As a result of the complex task of navigating service delivery, families of children and adolescents or young adults with ASD are more likely than families of individuals with any other special healthcare needs or related developmental disabilities to report unmet regular, specialty, or therapeutic care needs (Brachlow, Ness, McPheeters, & Gurney, 2007; Chiri & Warfield, 2012; Kogan et al., 2008; Tregnago & Cheak-Zamora, 2012), including difficulty with obtaining information about available services and difficulty with accessing school and community-based
services (Montes, Halterman, & Magyar, 2009; Taylor & Henninger, 2015; Vohra et al., 2014). In addition, when families are able to locate services, they generally report less satisfaction with services (Siklos & Kerns, 2006), inadequate insurance coverage (Taylor & Henninger, 2015; Vohra et al., 2014), higher healthcare costs (Taylor & Henninger, 2015; Tregnago & Cheak-Zamora, 2012), lack of shared decision-making and care coordination with service providers (Vohra et al., 2014), and heightened stress and anxiety within the family related to coordination of services (Dyke et al., 2013; Newsome, 2000; Russa, Matthews, & Owen-DeSchryver, 2015; Smith & Anderson, 2014). Young adults with ASD also describe feelings of stress and anxiety, particularly as it relates to uncertainty about receipt of services to promote access to postsecondary settings (Cheak-Zamora et al., 2015; Newsome, 2000).

As a result, there is a critical need to investigate factors that promote service delivery for individuals with ASD in a manner that best meets the needs of the individual and his or her family members. This need is particularly salient for transition-age individuals with ASD, given the multi-faceted nature of transition planning and the direct implications transition planning holds for life outcomes of individuals with ASD and their families (Westbrook et al., 2015). Therefore, one such critical factor, collaboration, will be the focus of this study. Specifically, this study will examine collaboration among family members of individuals with ASD, their service providers, and the individuals with ASD themselves, in relation to coordinating service delivery to meet the transition-related needs of young adults with ASD.

**Review of Collaborative Service Delivery**

Within the educational field, the importance of family-provider partnerships (i.e., between a family member and a provider) as well as interdisciplinary/interprofessional collaboration (i.e., between separate providers) has long been recognized (Haddara & Lingard,
In particular, researchers indicate the importance of collaboration for transition planning (Hendricks & Wehman, 2009; Noonan et al., 2008). In the medical field, the World Health Organization (WHO) first called for interdisciplinary collaboration as essential to ensure success of healthcare in 1978 (Petri, 2010), although this view is becoming increasingly recognized as important across medical professionals today (Haddara & Lingard, 2013). Further, interprofessional collaboration has been cited as key to increasing the effectiveness of healthcare services (D'Amour, Ferrada-Videla, Rodriguez, & Beaulieu, 2005). To better understand the implications of collaboration in practice, this section provides a review of literature regarding collaborative service delivery. Specifically, the purpose of this section is to: 1) review factors facilitating collaboration; 2) discuss proposed frameworks and models for collaboration; 3) discuss positive outcomes attributed to collaboration; 4) outline challenges and barriers to collaboration; and 5) briefly discuss the ongoing need for clarity of terms and factors contributing to practice, particularly for transition-age individuals with ASD.

**Factors Impacting Delivery of Collaborative Services**

For the purpose of this section, factors impacting collaboration in service delivery are reviewed. As defined, for the purpose of this study, collaboration is conceptualized as consisting of those activities comprising partnerships and interdisciplinary or interprofessional collaboration within existing literature. Therefore, factors impacting implementation of partnerships and interdisciplinary or interprofessional collaboration cited within existing literature, in order to provide a frame for those factors that will likely emerge within the current study are reviewed.
Partnerships

Many researchers have provided recommendations regarding facilitators to formation of partnerships between family members and service providers when planning services, including practices that should comprise partnerships. For instance, Brookman-Frazee and Koegel (2004) outline six necessary components to facilitate partnerships: 1) mutually agreed upon goals, 2) shared expertise, 3) shared responsibility, 4) ecocultural fit to a family’s needs, 5) collaborative problem-solving, and 6) a strengths-based approach. Likewise, Summers and colleagues (2005) provide a ‘two factor model’ for partnerships. This model describes: 1) important characteristics of the provider-child relationship including a sense of commitment, competency, respect, and trust (e.g., reliability, safety, dependability); and 2) important characteristics of the family-provider relationship including a sense of respect, trust (e.g., reliability, safety, dependability), communication, and equality.

Interdisciplinary/interprofessional collaboration

Researchers have also provided recommendations regarding facilitators to and practices that should comprise effective interdisciplinary/interprofessional collaboration efforts. For instance, Petri (2010) conducted a comprehensive review of nursing, medical, and social work literature to identify necessary elements for effective interdisciplinary collaboration. First, successful collaborations are problem-focused and flexible. The collaborative relationships among providers evolve, develop, and change over time to meet the client’s needs. Second, successful collaborations are characterized by role-sharing among all providers. Each member of the collaborative relationship has equal involvement, holds shared objectives and goals, works toward the common goal, holds shared responsibility and accountability for the outcome, and shares in power and decision-making. Third, providers within the collaborative relationship
work together to achieve the same goal. This achievement is only possible when providers work together, as each provider provides unique and important contributions to planning that complement one another. In addition, he identified important antecedents that facilitate effective interdisciplinary collaborations. Specifically, providers who have received prior education on interprofessional collaboration, are aware of others’ roles, have effective interpersonal relationship skills, engage in deliberate actions to build and maintain relationships (e.g., engage in team-building, relationship-building, collaborative skill-building activities), are committed to supporting one another and the collaborative process, and access organizational supports are most likely to effectively collaborate.

In their 2005 review, D’Amour and colleagues review characteristics of interprofessional collaborations within existing research literature. First, interprofessional collaboration is characterized by sharing of responsibilities, decision-making, healthcare philosophy, data, planning, intervention, and perspectives among participating providers. Second, interprofessional collaboration is characterized by open and honest communication, trust and respect, awareness of varying perspectives, and common goals for service delivery. Third, interprofessional collaboration is characterized by interdependency among providers rather than autonomous service delivery. Each member within the collaborative relationship contributes his or her expertise in order to meet the individual client’s needs, combining efforts to maximize outputs. Finally, the relationship is characterized by shared power among team members, with each team member contributing knowledge and experience. Overall, the relationship evolves through member negotiation and comprise, in order to make decisions and plan interventions.

Atkinson, Jones, and Lamont (2007) review four categories of factors facilitating collaborative relationships: 1) working relationships characterized by role demarcation between
agencies, a commitment from all staff to work together, trust and mutual respect across agencies, and shared understanding and joint training across providers; 2) facilitative multi-agency processes including transparent, constant, and clear communication between agencies for effective planning and consultation; 3) appropriate resources for multi-agency work including adequate funding, adequate staffing, adequate time, co-location of services, and the presence of a care coordinator; and 4) facilitative management and governance including strong leadership and clear accountability. Likewise, Cooper and colleagues (2016) identify the following facilitating factors in their review: 1) good communication across providers and services including both quantity of communication (e.g., frequency, regularity) and quality (e.g., clarity, transparency, ‘streamlined’), as well as willingness to communicate; 2) joint training in which providers from different disciplines come together to learn; 3) good understanding across providers and services in regard to the practical aspects of other services and providers (e.g., policies, referral criteria, responsibilities, roles, resources) and an ability to empathically understand the perspectives of other providers (e.g., priorities and philosophies of care); 4) mutual valuing, respect, and trust among providers characterized by an appreciation among providers of their unique experiences, skills, and contributions; 5) senior management support for collaboration; 6) formal agreements and protocols for interagency collaboration; and 7) a named person to link the providers. In addition, they cite a number of other potential facilitating factors including joint meetings, positive individual relationships between providers, shared office space, joint case conferences, adequate resourcing, all providers adopting a client-centered or family-centered perspective, consultative or supervisory role of older team members to younger members, joint assessments, and training in interagency collaboration among members in the collaborative relationship.
Frameworks and Models for Collaboration

In line with cited definitions and identified facilitators to collaboration, a number of frameworks and models for collaboration have been proposed. The purpose of this section is to briefly discuss example frameworks and models to further frame the discussion on collaboration.

Bronstein’s Model for Interdisciplinary Collaboration

The most extensively cited model on interdisciplinary collaboration in the social work literature is Bronstein’s Model for Interdisciplinary Collaboration (Petri, 2010). As described in his 2003 paper, Bronstein’s model is founded on ideas from multidisciplinary theory of collaboration, services integration framework, role theory, and ecological systems theory. He conceptualizes interdisciplinary collaboration as an interprofessional process in which one or more providers from different disciplines engage in work-related activities together, characterized by five core components for service delivery. First, providers work in a manner implying interdependence, whereby each provider holds an understanding of other providers’ roles and is dependent on the other providers’ input to accomplish his or her goals and tasks. Second, providers can only accomplish certain professional activities by working together. Third, providers work together in a flexible manner, or in a manner characterized by deliberate role-blurring and ongoing compromise. Fourth, providers share collective ownership of goals, including with the families of clients served. Further, each provider takes responsibility for his or her part in success and failure and encourages constructive disagreement and deliberation among clients and the other providers. Fifth, all providers reflect on the process of collaboration, incorporating feedback to strengthen their future collaborative relationships and effectiveness.

In addition, Bronstein acknowledges internal and external influences on the interdisciplinary collaborative relationship among families and providers. Specifically, he discusses four major
influences that either promote or hinder efforts on the part of all those involved in the relationships. First, one must consider each provider’s role in the relationship. Influences on roles might include values and ethics of the provider, the provider’s allegiance to his or her agency or profession, respect for other colleagues, the degree to which the provider holds an ecological and holistic view of practice, and whether the provider holds a perspective similar or complementary to other providers involved in the collaborative relationship. Second, one must consider structural characteristics of the agency in which providers work. For instance, structural influences might include whether a provider has a manageable caseload, whether the agency culture supports interdisciplinary collaboration, the role of administrative support and professional autonomy, and whether time and space is available for collaboration to occur. Third, one must consider personal characteristics of the providers involved in the relationship, including how they view each other as people, whether their relationships are based on trust, respect, understanding, and whether informal communication occurs among them. Finally, one must consider each provider’s previous experiences with collaboration, and how this might impact his or her views and current practice.

**Medical Home Model**

The American Association for Pediatrics (AAP) calls for the application of a Medical Home Model within pediatric medical services to meet the needs of families and children with complex health care needs (Russa et al., 2015). Within a Medical Home Model, the service provider works collaboratively with the family and child to ensure the child’s needs are met (Gabovitch & Curtin, 2009). Types of services for which the provider are responsible include those provided directly by the provider as well as those provided in hospital outpatient clinics, schools, community health centers, and health department clinics (AAP, 2002). The providers
implicated in this model might include the child’s pediatrician, social workers, nurses, or physician assistants (Russa et al., 2015). Services provided through the Medical Home Model should be accessible, family-centered, continuous (including providing for postsecondary transition planning), comprehensive, coordinated, compassionate, and culturally effective (AAP, 2002). Researchers note that services provided through a Medical Home Model are essential to ensure the best outcomes for children with ASD and their families, given that ASD is increasing in prevalence, a lifelong disorder, complex, and impacts the entire family’s functioning and the Medical Home’s philosophy is aligned with these needs (Gabovitch & Curtin, 2009).

**Careau and colleagues’ Continuum of Interprofessional Collaborative Practice in Health and Social Care**

In 2015, Careau and colleagues conducted a systematic review of the literature in order to develop a framework for interprofessional collaboration. Their final framework incorporates four components that are linked to five types of collaborative practice. The first component considers the situation of the client and his or her family, acknowledging that providers have to adjust the type and intensity of their collaborative practice to meet the biopsychosocial needs of clients and their families. The second component considers that providers must intend to establish authentic partnerships with clients and their families, and these relationships must evolve with changes in the client’s needs. The third component considers interactions between providers. Namely, as clients’ needs increase, the intensity of collaboration will increase. The fourth component involves the combination of discipline-specific knowledge among providers. That is, as the individual client’s needs increase, providers work decreasingly independently of one another and increasingly in collaboration. These four components dictate the complexity and intensity of the type of practice that characterizes the collaborative relationship: independent
practice, to parallel practice, to consultation and reference practice, to concerted practice, and finally to shared healthcare practice. Practitioners should be able to move easily in both directions along the continuum, in a manner responsive to the situation and the needs of the client and his or her family.

Positive Outcomes from Collaborative Service Delivery

Across reviews of existing literature, researchers have identified a number of positive outcomes linked to collaboration for target individuals, their families, service providers, and organizations. Cited outcomes for target individuals and families include enhancement of quality of services, holistic rather than fragmented service delivery, more appropriate goals and tools to reach goals, improved outcomes, greater service receipt, services that are better matched to need, lower disparities in service use, and greater empowerment and satisfaction among families (Bezdek et al., 2010; Cooper et al., 2016; Petri, 2010). For transition-age individuals with ASD, positive outcomes also include access to competitive employment, enrollment in postsecondary education, and integration into social and community life (Hendricks & Wehman, 2009; Noonan et al., 2008).

Documented outcomes for providers include enhanced job and professional satisfaction, improved morale, increased enthusiasm, reduced burnout, and increased confidence (Petri, 2010). In addition, providers can more effectively deliver services because collaboration allows them to overcome limitations of their individual disciplines, overcome limited understanding of roles and expertise of other providers, increase their own accountability and documentation, and accurately diagnose complex disorders and utilize treatment methods (Bronstein, 2003). Finally, at the organizational level, collaboration is linked to decreased costs, improved staff
productivity, improved efficiency of service delivery, and has been cited as essential for organization survival (Petri, 2010).

**Barriers to Collaborative Service Delivery**

A number of barriers to collaborative service delivery have been cited in existing research literature. These barriers primarily take two forms: 1) a lack of consensus on terms, frameworks, and models that constitute collaborative service delivery; and 2) practical barriers to collaborative service delivery. Aspects of these barriers are discussed below.

**Definitional challenges**

A number of researchers have pointed to inconsistencies across terms, practices, theoretical frameworks, and discourse regarding collaborative service delivery as barriers to future research regarding the delivery of coordinated services. For instance, in their 2013 review, Haddara and Lingard note that two major discourses have driven research regarding interprofessional collaboration. One discourse, which they label as utilitarian, is a positive, experimental approach that holds the truth that interprofessional collaboration is necessary because it produces better patient care and improves patient outcomes. This discourse makes use of language such as ‘evidence’, ‘outcomes’, ‘rigor’, ‘clinically relevant’, ‘test’, and ‘measure’ in discussing the importance of interprofessional collaboration. The second discourse, which they label as emancipatory, takes a constructivist approach and holds the truth that interprofessional collaboration is necessary because it diminishes medical dominance and equalizes power relationships among practitioners. This discourse uses language such as ‘struggle’, ‘dominate’, ‘liberate’, and ‘power’ to refer to opposition and liberation. Haddara and Lingard concluded that the extent to which practitioners align with one discourse over another might explain tensions regarding conceptualization, implementation, and assessment of interprofessional collaboration.
Therefore, providers need to acknowledge and pay attention to the discourse of all those involved in the collaborative effort to promote the group’s productivity.

Relatedly, Perreault and Careau (2012) described varying definitions and conceptualizations of collaboration that might contribute to inconsistencies in service delivery across providers. For instance, they noted that interprofessional collaboration could refer to a range of practices among providers, extending from independent parallel practice, to simple reference or consultation, to full team integration. They cited ongoing confusion about the nature of practice as a barrier. For instance, some providers might view collaboration as a structural practice, whereas others view it as a process. In response to their review, the authors posed the questions of whether interprofessional collaboration refers to one phenomenon or multiple realities, whether one common term can suffice for practice, and whether it is even possible for providers and researchers to settle on one term for interprofessional collaboration. In conclusion, they called for different definitions that can point to clear conceptualizations of practice, in order to move both research and practice forward.

Likewise, D’Amour and colleagues (2015) pointed to the need to understand the distinctions between concepts defining and driving collaborative relationships. They noted a range of concerns regarding research and current practice. First, they noted that providers might view collaboration as serving different purposes: 1) to serve the complexity of client needs versus 2) to better serve provider needs. In line with these distinct views, they noted that a range of outcomes might result from collaboration, and that providers might place different weight on various outcomes as important when evaluating the effectiveness of collaboration. For instance, providers might hold the quality of care and effectiveness of treatment, satisfaction among providers, or specific outcomes of collaboration of primary importance. Second, they described
that providers often hold different views regarding the role of the client on the collaborative team. For instance, they noted that researchers and providers might hold different views on how to most fully integrate clients into teams. They also cited current disagreements regarding the roles of clients on teams, and they questioned whether providers are ready to treat clients as true partners on teams. Finally, they cited a lack of a common theoretical framework driving research and practice, in addition to limited empirical data supporting the efficacy of current frameworks.

**Practical barriers**

Within existing reviews, researchers have also outlined a number of other practical barriers to collaborative service delivery. For instance, D’Amour and colleagues (2005) note that service providers are often taught to be specialized in their discipline throughout their education rather than work on collaborative teams. In addition, providers work in organizational environments that pose constraints on collaboration. In their 2016 review, Cooper and colleagues outline barriers related to: 1) working relationships, including poor role demarcation, struggles over status and power, and lack of equal representation across agencies; 2) multi-agency processes, including poor communication and inadequate or incompatible information technology systems; 3) resources, including funding difficulties and a lack of joint budgets; and 4) management and governance, including an absence of clear leadership, lack of management support, and lack of clarity around governance and accountability.

In addition, they described a number of inhibiting factors to formation and maintenance of collaborative relationships. These include: 1) inadequate resourcing, such as intense time pressures and clinical demands, no time to carry out interagency meetings, insufficient funding and budgets, and inadequate training on collaborative practices; 2) poor and unclear
communication across providers and services; 3) a lack of valuing, respect, and trust across providers, including feelings of patronization by individuals who saw themselves as superior; 4) differing perspectives and cultures across providers and services, including different understandings of children’s problems, different priorities, different goals and different cultures; 5) poor understanding across providers and services, including misunderstandings, misconceptions, and stereotypes across providers and services; 6) confidentiality issues; and 7) other factors, including lack of senior management support, a lack of team leader assuming responsibility, referral difficulties (e.g., long waiting lists, no direct referrals), unrealistic expectations of other providers and services, a lack of priorities, a lack of protocols on interagency collaboration, and bureaucratic barriers.

Finally, Cooper and colleagues (2016) outline potential negative outcomes resulting from efforts to form collaborative relationships. For service providers, collaboration likely requires a greater time investment, overcoming management difficulties, problems in information sharing, a fear of getting swamped with referrals, and potential challenges to one’s professional identity. In addition, collaboration could be linked to decreased service quality, decreased mental health service use, greater role overload, and emotional exhaustion among providers. With these challenges and barriers in mind, the need for future research emerges as critical. In particular, there is a need to continue to improve conceptualizations of collaborative service delivery, and to continue to investigate those practices that are most likely to be perceived by both providers and families served as efficient and meaningful.

Ongoing Need

Despite the range of research and best practice reviews pointing to the necessity of collaboration between caregivers and service providers in planning for and delivering services,
empirical evidence surrounding caregivers’ and providers’ experiences with collaboration service delivery for individuals with ASD remains limited. The need for collaboration becomes particularly evident when reviewing studies related to families’ and providers’ perceived unmet needs for service delivery, especially when targeting transition-related needs. This need is discussed briefly below.

**Service needs: Caregivers**

A study by McGill, Papchristoforou, and Cooper (2006) indicates that at least half of families surveyed report using medical, psychological, communication, and respite care services, with 26% of the families using at least one other service. However, these families continue to report receipt of insufficient support, perceive that providers lack an understanding of challenging behaviors, describe interactions with the service delivery system as a 'constant battle', report family strain when attempting to navigate services, report having to find information for themselves, and perceive that the only useful supports came from their own family, friends, or parents. Likewise, a study by Hodgetts, Zwaigenbaum, and Nicholas (2015) indicates that parents of children with ASD continue to report widespread unmet needs in regard to general information about services, behavioral supports, parents’ ability to find time for themselves, professional supports, family and social supports, financial supports, respite services, planning for adult services, and transparent information about services. Further, a study by Taylor and Henninger (2015) indicates that 90% of families of transition-age individuals with ASD report using at least one service, although families received three services on average (with a range of zero to nine services). However, two-thirds of families report at least one unmet service need, with 28% of families reporting three or more unmet service needs. The most
commonly reported unmet service needs for families included those related to career counseling, job skills training, and life skills training.

Moreover, studies indicate that unmet needs are greater for families of children with ASD than families of children with other disabilities and are greater for families with certain sociodemographic characteristics. For example, parents of children with ASD report greater needs for consistent therapies for their children, providers who are knowledgeable about their children’s disability (i.e., ASD), and less satisfaction with services than families of children with Down Syndrome (Siklos & Kern, 2006). Similarly, caregivers of children with ASD are significantly more likely to report difficulty using services, inadequate insurance coverage, a lack of shared decision-making and care coordination, and an adverse family impact as compared to caregivers of children with other developmental disabilities or mental health conditions (Vohra et al., 2014). In addition, caregivers of adolescents or young adults with ASD report greater unmet needs when the child’s ASD symptoms are less severe, when the child’s has a higher level of adaptive skills, when families have lower incomes, when a caregiver experiences decreased health, and when a caregiver has higher levels of anxiety (Taylor & Henninger, 2015).

**Service needs: Providers**

Like caregivers of children with ASD, providers serving children with ASD also identify barriers to access to services for families. These barriers exist for the caregivers and for the providers themselves, contributing to families’ unmet needs. For instance, a study by O’Reilly, Karim, and Lester (2014) included focus groups with providers who worked in the fields of pediatrics, psychiatry, psychology, general practice, mental health services, and charities. Providers cited feeling overwhelmed by the quantity of information available, feeling tired in regard to the time and motivation required to access information, perceiving that language used
in information sources is ‘too formal’ or ‘too rigid’, and feeling frustrated when searching for
information given the number of websites trying to sell products. In addition, they noted that
families are vulnerable to misinformation due to their desire to cure and reduce the child’s
symptoms, to try strategies that lack an adequate evidence base, and to make emotional decisions
such as being convinced by rhetoric that invokes imagery of miracles. Finally, they cited
challenges in determining what constitutes valid information, how to ensure quality of
information accessed given the mass of available information, how to make sense of evidence
bases, and how to teach parents to assess for quality assurance. Related to these barriers, they
also noted that families often desire information from 'real people' rather than scientists, and that
families might feel that providers are not fully informed.

Service needs: Importance of collaboration

To address these discrepant and unmet needs, these studies highlight the need for
improved shared decision-making among caregivers and service providers, more consistent
communication among providers serving individuals with ASD, and better use of child and
family-centered care (Vohra et al., 2014). Specifically, with enhanced collaboration between
caregivers and providers, caregivers can exist as central to decision-making, providers can
remain aware of and responsive to families’ support needs, and providers can work together to
address families’ needs in a comprehensive manner (Siklos & Kern, 2006). This collaboration is
especially critical for transition planning for adolescents with ASD, given that multiple service
providers, the adolescent’s family members, and the adolescent himself or herself must work
together to ensure the transition-related needs of the adolescent are met before exiting school
(Hendricks & Wehman, 2009; Noonan et al., 2008).
Unfortunately, collaboration often falls short of recommended practice, despite providers’ perceptions of the importance of collaboration (Careau et al., 2015; Summers et al., 2003; Summers et al., 2005). This is especially true for transition-age adolescents or young adults with ASD (Hendricks & Wehman, 2009; Noonan et al., 2008). Therefore, there is a need to understand specific skills and behaviors that might enhance collaborative training and practice (Summers et al., 2003; Summers et al., 2005). As part of this need, there remains a need to operationalize collaboration across different settings and across different individuals with ASD, particularly in light of theoretical frameworks and models (Careau et al., 2015). Further, there is a need to understand how individuals with ASD and their caregivers experience interagency collaboration, including how they experience the breakdown of collaborative efforts (Cooper et al., 2016).

To date, research has focused on recommended practices and clinical outcomes rather than experiences of families and individuals served. Specifically regarding transition-related studies, there is a critical need for research that allows families and individuals served to provide firsthand accounts of their experiences, challenges, and needs, in light of their own family strengths and characteristics (Cheak-Zamora et al., 2015; Dyke et al., 2013). This shift of focus might provide important insights into factors that act as facilitators and barriers to collaboration, and promote awareness of the importance of collaboration among all stakeholders. In turn, these insights and awareness ultimately might contribute to practices that improve outcomes from service delivery, including achievement of the ‘good life’ for adults with ASD (Dyke et al., 2015). In sum, there is a great need to move past ‘feel good rhetoric’ used to frame discussions of collaboration in order to drive practice and theory forward in a useful and meaningful manner (Wong & Sumison, 2013).
Review of Empirical Studies

The purpose of this section is to review studies conducted to date investigating caregivers’ and providers’ experiences with collaborating to coordinate service delivery. Studies to date have utilized a range of methods including interviews, focus groups, surveys, questionnaires, and randomized controlled trials. Further, while researchers have elicited perceptions of caregivers and providers, there is a dearth of studies investigating perceptions of individuals with ASD. A range of findings exists regarding factors that influence collaboration, the perceived roles of caregivers and providers in collaborative relationships, and outcomes linked to coordinated service delivery. Research investigating these aspects of service delivery exists for early childhood-age and school-age children with ASD, as well as for transition-age adolescents or young adults with ASD to a more limited extent. This section will review existing literature regarding these aspects of service delivery, in order to highlight the need for the current study.

Factors Influencing Collaboration

The purpose of this sub-section is to review facilitators and barriers to collaboration. A review of facilitators and barriers to collaboration from the perspectives of caregivers and service providers of early childhood-age, school-age, and transition-age individuals with ASD is provided.

Early childhood-age: Facilitators

Facilitators to collaborative service delivery have been identified among studies investigating the experiences of caregivers of young children with ASD. For instance, Coogle, Guerette, and Hanline (2013) surveyed families of young children, ages 0 to 3 years, diagnosed with or at-risk for ASD regarding their experiences working with early intervention service
providers. Parents described provider-related facilitators to service access including providers who enabled their access to resources, demonstrated ‘positive’ personal characteristics, provided opportunities for parents’ skill development, and provided convenient services for the family. Likewise, Coogle and Hanline (2014) interviewed parents of young children with ASD, ages 0 to 3 years. Their findings indicate that facilitators to coordinated service delivery include providers’ interpersonal communication skills, trustworthiness, and ‘good’ attributes (e.g., described as caring or helping). Further, providers who respond to a child’s progress in a flexible and ongoing manner and connect families to community resources facilitated collaboration.

**Early childhood-age: Barriers**

Regarding factors impacting collaborative service delivery, studies have also elicited caregivers’ perceptions of barriers to collaboration for young children with ASD. For instance, Coogle and colleagues’ (2013) survey results indicate that parents of young children with ASD report aspects of early intervention service delivery that need change: increased communication on the part of providers with families, providers taking family concerns more seriously, wait time, inconvenient scheduling, ineffective interventions, and ineffective therapists. These aspects can be perceived as barriers in the context of their study. Further, Houser, McCarthy, Lawer, and Mandell (2014) conducted interviews with parents of children diagnosed with ASD, with an average age of 3.4 years. Their study reveals that a work-life balance is often a barrier for families. In their study, parents described actively adapting their employment arrangements to manage schedules of therapy. Specifically, one parent in the family usually gave up his or her job to stay home with the child and to manage the child’s needs.
School-age: Facilitators

Facilitators to collaborative service delivery among school-age children with ASD have been identified across studies. Given the various findings on this topic, the review of facilitators was divided between those identified by caregivers versus those identified by service providers.

Caregivers’ perspectives. Auert, Tremath, Arciuli, and Thomas (2012) conducted a study in which they examined the experiences of parents of children with ASD, ages 3 to 6 years, in coordinating their children’s speech-language pathology services. They noted that parents’ expectations and prior experiences accessing speech-language services drive treatment. Hall and Graff (2010) examined the perceptions of parents of children with ASD, ages 2 to 12 years, in accessing services. Parents in their study identified provider-related facilitators to service delivery, including providers who understand autism, provide resources and supports for the entire family, specialize in ASD, and actively partner with parents to provide care. Parents also noted that parent support groups, other family members, child care, respite services, and trust funds and life insurance for the child facilitate access to care.

Minnes and Steiner (2009) examined the experiences of parents of children with ASD, ages 6 to 8 years, regarding their efforts to access and use healthcare services. Their focus group revealed that mothers of children with ASD describe ‘optimal’ practitioner characteristics, knowledge transmission, and parent advocacy as facilitators to coordinated service delivery. Moodie-Dyer, Joyce, Anderson-Butcher, and Hoffman (2014) examined the perspectives of caregivers of children with ASD, ages 1 to 23 years, regarding their experiences with the ASD service delivery system. Caregivers reported facilitators related to service access and delivery including open communication with providers, financial resources, receipt of high quality services, insider knowledge (i.e., ‘knowing someone’), parent-provided care, and ‘luck’.
Tucker and Schwartz (2013) surveyed caregivers of children with ASD, ages 2 to 21 years, regarding their perceptions of facilitators and barriers to collaboration with school providers. Facilitators to involvement included school teams asking parents for input, communicating about progress, and working with parents to plan and write goals and objectives. Parents reported most valuing regular contact from the school, including school personnel allowing parents to make suggestions for goals, objectives, and instructional approaches. Further, parents valued school providers' presence at meetings, quick communication, leadership, promotion of access to resources, and openness to parents' input. In addition, parents noted the value of bringing an advocate to meetings. Of note, perspectives of parents in this study likely varied from parents described in above studies, given educational laws governing delivery of services in school settings.

**Providers’ perspectives.** Few studies exist regarding providers’ perspectives on facilitators to collaborative service delivery for school-age children with ASD. In one such study, pediatricians and family physicians endorse high self-perceived ASD competency, use of empirically supported therapy strategies, service to a high number of children with ASD, the physician personally having a friend or relative with ASD, and prior training about ASD as facilitators to delivery of services in a Medical Home Model to children with ASD (Golnik, Ireland, & Borowsky, 2009). However, a greater number of studies exist garnering caregivers’ perspectives.

**School-age: Barriers**

In contrast to studies investigating facilitators to collaboration, a number of studies exist investigating barriers to collaborative service delivery exist for school-age children with ASD. Of note, a majority of studies that investigate facilitators to collaboration also investigate barriers
to collaboration. Again, the barriers identified by caregivers will be reviewed first, followed by the barriers identified by service providers.

**Caregivers’ perspectives.** Regarding caregivers’ perspectives, Auert and colleagues’ (2012) study reveals that caregivers perceive that speech-language pathologists only provide them with vague information and feedback regarding services, if any at all. Parents desire to receive more information and feedback, in order to better facilitate collaboration with providers. Carbone, Behl, Azor, and Murphy (2010) conducted a study to investigate parents’ perspectives regarding receipt of services through a Medical Home Model for a child with ASD. Their findings indicate that parents report pediatricians are too busy to provide care aligned with a Medical Home model, pediatricians lack knowledge and experience in managing care of children with ASD, and parents face a range of stressors when attempting to access and plan for care (e.g., feelings of isolation, anger, frustration, fatigue). Further, Minnes and Steiner’s (2009) study reveals that mothers of children with ASD, ages 6 to 8 years, report their beliefs regarding how services should be delivered do not align with system realities and various systemic and social factors act as barriers to care. In addition, they described a need for better education of practitioners, expansion of services, and a 'central place' for services to better promote collaboration. Each of these factors acted as barriers to delivery of coordinated services.

Regarding educational service provision, Fallon and Zhang (2013) conducted a study in which they investigated the perceptions of in-service teachers and families regarding skills that are important for collaboration with one another. Their findings reveal that both caregivers of and service providers for children with ASD, ages 18 months to 19 years, report a need for greater communication and information exchanges during collaboration. Moodie-Dyer and colleagues’ (2014) study regarding caregivers’ experiences with the ASD service delivery
system indicates that caregivers perceive the following factors as barriers to accessing services: delays in diagnosis, system disconnects (e.g., a lack of communication between providers), a lack of information provision, inadequate service provision (e.g., providers used inappropriate strategies), financial and logistical challenges, feelings of devaluation by providers, and geographic inconsistencies in service availability. In addition, Tucker and Schwartz’s (2013) surveys reveal that caregivers report barriers such as a need for greater training of school personnel on disabilities, a need for increased provision of services targeting specific skills, feelings of devaluation of parental and outside provider input in service planning, and conflict with school teams over IEP content, child placement, or use of curriculum or instruction.

**Providers’ perspectives.** Researchers also have investigated providers’ perspectives regarding barriers to collaborative service delivery for school-age individuals with ASD. Bezdek and colleagues (2010) conducted a study in which they examined the perspectives of providers regarding characteristics of effective and ineffective partnerships with parents. Providers included occupational therapists, physical therapists, speech-language therapists, special education teachers, paraprofessionals, and other health providers serving individuals with disabilities between the ages of 0 to 21 years. Barriers to coordinated service delivery included a gap between providers’ use of family-centered language and actions (i.e., their actions contradicted their stated values), and providers’ tendencies to blame parents for problems in maintaining partnerships, rather than acknowledge the stressors and emotional impact of coordinating services and raising children. As noted previously, Fallon and Zhang’s (2013) study indicates that both in-service teachers and families report a need for greater communication and information exchanges during collaboration. Moreover, Kelly and Tincani (2013) surveyed behavior analysts regarding their training on, practices of, and facilitators and
barriers to interdisciplinary collaboration. Despite endorsing interdisciplinary collaboration as a frequent practice, survey results indicate that behavior analysts receive very little training in collaboration through graduate school or field placements. Specific barriers to collaboration include conflicting ideologies, conflicting perspectives, little training, ineffective contingencies, and limited time.

Carbone and colleagues (2010) identified barriers to coordinated service delivery provided within a Medical Home Model from the perspective of pediatricians serving children with ASD. Pediatricians reported a lack of awareness of available community resources, a lack of time, a lack of reimbursement for coordinating care activities, and a lack of specialized expertise. Likewise, Golnik and colleagues (2009) investigated barriers to coordinated service delivery in a Medical Home Model for children with ASD. Pediatricians and family physicians identified the following barriers: a lack of reimbursement, family skepticism of traditional medicine and vaccines, low self-perceived competency, and a need for education about ASD.

**Transition-age: Facilitators**

Regarding the transition-related needs of adolescents or young adults with ASD, studies have investigated facilitators to collaboration from the perspectives of providers. For instance, Havlicek, Bilaver, and Beldon (2015) examined the perspectives of service providers regarding perceived facilitators to postsecondary transition planning for young adults with ASD, ages 18 to 21 years, in foster care. Specifically, they garnered the perspectives of social workers, psychologists, private agency case managers, eligibility specialists, and program managers. Researchers identified the following facilitators: 1) persistence and professional relationship building, specifically in relation to gathering information and implementing plans to meet young adults’ needs; and 2) consistent communication and information-sharing, including collaborative
problem-solving and willingness to use technology to overcome geographical barriers (e.g., conference calls, Skype). Kuhlthau, Warfield, Hurson, Delahaye, and Crossman (2015) investigated the perspectives of physicians, psychologists, social workers or care coordinators, and registered nurses or pediatric nurse practitioners regarding strategies to support the transition of youth with ASD to adult healthcare providers. Providers endorsed the following strategies as promoting transitions: compiling lists of available adult providers or community resources to provide to families, coordinating care and communication between individual pediatric and adult providers, making transition-specific appointments for families, and using checklists to track transition progress.

Noonan and colleagues (2008) conducted a study in which they investigated strategies to promote interagency collaboration surrounding postsecondary transitions for adolescents with ASD. They interviewed 36 school-based personnel from ‘high-performing’ districts (i.e., those in which students access desirable postsecondary outcomes), including transition coordinators, department chairs, special education directors, assistance special education directors, special education teachers, and ‘blended’ staff members (i.e., those holding multiple roles). Data analysis revealed 11 key strategies to promote interagency collaboration: 1) flexible scheduling and staffing, including the need for staff time; 2) follow-up after transition, meaning providers continue to assist families and target individuals post-graduation; 3) administrative support for transition, including allocation of flexible scheduling, compensation for time, and paid summer training, as well as collaboration with administrators; 4) varied funding sources, including sharing of funds among agencies and applying for external grants; 5) state-supported technical assistance, including provision of ongoing support and training; 6) relationship-building, such as by attending meetings, holding positions on boards, and sharing in problem-solving; 7)
facilitation of agency meetings with students and families, including having agency representatives attend IEP meetings; 8) training for students and families, including holding agency fairs and weekend trainings; 9) joint training of staff, such as attending statewide transition conferences; 10) meetings with agency staff and transition councils, to ensure ongoing collaboration; and 11) dissemination of information to broad audiences, including parents, students, teachers, and other agencies.

In addition, case studies have been conducted that investigate facilitators of collaborative service delivery to meet the transition-related needs of young adults with ASD. For instance, Ferguson, Cross, O’Neill, and McCaffrey (2015) conducted a case study in which they examined the transdisciplinary approach one team adopted in working together to meet the needs of a young adult with ASD, age 18 years. The team included the young adult, his mother, an intervention coordination, and multiple providers including a school-based psychologist, occupational therapist, and behavior support therapist. Participants identified facilitators to the process such as each team member adopting specific roles in line with his or her area of expertise, the team developing individualized goals for the young adult, team members explicitly discussing their roles and the guiding philosophy of the team, and the team conducting ongoing assessments to ensure progress toward goals. Likewise, Wehman and colleagues (2012) conducted a multiple case study of two individuals with ASD who participated in a transition program while in high school, enabling them to achieve competitive postsecondary employment. Facilitators that emerged in their study included team members working together to identify goals and coordinate transportation, as well as team members adopting roles in line with their areas of expertise.
Transition-age: Barriers

Regarding the transition-related needs of adolescents or young adults with ASD, studies have also investigated barriers to collaboration from the perspectives of social workers, psychologists, private agency case managers, eligibility specialists, and program managers serving young adults with ASD, ages 18 to 21 years, in foster care (Havlicek et al., 2015). Researchers identified the following barriers: 1) presence of two separate systems of service delivery for children and adults with ASD; 2) abrupt transitions, meaning perceptions that transitions occurred without proper planning; 3) a lack of training on the part of providers; and 4) confusion about services provided through other agencies and funding structures, specifically in seeking reimbursements.

Stakeholders’ Roles in Collaboration

The purpose of this sub-section is to review stakeholders’ perceived roles in collaborative relationships promoting coordinated service delivery. A review is provided of the perceived roles of caregivers and providers of early childhood-age and school-age individuals with ASD. Then, comments are provided on the paucity of research regarding the perceived roles of caregivers, providers, and adolescents or young adults in collaborative relationships to promote service delivery to meet the transition-related needs of the individual with ASD.

Early childhood-age: Caregivers’ roles

Several studies reveal caregivers’ perceived roles in collaboration for early childhood-age individuals with ASD. For instance, Coogle and colleagues’ (2013) study reveals that parents of young children diagnosed with or at-risk for ASD believe their role in collaborative service delivery is to facilitate child development, share information with service providers, observe the child and provider, learn new skills, and participate minimally. In another study, Coogle and
Hanline (2014) note that parents perceive their primary roles in collaborative relationships are to provide information about their children and make decisions regarding their children’s goals and services. In addition, caregivers might view their role in coordinating service delivery as a full time job (Houser et al., 2014).

**Early childhood-age: Providers’ roles**

Limited research exists regarding the perceived roles of service providers in collaborating to coordinate the young children’s services. One such study reveals that parents of young children diagnosed with or at-risk for ASD report that the role of service providers is to facilitate child development, share information, and promote development of new family skills (Coogle et al., 2013).

**School-age: Caregivers’ roles**

Several studies reveal the perceived role, or lack thereof, of caregivers in collaboration for school-age children with ASD. For instance, a study by Carbone and colleagues (2010) indicates that parents of children with ASD receiving services with a Medical Home Model perceive that service providers do not view them as experts when collaborating together. In his 1999 study, Kohler administered questionnaires to caregivers of children with ASD, ages 3 to 9 years. Parents in his study report their involvement in service delivery most often includes assistance in planning for and development of services, carrying out services independently, and awareness of methods for progress monitoring. In their 2012 study, Mackintosh, Goin-Kochel, and Myers collected questionnaire data which indicates that parents of individuals with ASD, ages 2 to 21 years, experience both supportive and adversarial relationships with providers. Importantly, the nature of these relationships are related to the amount of information-sharing that occurs between parents and providers. In addition, Minnes and Steiner’s (2009) study
indicates that parents often feel alone when working with providers and attempting to navigate service delivery systems. Finally, a study by Bezdek and colleagues (2010) reveals that providers perceive that parents should assume an amount of involvement in partnerships that can be characterized as ‘just right.’ That is, providers hold a ‘Goldilocks’ perception of the amount parents should be involved in service delivery, with too little or too much involvement negatively perceived.

**School-age: Providers’ roles**

Regarding service providers’ perceived role in service delivery, both caregivers and providers comment on providers’ roles. For instance, Auert and colleagues’ (2012) study notes that parents of children with ASD, ages 3 to 6 years, perceive that speech-language providers should have specialized knowledge and experience with children with ASD, and their role is to contribute this knowledge to the working relationship. Carbone and colleagues’ (2010) study reveals that pediatricians believe their own role within a Medical Home Model of coordinated service delivery is to provide diagnostic screening, make referrals as appropriate, monitor medication use, identify systems of support for family members, and ‘keep children safe.’ Further, Minnes and Steiner’s (2009) study indicates that mothers of children with ASD view the family physician as the ‘gatekeeper’ to services and information.

**Transition-age: Stakeholders’ roles**

Notably, a number of studies investigate caregivers’ and adolescents’ or young adults’ experiences with transition. However, studies do not generally investigate stakeholders’ perceptions of their roles in collaborative relationships. Among existing studies, caregivers report a lack of knowledge and provision of information regarding postsecondary options for the adolescent or young adult with ASD on the part of providers (Chambers, Hughes, & Carter,
Caregivers report teaching skills to adolescents or young adults themselves, advocating for services, and feelings of worry and stress regarding postsecondary outcomes and lack of available postsecondary services (Cheak-Zamora et al., 2015; Dyke et al., 2015; Newsome, 2000). They also note that adolescents or young adults are not actively involved in planning services and might hold unrealistic expectations of outcomes (Dyke et al., 2015; Turcotte et al., 2015). In addition, adolescents or young adults report fear and anxiety about postsecondary outcomes and reluctance to discuss postsecondary options with caregivers (Cheak-Zamora et al., 2015).

**Outcomes from Collaboration**

The purpose of this sub-section is to review perceived outcomes that might result from collaborative service delivery. Examples of outcomes include stakeholders’ perceptions of progress toward goals for the individual with ASD, the impact of service delivery on the quality of life of the family or individual with ASD, and stakeholders’ feelings of satisfaction resulting from coordinated service delivery. Specifically, perceived outcomes related to service delivery for early childhood-age, school-age, and transition-age individuals with ASD will be reviewed.

**Early childhood-age**

Several studies exist investigating perceived outcomes from collaborative service delivery for early childhood-age individuals with ASD. For instance, a study by Coogle and Hanline (2014) reveals that parents of young children with ASD, ages 0 to 3 years, perceive decreased family stress, improved family progress, increased knowledge regarding strategy use, changes in family expectations, and increased feelings of competence following participation in coordinating services. Questionnaire data in a study by Dunst and Dempsey (2007) indicates that parents of young children, ages 1 to 5 years, with developmental disabilities report feelings
of empowerment as a result of family-provider partnerships for coordinated service delivery. In addition, in a study in which parents of children with ASD, ages 24 to 48 months, received services through an interprofessional clinic, parents report greater continuity of care receipt (Koushik, Bacon, & Stancin, 2015).

**School-age**

Regarding outcomes for school-age individuals with ASD and their families, studies investigate both caregivers’ and providers’ perspectives regarding outcomes from collaborative service delivery. For instance, Auert and colleagues’ (2012) study indicates that parents of children with ASD, ages 3 to 6 years, perceive that providers’ approach to service delivery has clear implications for parental perceptions of the therapy process and outcomes from treatment. Carbone and colleagues’ (2010) study reveals that parents experience more positive feelings of coping when services are coordinated, such as through a Medical Home Model. Cheak-Zamora and Farmer’s (2015) study reveals that parents of children with ASD, ages 0 to 17 years, who are able to access services through a Medical Home Model report substantially fewer unmet needs (11% report unmet needs) than parents of children who do not access these types of services (89% report unmet needs). Likewise, a study by Golnik, Scal, Wey, and Gaillard (2012) indicates that families randomly assigned to receive services through a Medical Home Model report statistically significantly greater feelings of satisfaction with service delivery, involvement in shared decision-making, and fewer unmet needs as compared to families receiving ‘standard’ care. Of note, the exact length of involvement with services and the potentially shifting composition of collaborative teams across time for participants in these studies were not reported.
A number of studies also exist in which researchers put collaboration efforts in place, in order to evaluate outcomes from coordinated service delivery. In one such study, Warfield, Chiri, Leutz, and Timberlake (2014) examined parents’ perceptions of well-being following participation in a state-funded program in which parents and providers collaborated to develop participant-directed support plans. Parents each had a child with ASD between the ages of 4 to 9 years. Following at least 6 months of participation, parents reported improved family functioning, improved coping skills, an improved ability to care for the child with ASD, and that the program made a positive difference in the family’s life. In another study, Murray, Ackerman-Spain, and Williams (2011) conducted a training program on collaboration with parents of and providers for individuals with ASD, from preschool to adulthood ages. As a result of program participation, parents and providers endorsed learning to overcome intimidation from one another, viewing problem-solving from each other's perspectives, and building a foundation of trust and respect. Further, they identified that families’ participation facilitated growth, collaboration, understanding, knowledge of ASD, and use of strategies.

Regarding the impact of participation in intervention efforts designed to facilitate collaboration, findings also exist for providers. In one study, Loutzenhiser and Hadjistavropoulos (2008) evaluated the perceptions of pre-licensure education students regarding their experiences in an interprofessional training program for serving children with ASD. Following program participation, students reported increased knowledge of the roles of other care providers, increased recognition of their own limitations and who to ask for help, and improved understanding of families of children with ASD. Likewise, Howell, Wittman, and Bundy (2012) conducted a study in which they evaluated the perceptions of occupational therapy and psychology graduate students regarding a collaborative training experience. As a result of
participation, students reported increased understanding of their own and others’ professional roles, an improved ability to shift roles, an improved ability to appreciate professional differences, improved recognition of the importance of compromising and flexibility, increased communication, an improved ability to provide and process feedback in the collaborative relationship, and increased recognition that the child’s needs should exist as the driving force for the collaborative relationship.

**Transition-age**

Two studies were located that examined perceived outcomes from collaborative service delivery to meet the transition-related needs of an adolescent or young adult with ASD. In Ferguson and colleagues’ (2015) case study, they identified outcomes linked to the provision of services for a young adult with ASD on the part of a transdisciplinary team. Reported outcomes included the following: 1) all team members reported positive outcomes from the effort, including that intervention efforts continue to work; 2) the young adult’s mother described the team’s planning as a ‘positive turning point’ in the young adult’s life, in that he could access community settings and participate in activities as a result of supports; 3) the young adult’s mother reported the young adult experienced a sense of purpose, increased self-confidence, improved coping skills, and improved social skills as a result of the effort; and 4) the young adult continued to be employed two years following the effort. In addition, the two adolescents who participated in the transition program in Wehman and colleagues’ (2012) study successfully transitioned from high school to competitive employment positions following high school graduation as a result of coordinated planning.
Summary of Literature Review and Current Need

Services for individuals with ASD and their families have significantly evolved since ASD was first recognized as a diagnosis in 1980. Today, the prevalence of ASD is widespread, while the range of available services and policies governing provision of services to individuals with this complex disorder are proliferating. Millions of families are faced with the daunting task of navigating largely disparate systems of service delivery, with the hopes of achieving the best outcomes for their children and members of their families. Despite their best efforts, however, significant stress is often placed on family members when attempting to coordinate services, resulting in feelings of dissatisfaction and frustration. These concerns are particularly salient for families of adolescents or young adults with ASD, given that multiple service providers play a necessary part in collaborating to coordinate services to meet a given adolescent’s or young adult’s needs. Further, the success of this transition planning has serious implications for the individual’s adult life outcomes, placing additional stress on family members and the individual himself or herself.

To address this concern, partnerships and interdisciplinary or interprofessional collaboration within service delivery emerge as critical. Although these types of collaboration have been recognized as important to service delivery for a long time, gaps in delivery of coordinated services are widespread. With successful collaboration, individuals with ASD, families, and providers benefit in important ways. For instance, family members of, service providers for, and adolescents or young adults with ASD can work together to establish goals for postsecondary life of the individual with ASD, assess the individual’s transition-related needs, develop a plan to address the individual’s needs, and evaluate and adjust services as needed. However, when collaboration is unsuccessful or not attempted, individuals with ASD, their
families, and their providers fail to maximize efficient delivery of and positive outcomes resulting from services. Therefore, there is a critical need to understand the first-hand experiences of families, providers, and adolescents or young adults with ASD when collaborating to plan for adolescents’ or young adults’ postsecondary transition-related needs, in order to fully inform ‘best practice’ recommendations.

To date, a range of studies have focused on caregivers’ and providers’ perceptions of factors that influence collaboration, their own roles in collaborative relationships, and the outcomes linked to coordinated service delivery. Studies exist regarding service delivery for early childhood-age individuals with ASD, school-age individuals with ASD, and to a more limited extent, transition-age individuals with ASD. Regarding facilitators to collaboration, caregivers endorse open communication, information-sharing, regular meetings, providers teaching caregivers intervention approaches, convenient services, providers’ helping characteristics (e.g., trustworthy, caring), flexibility, access to social supports, financial resources, ‘luck,’ and engagement in advocacy activities as key. Providers report higher self-perceived competency regarding ASD-related issues, use of empirically supported therapy services, years of service to individuals with ASD, having a friend or relative with ASD, and prior training are key. Regarding collaborative transition planning for adolescents or young adults with ASD specifically, caregivers and providers identify persistence, relationship building, communication, information-sharing, flexibility, ongoing contact, administrative and financial support, meetings, provider and family trainings, and adoption of specific roles as key.

Regarding barriers to collaboration, caregivers endorse a lack of training of providers, a gap between providers’ stated values and practice, busyness of providers, wait time for services, cost of services, a lack of communication and information-sharing, feelings that providers
devalue or blame caregivers, disagreements regarding goals, employment constraints, and a lack of centralized services as barriers. From the perspective of providers, barriers to collaboration include a lack of awareness of available community resources, limited time, a lack of reimbursement for coordination activities, a lack of specialized expertise, conflicting ideologies or perspectives, and ineffective organizational contingencies. In regard to transition planning for adolescents or young adults with ASD, barriers include separate child versus adult service delivery systems, inadequate planning, limited training of providers, and confusion regarding agency funding structures.

Although studies exist pointing to potential facilitators and barriers to collaborative service delivery for individuals with ASD broadly, and for transition-age individuals with ASD specifically, research regarding stakeholders’ perceived roles in collaborative relationships is more limited. Research regarding stakeholders’ roles in planning services for early childhood-age children with ASD reveals caregivers view their roles as information-sharing, observing, learning new skills, and shared decision-making. Providers view their roles as information-sharing and promoting development of new family skills. However, research indicates caregivers’ roles might become more limited and adversarial when planning for school-age services. Caregivers might assist in planning, although they might not be viewed as experts and providers might not desire ‘too much’ participation on the part of caregivers. On the other hand, providers act as gatekeepers to service, contribute specialized knowledge when planning for service delivery, and provide other types of support services as needed. Notably, a minimal amount of research regarding stakeholders’ roles in planning for postsecondary transition needs of an adolescent or young adult exists. Caregivers perceive that providers might lack knowledge and offer limited information regarding services, caregivers act alone to meet the adolescent’s or
young adult’s needs, and adolescents or young adults do not actively participate in transition planning.

Importantly, researchers have conducted studies identifying outcomes potentially linked to coordinated service delivery. Among families of early childhood-age or school-age individuals with ASD, caregivers report decreased family stress, improved family progress, increased knowledge regarding strategy use, changes in family expectations, increased feelings of competence and empowerment, improved coping skills, greater satisfaction, fewer unmet needs, improved problem-solving, and greater continuity of care following participation in coordinating services. Providers report increased knowledge of the roles of other providers, improved appreciation of professional differences, increased recognition of their own limits, improved flexibility and ability to compromise, improved understanding of families of children with ASD, and an improved understanding that the child’s needs should drive the relationship. However, few studies exist regarding outcomes linked to collaborative service delivery to meet the needs of transition-age individuals with ASD. Among existing studies, outcomes include that stakeholders report positive outcomes such as achievement of competitive employment, caregivers report an increased sense of purpose and self-confidence for the adolescent or young adult, and caregivers indicate improved parental coping skills.

In sum, although some foundational research exists regarding caregivers’ and providers’ experiences with collaboration for coordinated service delivery, a number of limitations are present. Current research reveals potential facilitators and barriers to collaboration for children with ASD, caregivers’ and providers’ roles in collaborative relationships, and outcomes that might be linked to such coordinated service delivery. However, empirical research is limited regarding the experiences of caregivers and providers in collaborating to meet the transition-
related needs of young adults with ASD, while research from the perspective of young adults is virtually nonexistent. Given the complexity of coordinating services to meet the transition-related needs of young adults with ASD in combination with the poor outlook for postsecondary outcomes of young adults with ASD, there is a critical need for research in this domain. Further, research investigating the perspectives of caregivers and providers regarding planning for the same individual with ASD is scarce. An in-depth investigation of shared experiences might best inform practice, highlighting unique and nuanced factors impacting collaboration. To address these gaps, the current study will examine the lived experiences of young adults with ASD, their caregivers, and their service providers in collaborating to coordinate services to meet the young adults’ transition-related needs. The following research question will guide this line of inquiry: What are the lived experiences of caregivers of, service providers for, and young adults with ASD in collaborating to coordinate services to meet the transition-related needs of the young adult? Further sub-questions guiding inquiry include: What factors influence collaboration? How do participants perceive their roles in collaboration? How do participants describe progress toward outcomes resulting from collaboration?

**Theoretical Framework**

For the current study, a family systems framework will be adopted. As described by Cridland, Jones, Magee, and Caputi (2014), a family systems approach to clinical practice and research is an important lens through which to examine the needs of families of individuals with ASD, particularly when considering service delivery. A family systems framework is based on the Bronfenbrenner’s ecological systems model (1979) and has been applied to families, through recognition of a given family as a relational environment with systems qualities (Cox & Paley, 1997). Moreover, Bronfenbrenner’s model has specifically been applied to conceptualize the
functioning of families that include a child with a disability, with implications for family support services. The purpose of the current section is to review theory and research related to the family systems framework and outline implications for the current study.

**Bronfenbrenner’s Ecological Systems Model**

Bronfenbrenner’s ecological systems model (1979) serves as the guiding framework for the family systems framework utilized in research today. Broadly, an ecology is defined as “the collection of reciprocal and interrelated forces around us” (Fine, 1985, p. 263). As described by Fine (1985), these forces include a number of factors that impact human functioning such as climate, habitat, life organisms, food chains, water, and other natural resources. In turn, humans impact these factors, creating a reciprocal relationship between humans and the environment. With this in mind, an ecological perspective views an individual as functioning and developing in the context of his or her environment (i.e., daily settings), with the individual and the environment dynamically influencing one another.

Within his model, Bronfenbrenner (1979) conceptualizes that a given individual’s environment is composed of multiple systems. The individual exists in these systems, influences these systems, is influenced by these systems, and these systems interact to influence one another. The first and most immediate system is the individual’s microsystem and includes interactions between the individual and his or her daily environment, such as the individual’s interactions with his or her classroom, home, or other individuals within these settings. The second system is the individual’s mesosystem, which includes interactions among the individual’s microsystems. The third system is the individual’s exosystem and includes the social structures and institutions of society, such as government agencies, mass media, or transportation systems. The fourth system is the individual’s macrosystem and includes the
cultural and institutional patterns that govern the other systems, such as economic, political, legal, social, and educational systems. Finally, a fifth system, the chronosystem, acknowledges that these systems change across time. The individual experiences transitions in historical and personal events in his or her environment, which accumulate to determine the individual’s life course. Overall, the individual and his or her environment (i.e., his or her ecological systems) are viewed as members in a dynamic relationship, ultimately determining the individual’s course of development and functioning throughout his or her life.

**Family Systems Framework**

**The family unit**

Within a family systems framework, the basic unit of analysis is the ‘family unit’ (Davies & Cicchetti, 2004). Researchers generally agree that a family unit can be conceptualized as an organized system with characteristics specific to the unit (Cox & Paley, 1997; Davies & Cicchetti, 2004). Fine (1979) defined a family unit as “a system in the ways that the parts of the family interact. Each family member takes on a role, has certain relationships with other family members, and performs certain activities in relation to the family.” (p. 151). Similarly, Gardiner and Iarocci (2012) noted that a family unit consists of a variety of members who operate within a number of interconnected systems in their daily environment. In general, the family unit is interactional and is made of subsystems of individual family members whose roles impact one another and change throughout each member’s lifetime (McGoldrick & Carter, 1980; Minuchin, 1974). Furthermore, both the family unit and individual family members exist within the broader systems defined in Bronfenbrenner’s model, responding to input from these systems in a dynamic manner (Cox & Paley, 1997; Davies & Cicchetti, 2004). Finally, a given family unit is characterized by certain cultural, religious, philosophical, and social values and resources that
impact its functioning (Powers, 1991; Wehman, 1998). Therefore, an understanding of the family’s internal subsystem and external systems, in light of the family’s characteristics, is critical to understand the family as a unit.

**Internal subsystems.** In general, subsystems within the family unit consider the roles, relationships, implicit rules, interpersonal boundaries, communication patterns, power structures, and balance of forces between individual family members within the microsystem of the family unit (Davies & Cicchetti, 2004; Fine, 1985). In particular, several characteristics have been proposed as important when considering the family’s functioning in light of its subsystems, in line with a general systems theory. First, the family exists as a whole but is made of important parts. That is, although each member of the family is independent, he or she is embedded within the broader unit, dynamically influences the unit, and cannot be considered apart from the whole (Cox & Paley, 1997; Davies & Cicchetti, 2004). Second, the family unit exists as a hierarchical structure of subsystems with important boundaries existing among subsystems. In general, subsystems are hierarchically organized within the broader family unit with internal boundaries existing between subsystems (Cox & Paley, 1997; Cridland et al., 2014). However, to obtain optimal functioning within the family unit, boundaries should be appropriately permeable across time, allowing family members to differentiate and become independent within their own subsystems while simultaneously permitting them to interact with and access resources from the broader family unit as needed (Cox and Paley, 1997; Cridland et al., 2014). Third, the family unit constantly adapts toward self-stabilization. That is, the family unit constantly strives to achieve homeostasis within its broader, ever-changing systems. The family does so by developing regularities, rules, and structures that return the family to a state of balance, even when deviations occur (Cox & Paley, 1997). Fourth, the family unit constantly adapts toward
self-organization. Again, deviations in the systems surrounding the family inevitably occur across time, but the family continues to adapt, change, and challenge its own system to achieve continuity as a unit (Cox & Paley, 1997).

**External systems.** Within a family systems model, the family as a unit as well as its individual members are conceptualized as influenced in a manner that is parallel to that of any given individual within Bronfenbrenner’s wider ecological systems model. The family as a unit is impacted by forces from its external mesosystems, exosystems, macrosystems, and chronosystems while simultaneously acting to shape and select its environment (Cox & Paley, 1997). As part of this dynamic relationship, the family unit strives to achieve external boundaries, in order to regulate its transactions with environmental systems while preserving internal family boundaries (Cox & Paley, 1997; Cridland et al., 2014). Over time, deviations occur in external systems, creating discontinuities and maladaptations among the family’s other external and internal systems (Davies & Cicchetti, 2004). Again, however, the family unit evolves to a state of order, primarily through hierarchical integration of systems across all external and internal levels (Davies & Cicchetti, 2004). In addition, the family might experience a range of risk and protective factors as a unit, in the form of stressors and supports (Cridland et al., 2014). Over time, they adapt to or cope with each factor, with the bi-directional relationships between these factors and the family unit determining the course of development and functioning for the family (Cridland et al., 2014).

**Individual family members**

For the purpose of this study, the individual role of a child within the broader family unit will be discussed in line with a family systems framework. Within a family systems framework, child development is viewed as an ongoing process of dynamic interactions between the child,
his or her family contexts, and the child’s broader social contexts (Sameroff & Chandler, 1975). Within the family unit, a child is influenced by: 1) his or her microsystem, including the immediate family environment and boundaries within this environment; 2) his or her mesosystem, including the interactions between the family environment and other settings (e.g., schools) or individuals (e.g., peers); 3) his or her exosystem, including community contexts or the contexts in which his or her other family members operate (e.g., parents’ places of work or social networks); and 4) his or her macrosystem, including the wider contexts (e.g., social, cultural, political) in which the child lives (Bronfenbrenner, 1986; Wehman, 1998; Xu & Filler, 2008). Across time, the child, other family members, and the systems themselves dynamically interact to influence development, reflecting the child’s chronosystem (Cox & Paley, 1997). In addition, the child’s behavior influences the family’s behavior and systems external to the family, causing ongoing shifts in the family’s functioning (Wehman, 1998).

**Family member with a disability**

Over time, the family systems framework has been applied to conceptualize functioning among individual members of a family, parent-child relationships, marital relationships, sibling relationships, and interactions of family members with extended family members (Cox & Paley, 1997; Morgan, 1988). For the purpose of this study, the family systems framework will be used to conceptualize the shared impact of a family member with a disability on the family unit as a whole as well as individual members of the family unit. Similar to a child’s impact on any family, the child with a disability has a shared and bi-directional impact on all family members (Morgan, 1988). However, the child’s complex needs might have an additional impact than that of a typically-developing child (Morgan, 1988).
Given the range of needs for a child with a disability, additional supports and stressors are likely to emerge within the family unit and in the family unit’s broader environmental systems (Cridland et al., 2014; Morgan, 1988). For instance, within the family unit, the child’s parents and siblings are likely to face increased social-emotional stress (Morgan, 1988). As described by Morgan (1988), the child’s parents might experience sadness and fear surrounding the child’s initial diagnosis, or they might experience stress and anxiety in providing daily care for the child, coordinating services for the child, navigating educational and political systems, and managing finances. In turn, this might impact the quality of marital relationships, and siblings might experience sadness and worry related to increased parental attention to the child with a disability. In addition, families might experience boundary ambiguity during times of transition and fluctuate between periods of worry and hope for the child with a disability (Cridland et al., 2014). For a child with ASD specifically, the family’s functioning might be impacted given the child’s potential inflexibility with routines, idiosyncratic preferences and intolerances, difficulties with social interactions and communication, and other difficulties with daily living skills (Cridland et al., 2014). As a result, families will likely need to leverage additional supports within their environment to aid in the family’s functioning.

Application of Family Systems Framework to Service Delivery

Characteristics of support services

Within a family systems framework, support services have been characterized as targeting the functioning of the entire family unit, rather than just the individual behavior of the child with a disability (Powers, 1991). Given that the family unit is a system, support services should include all members of the family to the extent possible (Cridland et al., 2014). In turn, support services affect all members of the family unit by nature of their interactions with one
another and the systems within their environment (Minuchin, 1974; Wehman, 1998).

Specifically, support services might impact the structure of the family unit as a whole, roles of individuals within the family unit, stressors and coping strategies within the unit, or the external support networks of the family unit as a result of changes at the microsystem, mesosystem, exosystem, or macrosystem levels of the family unit (Fine, 1985; Guralnick & Bennett, 1987).

Further, as described by Powers (1991), the family systems framework offers a useful lens through which to consider the design of support services to match a family’s needs. Specifically, Powers (1991) outlined seven important characteristics of the family to consider when designing services within a family systems framework: 1) ability, including the resources available to a family and their willingness to commit to resources to bring about change; 2) values, including the family’s cultural, philosophical, and religious views regarding change; 3) circumstances, including specific characteristics of the family’s current life environments; 4) timing, including the current events the family is experiencing; 5) obligations, including the family’s perceived need for support or change; 6) resistance, including the family’s fear of change; and 7) yield, or the family’s perception of benefits that might be obtained from support or change. The interactions between these characteristics are also critical to consider, such as in the case of a family who desires change but might have accepted some problematic behavior as a result of religious or cultural views regarding tolerance.

**Implications for design of support services**

In line with the aforementioned considerations, a family systems framework offers a number of useful implications for design of support services. For instance, multiple researchers suggest that support services should target influences across systems, considering targets for intervention in light of the needs of the individual with a disability, the family’s context, and the
interrelationships among systems (Cridland et al., 2014; Fine, 1985). Cox and Paley (1997) suggest that support services are most likely to be viewed as necessary and helpful when they target a breakdown in the network of relationships among family members or between family members and their external environment. Cridland and colleagues (2014) suggest that support services are most likely to target the family’s functioning in a meaningful manner when the services are appropriately individualized to the family, are evidence-based, and utilize a strengths-based approach, so as to develop the family’s personal resources. In addition, multiple researchers recognize that support services are likely to be of most benefit during times of transition or major life events, during which the family is experiencing additional stressors that might ultimately influence the family’s course of development and well-being (Cox & Paley, 1997; Cridland et al., 2014).

**Outcomes from supports**

Within the family systems framework, researchers have suggested specific goals for support services that are most likely to aid in a family’s functioning and best outcomes for the child with a disability. For instance, at the microsystem level, goals should include a family’s acceptance of the child’s diagnosis in a healthy manner, structural balance within the family, functional organization within the family, and the ability of family members to express feelings openly and support one another (Morgan, 1988; Powers, 1991). Families should develop knowledge about the child’s disability, and families should experience increased resiliency, increased perceived competency, and decreased stress as a result of the efforts (Cridland et al., 2014). To target external systems in which families operate, appropriate goals include promotion of access to services for families and development of support networks for the family (Powers, 1991). In addition to formal networks of supports, families should access informal
networks of support including extended family members, friends, other families of children with disabilities, and involvement in recreational activities (Morgan, 1988). Especially at times of transition or stress, support services should aid in the family’s process of development, restoring the family to self-stabilization and optimal functioning (Powers, 1991).

**Implications for collaborative service delivery**

Given that a family systems framework recognizes bi-directional sources of influence across all systems in which a family operates, a family systems framework naturally lends itself to consideration of collaborative relationships for coordinated service delivery for a child with a disability. Specifically, researchers have noted the importance of considering implementation of support services across settings to promote achievement of goals and outcomes from services (Fine, 1985; Wehman, 1998; Xu & Filler, 1998). For instance, Fine (1985) noted that a change at any one level of the family’s system might disrupt the balance of other systems. By working together, providers and families can ensure homeostasis is achieved across systems, promoting optimal family functioning and generalization of effects from services across the settings. Similarly, Wehman (1998) implicated role boundaries in a discussion regarding the importance of collaborative relationships for service delivery. That is, collaboration among families and providers will best promote ideals of balanced power and open boundaries among families and providers. In turn, families will perceive that their participation in service design is accepted and welcomed and the relationship among providers and families will be characterized by feelings of acceptance, respect, care, and recognition of expertise. In this way, families and providers can work together in a way that is most likely to result in efficient and responsive service delivery to meet the needs of a given family and child.
Further, researchers have offered specific implications for collaboration for service design and delivery, when guided by a family systems framework. For instance, Xu and Filler (1998) discussed collaborative teaming to design inclusive educational services for children with disabilities. They indicated that teams should consider parental concerns and general family needs at a microsystem level, peer involvement and supports within the classroom at a mesosystem level, connection of the child with a disability to community activities and supports at the exosystem level, and consideration of wider cultural influences at the macrosystem level. In this way, family needs can exist as central while teams work together to leverage supports across each of the target child’s systems. Likewise, Fine (1985) provided the example of consultation among educational teams as a means through which to consider interactions that influence the child and design of supports across settings. Again, this will ensure proper consideration of the family’s context and needs and promote the child’s success across settings.

**Family Systems Intervention Model**

Dunst, Trivette and other colleagues have proposed and refined a specific model to guide design of support services and interventions for children with disabilities and their families, in light of a family systems framework. As they described in a 2009 paper, Dunst, Trivette, and Deal (1988) initially proposed their family systems intervention model in the 1980s as a tool for assessment and intervention conceptualization for families of children with disabilities. In general, their model was based on eight concepts: 1) a social-systems perspective of families and a family-systems definition of interventions; 2) a focus on the family as the unit of intervention; 3) family member empowerment as the goal of intervention; 4) promotion models as guiding interventions; 5) a focus on family-identified needs as targets of intervention; 6) identification and building upon family strengths as the goal of intervention; 7) the use of family’s informal
social support network as primary sources of supports and resources for meeting a family’s needs; and 8) leverage of professional help-giving practices based on competency. Specifically, their model sought to promote family functioning, contribute to design of interventions to meet a family’s needs, build upon a family’s strengths to meet needs, and enhance a family’s ability to independently meet its own needs. In addition, their model outlined 12 help-giving practices for providers. These included that providers should engage in positive and proactive service delivery, offer services in response to indicated needs, engage families in decision-making, design services in line with a family’s culture and values, ensure families view efforts as appropriate, consider that benefits of service outweigh costs, provide opportunities for families to reciprocate so as to limit feelings of indebtedness, ensure acquisition of resources in order to bolster the self-esteem of families, promote informal supports of families, collaborate with families, ensure services negate the need for additional services to target the same behavior of interest, and involve families so as to bolster their self-efficacy beliefs.

In 2009, Dunst and Trivette updated their model, so as to reflect updated research in the field. First, they defined that family needs should be conceptualized as family concerns and priorities. This reflects a conceptualization in which the family perceives a discrepancy between their current state of being and their desired state of being and determines that this discrepancy deserves attention, in the form of an intervention. Second, they emphasized that appropriate services are those that actively involve family members in obtaining and designing the services. Third, they emphasized the importance of considering a family’s abilities and interests in choosing services. Fourth, they renamed “help-giving behavior” to “capacity-building help-giving practices” to reflect the most effective type of help-giving behavior and to demonstrate the importance of active involvement of family members. In addition, they again pointed to the
importance of providing services in light of a family’s systems-level context, considering the systems in which the family is embedded. They acknowledged that daily behavior is impacted by events at all levels of systems and supports must adequately address each system. They also discussed the importance of framing supports in a “capacity-building” paradigm, to emphasize the strengthening of family functioning.

Most recently, Trivette, Dunst, and Hamby (2010) again reviewed development of their model and implications for service design and delivery. They emphasized the importance of applying their model to help family members identify their needs, access necessary supports and services to meet their needs, build upon their own capabilities and strengths in designing services, and continue to develop abilities to independently obtain services to meet their needs. In turn, families develop knowledge, skills, competence, and confidence, enabling their children with disabilities to learn, grow, and develop in an optimal manner. Further, citing Bronfenbrenner (1979; 1992; 1999), they contended that families should be provided supports so as to alleviate their stress and promote positive engagement with their children, and that parent-child relationships and parental well-being are determined by the interactions between families’ supports within their systems of living. Finally, they acknowledged the potential importance of structural variables related to service delivery in their model, such as length of service provision, location of service provision, number of services used, and frequency of service use. Regarding outcomes from service delivery within their model, they concluded that practices guided by their framework are most likely to promote parental self-efficacy beliefs and parental well-being, which in turn impact parent-child interactions, which in turn influence child development. This process is explained by components of their model, as framed within a family systems framework guided by Bronfenbrenner’s ecological systems model.
**Implications for the Current Study**

The current study will be guided by a family systems framework, specifically as this relates to conceptualization of service delivery for individuals with ASD and their families and the need for collaboration among families and providers. At the family level, this study will consider families as a unit and as functioning within interrelated and interacting internal and external systems in their daily lives. These systems are synonymous to those proposed by Bronfenbrenner (1979) in his ecological systems model. This study will consider the role of families’ cultural, religious, philosophical, and social values and resources in determining their functioning across systems and need for services. This study will conceptualize that all family members experience a shared influence of having a family member with ASD as part of the family, and all members are impacted by stressors and supports to the family’s systems. In addition, this study will adopt the view that families seek services and additional supports when faced with stressors, life events, or transitions. They seek these services as a means by which to restore balance to their lives, alleviate stress, and overcome perceived discrepancies between their current functioning and desired functioning.

Regarding collaboration for service delivery, this study will adopt a framework for understanding the importance of and potential outcomes from service delivery in line with proposed paradigms framed within a family systems framework. Specifically, this study will recognize that services should be designed and coordinated in a manner that addresses the functioning of families and their children with ASD across all systems of their lives. To maximize efficiency, service providers and family members should work together to plan for coordinated delivery of a given individual’s services. Service delivery plans should be appropriately individualized to meet the family’s needs and should be responsive to the family’s
needs across time. In doing so, families can achieve balance across systems of their lives, families and providers can overcome boundaries between one another, supports and intervention efforts can be put in place across the child’s and family’s everyday settings, and the child’s skills can be generalized across settings. In turn, families are likely to perceive improved outcomes related to service delivery, experience decreased stress, and experience increased feelings of competency and self-efficacy. As a result, the family and individual with ASD are likely to follow a positive developmental trajectory, achieve optimal outcomes, and have the capacity to respond to future life events in an adaptive manner, as guided by any necessary services.
Existing research and policy emphasize a critical need to understand family and service provider perceptions of experiences with coordinated service delivery, particularly in providing key stakeholders a ‘voice’ regarding ‘how’ stakeholders experience processes of service delivery aligned with families’ needs (Blue-Banning et al., 2004; Hodgetts, Nicholas, Zwaigenbaum, & McConnell, 2013; Minke & Anderson, 2005). This need is especially critical for individuals with ASD transitioning to adulthood, given the variety of transition-related needs of stakeholders involved in the process and the important role of coordinated services in facilitating this transition (Hendricks & Wehman, 2009; Noonan et al., 2008). To address this need, the present study employed a qualitative phenomenological research methodology to describe the lived experiences of caregivers of, service providers for, and young adults with ASD in coordinating services to meet the transition-related needs of the young adult. Coordinating services is defined as the caregiver, service providers, and young adult collaborating together to plan for services to meet the needs of the young adult with ASD and his or her family members.

To this end, the study seeks to answer the following question: What are the lived experiences of caregivers of, service providers for, and young adults with ASD in collaborating to coordinate services to meet the transition-related needs of the young adult? In addition, three sub-questions will further guide this inquiry: What factors influence collaboration? How do participants perceive their roles in collaboration? How do participants describe progress toward outcomes resulting from collaboration?

The purpose of this chapter is to outline the methodology for the present study. Specifically, overarching considerations for each component of the research design and describing the procedures for the current study are described alternately. Therefore, this chapter
Overview of Qualitative Research

As described by Merriam (2009), qualitative research methodology is best suited to answer research questions aiming to explore, describe, or develop an understanding of a given topic. Specifically, this type of research seeks to understand how research participants interpret their experiences, construct knowledge about the world in which they live, and attribute meaning to their experiences in the world. Qualitative research is conceptualized as situated in a lived context (i.e., the participant’s world) rather than in a contrived setting (e.g., a laboratory). Qualitative research is guided by an inductive process, meaning the researcher collects data in order to form hypotheses or theories rather than collecting data to support a hypothesis. The research design is emergent and flexible, and samples are small and purposefully chosen to capture an experience for a specific group of participants. The researcher acts as the instrument for both data collection and analysis, so acknowledgement of researcher biases is critical. Finally, the product of a qualitative research study should include rich descriptions of the topic studied, including data such as field notes and quotes from interviews.

As described by Crotty (1998), four elements comprise and guide the design of a qualitative research study. The first element is the epistemology, which describes the researcher’s viewpoint regarding the nature of knowledge. That is, the epistemology exists as “a way of understanding and explaining how we know what we know” (Crotty, 1998, p. 3). The second element is the theoretical perspective, which describes the researcher’s philosophical
stance. This perspective serves as the context for the study and guides the methodology adopted in the study. The third element is the methodology, which guides the research strategy, process, or design that enables. The researcher adopts methods based on the methodology. The fourth element is the study’s methods, or the techniques and procedures used to gather and analyze data. Each of these elements will be described for the current study in the following section.

**Framework**

Crotty’s (1998) conceptualization of phenomenological inquiry was adopted to guide the present study. Crotty places a phenomenological methodology within an overarching constructionist epistemology and an interpretivist theoretical framework. Interviews follow as the primary method by which to answer research questions with a phenomenological methodology. See Figure 3-1 below as a visual aid for this framework. The purpose of the following subsections are to describe each of these elements of phenomenology, and to provide a detailed outline regarding phenomenology as a methodological framework.

![Figure 3-1. Framework for the current study. This figure illustrates the elements of the present phenomenological study, based on Crotty’s conceptualization (1998).](image-url)
**Epistemology: Constructionism**

The epistemology of a study describes the researcher’s viewpoint regarding the nature of knowledge, including describing “how we know what we know” (Crotty, 1998, p. 3). Within Crotty’s (1998) view, phenomenology exists within an epistemology of constructionism, which holds the viewpoint that knowledge is constructed through humans’ interactions with the world. Humans construct meaning about the world when their consciousness engages with objects of the world. This process has been termed ‘intentionality,’ meaning humans direct their actions toward objects to obtain meaning. This process does not necessarily occur purposefully, nor is the process meant to produce true and valid meaning. Rather, the process is unique to each human and creates the ‘lifeworld’ in which humans exist.

**Theoretical Framework: Interpretivism**

The theoretical framework of a study provides a context for the study and outlines the researcher’s philosophical stance. Within Crotty’s (1998) model, an interpretivist theoretical framework guides a phenomenological methodology. Interpretivism holds the viewpoint that knowledge is experienced and interpreted through the actions of humans (Crotty, 1998). That is, reality is a socially constructed phenomenon based on a given individual’s interpretation of a single event (Merriam, 2009). Therefore, one could argue that multiple realities exist based on each individual human’s interpretation of his or her reality, particularly as this is influenced by social, cultural, and historical factors in the individual’s life (Merriam, 2009). In general, the purpose of an interpretivist framework is to describe, understand, and interpret an individual’s experience of a life event or reality (Merriam, 2009).
Methodology: Phenomenology

The methodology, or design, adopted in the present study is a phenomenology. As described by Crotty (1998), phenomenology “refers to what we directly experience, that is, the objects of our experience before we start thinking about them, interpreting them, or attributing any meaning to them” (p. 79). Within a phenomenological study, the researcher studies the experience of a given group of individuals with a phenomenon (Creswell, 2013; Merriam, 2009). In this case, a phenomenon is defined as the objects or experiences with which individuals interact (Crotty, 1998). Typically, participants in a study are selected because they have a certain experience in common and the goal of the researcher is to examine this ‘shared experience’ (Creswell, 2013; Merriam, 2009). Specifically, the researcher seeks to determine the universal ‘essence,’ or the nature, of the shared experience for the participants (Creswell, 2013; Merriam, 2009). In turn, the researcher can derive meaning and an overarching understanding about the experience through identification of the inner structure of the phenomenon (Creswell, 2013; Merriam, 2009). This identification should occur free from social and cultural biases, assumptions, and beliefs on the part of both the researcher and the participants, in order to arrive at the most basic structure of the essence (Crotty, 1998). The resulting description of the phenomenon should be rich, allowing a reader to feel as if he or she is experiencing the event as it first presented itself to the participant (Van Manen, 2014).

Historical background

As described by Van Manen (2014), phenomenology originated in the 20th century in Europe and was based on the early work of Edmund Husserl. Husserl originally conceptualized a ‘science of essences’ that examined experiences resulting from the meaning humans attribute to objects encountered in the world through reflection. Today, Husserl’s tradition of
phenomenology is known as transcendental phenomenology. Since Husserl, a number of philosophers have expanded upon his transcendental phenomenology, describing different aspects of humans’ beings and experiences. Arguably the most widely recognized tradition since Husserl is that of Martin Heidegger’s hermeneutic phenomenology, which examines humans’ modes of being and experiences in the world. In his view, all experiences are already interpretations of the experiences, rather than Husserl’s sole conceptualization of experiences as descriptions. For the purpose of this study, a hermeneutic phenomenology in line with Heidegger’s conceptualization was adopted.

**Theoretical underpinnings**

Before outlining specific elements of a hermeneutic phenomenology, I first outline major theoretical underpinnings characterizing phenomenology as an overarching methodology. These elements guide phenomenological inquiry in general and thus serve as an important frame when considering the specific methodology one chooses. Within this section, the purpose of phenomenological research is outlined, followed by a description of critical aspects of phenomenological research.

**Purpose.** In general, all forms of phenomenology seek to examine the lived experiences of a group of people, looking for the logic and meaning those individuals ‘see’ when engaging in an experience (Dukes, 1984; Van Manen, 1990). As described by Van Manen (2014), a researcher first engages in phenomenological inquiry in response to a sense of wonder regarding how a phenomenon gives itself to humans. The researcher holds the view that the phenomenon has a discoverable structure, and he or she is motivated to search for that structure as it exists in the world (Dukes, 1984). That is, the researcher seeks to garner an understanding of a phenomenon as a group of individuals live through it, rather than in a contrived setting guided by
empirical methods (e.g., a carefully controlled experiment in a laboratory) or in a state clouded by judgments, biases, or theories (Dukes, 1984; Van Manen, 2014). To guide this aim, the researcher adopts a perspective of ‘intentionality’ and refuses to accept a standpoint of subject-object dichotomy. That is, the researcher acknowledges that humans are of the world and direct their consciousness toward objects, creating one’s reality of an object (Van Manen, 1990). The perceived reality of the object only exists in light of the meaning an individual attributes to his or her experience (Van Manen, 1990). The goal of the researcher, then, is to identify and develop an understanding of the essence of the phenomenon of interest as it is experienced (Dukes, 1984; Van Manen, 2014). In turn, this generates insights and understandings to challenge existing assumptions and ‘truths’ of the world, allowing the researcher to articulate the ‘how’ and ‘what’ of human experiences (Van Manen, 2014).

**The lifeworld.** One key assumption guiding phenomenological research acknowledges that all humans reside in a so-called ‘lifeworld.’ Van Manen (1990) notes that the lifeworld consists of those events which an individual experiences with a ‘natural attitude,’ before the individual conceptualizes, categorizes, classifies, abstracts, or reflects on the events. Although the individual’s experience with the event might be situated in the world of the ‘other’, the whole, the communal, or the social, the lifeworld seeks to capture an individual’s experience with the event before a reflective or theoretical attitude pervades the experience. Thus, the goal of capturing the lifeworld is to capture the nature of one’s experiences, improve one’s insight into experiences, uncover aspects of experiences that might be taken for granted, and explain phenomena as they first present themselves to one’s consciousness.

**Intentionality.** Another key concept guiding phenomenological research, ‘intentionality’, describes the process by which a person relates to his or her lifeworld. Van
Manen (2014) describes that humans are always ‘in’ and ‘of’ the world and therefore experience ‘things’ (e.g., objects or events) as they appear in the lifeworld. Consciousness places humans at the center of their own lifeworlds, and each human exists as a separate entity apart from other humans, giving rise to unique experiences. Humans are constantly experiencing the ‘things’ of the world and are able to comprehend or grasp the ‘things’ due to direction of consciousness toward those things as they exist in the world. In directing consciousness, humans might name those things and experience those things as they are presented, giving meaning to the experiences. Over time, humans might experience a certain thing repeatedly, turning the experience into a lived phenomenon. Thus, the goal of phenomenology is to gain an understanding of humans’ experiences with a given ‘thing’ and the phenomenon they might experience, as a result of the individual’s intentional existence in the world.

**Nature of lived experiences.** Following from the concepts of lifeworld and intentionality, one must understand the nature of a lived experience to fully capture it in a phenomenological study. As Van Manen suggests (1990; 2014), the true nature of a lived experience exists when a person first encounters the experience in an immediate state of pre-reflective consciousness. However, this moment immediately subsides and a person can only again recognize the experience through naming, recollection, or reflection on the experience. Therefore, the goal of phenomenology becomes to uncover lived experiences as they were experienced in the ‘now’ while acknowledging that recollections will always be retrospective. In turn, this points to the importance of setting aside beliefs, biases, assumptions, theories, and language one has attributed to a lived experience, in order to capture the immediate nature of the lived experience.
**Essences.** When engaging in the task of unveiling the nature of lived experiences, the researcher specifically aims to capture the ‘essence’ of these lived experiences. Van Manen (1990) describes that the essence of a lived experience refers to the nature of a phenomenon, or ‘what’ a phenomenon is. An essence arises from a person’s exposure to a certain experience that arises in the person’s awareness. A person has the ability to capture this experience through language and description. The essence itself is conceptualized as composed of layers of internal structure, including both concrete facts and abstract details. One might conclude that the essence of a phenomenon has been captured when the description of the essence feels fully alive.

**Epoche and bracketing.** Prior to identifying the essence and meaning of a phenomenon in a phenomenological study, the researcher first engages in a process of epoche, or bracketing, to ‘put aside’ all preconceived understandings, judgments, assumptions, and scientific theories (Merriam, 2009). Within phenomenological research, the task of the researcher is to identify the basic structure of an experience, so the researcher engages in this process to put aside those beliefs that might obstruct access to the experience in its most natural or ‘raw’ form (Merriam, 2009; Van Manen, 2014). The researcher holds four critical aspects of epoche in mind when engaging in the process: 1) wonder, meaning the researcher engages in a pure sense of wonder about the phenomenon; 2) openness, meaning the researcher engages with the phenomenon in a manner free from beliefs and linguistic attributions; 3) concreteness, meaning the researcher obtains explicit information regarding the ‘what’ of a phenomenon; and 4) approach, meaning the researcher approaches described experiences in a manner individually suited for the topic undergoing study (Van Manen, 2014). Although researchers acknowledge the difficulty in viewing lived experience totally free from societal and personal beliefs, the goal of epoche
remains to maintain curiosity regarding new meaning structures characterizing experiences that might not be recognized in everyday life (LaVasseur, 2003).

To facilitate the process from a practical standpoint, the researcher should physically write his or her beliefs in parentheses or brackets (Van Manen, 2014). The purpose of this text is to allow the researcher to revisit his or her acknowledged biases while engaging in the phenomenological study, as a reminder to orient himself or herself to the lived experience as if he or she is experiencing it for the first time (Van Manen, 2014). Moustakas (1994) notes that the researcher may choose where to introduce this description in the manuscript. He suggests that the researcher might include it at the beginning of the manuscript, in the methods section to aid in a discussion of the role of the researcher in the study, or with the description of participants in the study.

**Phenomenological meaning.** Ultimately the purpose of phenomenological research is to capture ‘phenomenological meaning.’ Van Manen (2014) notes that phenomenological meaning arises from description and interpretation of lived experiences, as opposed to explanation that might arise from traditional empirical research. He acknowledges that phenomenological inquiry intends to orient the researcher toward meaning, since all meaning experienced in an event might not be fully captured through language. Further, he describes that meaning is likely embedded in an experience, so one must adopt a metacognitive stance in which one acknowledges that he or she might not fully ‘know’ or be able to describe that which is known. In these ways, one can arrive at the type of meaning that can be captured through phenomenological inquiry. This meaning can be captured regarding a range of human experiences such as events, incidents, objects, relations, thoughts, or feelings. Again, however, the aim is to provide description and
interpretation to satisfy a sense of wonder rather than to explain, diagnose, or interpret such as for the sake of therapeutic services.

**Relationship to theory.** Although phenomenological inquiry intends to capture an experience as it presents itself to a person, free from assumptions, biases, theories, and the like, the description of the lived experience still holds a relation to existing theory (Van Manen, 2014). As Van Manen (2014) explains, the description of the lived experience intends to provide the reader with meaning regarding a certain object or event, free from reflection or attributions of theory. This meaning should directly connect the reader to an experience lived in the world. In turn, insights gained from meaning can inform existing theory in several important ways. First, phenomenological inquiry might provide insights regarding the essential structure of a phenomenon which inform meaningful empirical study of the phenomenon (Dukes, 1984). Second, the insights garnered through phenomenological inquiry can highlight where a theory might ‘fail,’ such as lacking a link to people’s true experience with a certain event (Van Manen, 2014). Third, phenomenological descriptions might intersect with theory, together contributing to a rich explanation of human phenomena (Van Manen, 2014). Thus, phenomenological inquiry does have an important relationship to theory, although this relationship emerges once phenomenological insights are garnered free from theoretical influences.

**Practical value.** Following from the discussion regarding the contribution of phenomenological inquiry to theory, a discussion of the practical value of phenomenology as a mode of inquiry is necessary. Researchers have pointed to the practical value of phenomenological inquiry, specifically as it relates to the human service field. For instance, within nursing literature, researchers indicate that phenomenological insights might improve practitioners’ understanding of individuals’ unique experiences with healthcare, illnesses, receipt
of supports, and ability to cope (LaVasseur, 2003). This type of inquiry acknowledges their contextual realities, their concerns, and the meaning they garner from interactions with their environments (LaVasseur, 2003). In turn, practitioners can use obtained understandings to inform sensitive and responsive care (LaVasseur, 2003; Lopez & Willis, 2004).

**Limitations.** As with all research methodologies, limitations also exist with this type of research. For instance, methods to conduct a phenomenological study are not clearly delineated, especially in comparison to other types of inquiry (Dukes, 1984). Due to this limitation, researchers must be comfortable adopting a stance of flexibility, ingenuity, and continual self-checking (Dukes, 1984). Further, only descriptions result from this type of research rather than factual statements, so researchers cannot make conclusions regarding correlation or causation as a result of the research (Dukes, 1984). Therefore, one must weigh these limitations against practical benefits before engaging in a phenomenological study.

**Hermeneutic phenomenology**

In the current study, a specific methodology of hermeneutic phenomenology is applied. As stated, the two dominant approaches to phenomenology are hermeneutic phenomenology in the Heidegger tradition and transcendental phenomenology in the Husserl tradition (Van Manen, 2014). Within both approaches, the researcher approaches a phenomenon for study with a sense of wonder of what it means to experience that phenomenon in a person’s natural lifeworld (Van Manen, 1990). The researcher garners the individual’s description of the lived experience, with the goal of uncovering the structure and themes characterizing the experience (Van Manen, 1990). Following this, the researcher produces a vivid description of the nature of the experience, relating the structures of the experience to the whole of the experience (Van Manen,
Hermeneutic phenomenology extends this process, adding interpretation to described experiences and meaning (Van Manen, 1990). Specifically, a researcher engaging in hermeneutic phenomenological inquiry conceptualizes described lived experiences as ‘texts of life’ that can be interpreted in relation to a person’s lifeworld (Van Manen, 1990). The task of the researcher is twofold: to point out the meanings within the experience and to make interpretations both among identified meanings and between the meanings and contextual influences on the individual (Van Manen, 1990). To guide this process, the researcher adopts an assumption of ‘situated freedom’; that is, individuals have freedom to make choices in their daily lives but those choices are bounded by the context in which an individual resides (e.g., social or cultural influences; Lopez & Willis, 2004). Therefore, humans make meaning of experience in relation to the world in which they live, and the job of the researcher is to mediate between the meaning of an experience and meaning arising from a context, as humans cannot totally separate themselves from this context (Lopez & Willis, 2004; Van Manen, 1990). In addition, the goal of the researcher is to identify commonalities of experiences shared among a group of individuals, also in relation to their lifeworlds (Lopez & Willis, 2004).

To engage in this interpretive process, the researcher must employ specific strategies and hold specific assumptions in mind. For instance, the researcher must act as the ‘expert’ guide while using systematic questions to garner experiences, and the researcher must remain self-critical both in regard to making interpretations free from biases and in regard to continually viewing structures and meaning in light of the overarching research question (Lopez & Willis, 2004; Van Manen, 1990). The researcher must develop an intersubjective dialogic relation with
obtained data, in order to use experiences to validate other experiences in light of the phenomenon (Van Manen, 1990). The researcher remains objective and oriented to the phenomenon, while offering subjective insights to unveil the phenomenon in full (Van Manen, 1990). As such, the researcher must write in an explicit manner to articulate the structures of meaning in lived experiences while fully capturing what it means to experience a situation, almost in a ‘poetic’ manner (Van Manen, 1990). Finally, the researcher continually acknowledges that life is more complex than could ever be captured or unveiled through writing, and that there likely is not one universal meaning to describe a phenomenon (Lopez & Willis, 2004; Van Manen, 1990).

In sum, as articulated by Van Manen (2014), “Hermeneutic phenomenology is a method of abstemious reflection on the basic structures of the lived experience of human existence” (p. 26). By ‘method,’ Van Manen refers to “the way or attitude of approaching a phenomenon” (2014, p. 26). By abstemious, Van Manen refers to reflection that is free “from theoretical, polemical, suppositional, and emotional intoxications” (2014, p. 26). By hermeneutic, Van Manen encourages the researcher to use “discursive language and sensitive interpretive devices that make phenomenological analysis, explication, and description possible and intelligible” (2014, p. 26). Finally, by lived experience, Van Manen implies the “prereflective or prepredicative life of human existence as living through it” (2014, p. 26). Thus, hermeneutic phenomenology is a methodology to describe and interpret the meaning that is present in lived human experiences, free from but acknowledging external influences.

Method: Phenomenological Interviews

The specific method adopted in the study was phenomenological interviews. As described by Van Manen (1990), the methodology adopted in a qualitative study directly
implicates the methods a researcher should use. In the case of a phenomenology, the purpose of inquiry is to uncover the meaning and lived experience of a phenomenon for a group of individuals. Thus, the researcher must adopt methods that will enable him or her to explore a phenomenon and grasp the meaning of the phenomenon. The most commonly employed method for phenomenological inquiry is the phenomenological interview, although other methods such as observations, document analyses, and participant journaling also provide support for phenomenological inquiry (Merriam, 2009; Van Manen, 1990; Van Manen, 2014). Within these methods, the researcher acts as the primary instrument of data collection and analysis, so he or she must engage in reflective questioning and writing in order to capture and put language to participants’ lived meaning (Van Manen, 1990).

**Sampling**

Before engaging in data collection (i.e., through interviews and other chosen methods), the researcher must identify participants for the study who can provide rich descriptions of lived experiences regarding the phenomenon of interest (Creswell, 2013; Van Manen, 2014). Creswell (2013) recommends that the sample in a phenomenological study include 5 to 25 individuals who have experienced the phenomenon. The researcher should use a combination of purposeful and criterion sampling to select those participants who meet a certain criterion and have experienced the phenomenon of interest (Creswell, 2013). Notably, diversity in participant characteristics will make identification of a shared experience more difficult and should be avoided in a phenomenology (Creswell, 2013). In addition, the primary objective of the researcher should be to recruit individuals who are able to speak for themselves and provide rich descriptions about their experiences, even if this comes at the expense of recruiting a larger number of participants (Creswell, 2013; Dukes, 1984).
Phenomenological interviews

A phenomenological interview serves as the primary method by which a researcher gathers narratives, anecdotes, stories, and examples of a lived experience from a group of individuals (Van Manen, 1990; Van Manen, 2014). These descriptions should delineate details of the experience as the individual lived it, rather than capturing the individual’s own interpretations of the experience (Van Manen, 1990). As such, the purpose of interviewing is to garner an understanding of the nature and meaning of the experience of interest, free from reflection (Van Manen, 1990). To accomplish this objective, the researcher should maintain awareness of key assumptions that guide the process, particularly when considering challenges the researcher might face during data collection: lived experiences are often taken for granted when initially experienced, so the researcher must work diligently to uncover pure descriptions; experiences are transformed when language is attributed to an experience or an individual attempts to recollect an experience; and the researcher’s own experiences might color the researcher’s orientation to the phenomenon (Van Manen, 1990).

A number of researchers have offered suggestions regarding the structure of a phenomenological interview. Regarding overall structure, Dukes (1984) recommends that interviews are open-ended and take place over a prolonged period of time, in order for the researcher and participant to establish a strong shared understanding of the phenomenon and so that the participant can have the time he or she needs to speak in-depth about the experience. Creswell (2013) advises that interviews should revolve around two broad questions: “What have you experienced in terms of the phenomenon?” and “What contexts or situations have typically influenced or affected your experiences of the phenomenon?” (p. 61). Other questions should narrow down from these broad questions, with the study’s purpose guiding question formulation.
Van Manen (2014) suggests that the researcher proceed through the interview in a reflective manner, in which he or she pauses to reflect on information obtained and additional questions needed to gather natural descriptions of experiences. Further, the researcher should continue gathering stories through the interview process until the researcher feels no additional meaning will be captured through further data collection, or saturation has been achieved.

Researchers have also provided recommendations regarding specific questions to use in an interview. For instance, Van Manen identifies the following questions as central: “What is this experience like?”, “How does the meaning of this experience arise?”, and “How do we live through an experience like this?” (2014; p. 31). Further, the researcher might ask about one’s first encounter with the experience, one’s most vivid encounter with the experience, the setting events surrounding the experience, the purpose of engaging in or the outcome arising from the experience, one’s thoughts during the experience, one’s feelings and emotions during the experience, one’s body sensations during the experience, and one’s actions during the experience (Van Manen, 1990; Van Manen, 2014). However, the researcher should avoid asking questions about the individual’s viewpoint, opinions, beliefs surrounding correlation or causation, moral attributions to the experience, or other related interpretations regarding the experience (Van Manen, 2014). In addition, the researcher should explicitly remind the participant to avoid causal explanations, generalizations, abstract interpretations, and use of idioms or other flowery language (Van Manen, 1990). Notably, Van Manen indicates that a participant can be offered the opportunity to engage in reflection and interpretation of texts, but this should occur during a separate meeting apart from the interviews (1991).
Data Collection Procedures for the Current Study

All data collection procedures followed from the research question, sub-questions, and adopted framework, including use of those strategies, suggestions, and considerations outlined in the previous section. In this section, descriptions are provided for: 1) application of the phenomenological framework to the study method; 2) my use of epoche and bracketing prior to and during the study; 3) the recruitment procedure including an outline of the inclusion criteria and a description of demographic information for my participants; 4) the interview procedure; and 5) the use of a pilot study to engage in an iterative development process for the final interview protocol.

Framework

In the present study, I examined the phenomenon of collaboration among caregivers, service providers, and young adults to meet the transition-related needs of the young adult with ASD in a coordinated manner. I attempted to garner an understanding of the essence of caregivers,’ service providers,’ and young adults’ shared experience with this phenomenon. Specifically, I attempted to understand the structures comprising participants’ experience with collaboration, based on the assumption that a shared essence exists between caregivers, service providers, and young adults.

To arrive at this understanding, I adopted the viewpoint that each participant constructs and interprets his or her understanding of the experience through his or her interactions with other members of the collaborative team (i.e., the caregivers, service providers, and young adult), driven by a shared need to meet the transition-related needs of the young adult with ASD. Each understanding is likely influenced by each participant’s history with collaboration, history with meeting the young adult’s needs, and current cultural and social influences (e.g., access to
supports, cultural conceptualization of disability, level of priority of having the need met), reflecting the participant’s lifeworld. However, I attempted to gather descriptions and meanings of the phenomenon free from these influences, and then considered meaning in light of these influences. In this way, I attempted to satisfy the aforementioned components of hermeneutic phenomenology, in order to unpack the essence of collaboration.

**Epoche and Bracketing**

As noted, a researcher’s first task when undertaking phenomenological inquiry is to engage in a process of epoche, or bracketing, of prior experiences, biases, assumptions, theoretical perspectives, and judgements that might impact data collection and analysis (Merriam, 2009). My own motivation to perform this study is a result of several years of experience with working with families of children and young adults with ASD. I have served families of and individuals with ASD in a variety of clinical, educational, community, recreational, and research settings. In these settings, I have provided diagnostic, therapeutic, and consultative services, and I have facilitated research involvement and recreational programs. I have worked with individuals with ASD across the lifespan throughout these years, witnessing issues that families and individuals with ASD experience at each stage of life. In addition, I have worked with multiple types of providers, gaining a firsthand understanding of their work and the types of services they can offer to families and individuals with ASD.

As a result of this work, several factors emerge as particularly influential on my motivation to perform the current study. First, I have always been particularly struck by the comparative lack of information and services available for young adults with ASD. After hearing families narrate their frustrations with the lack of services for young adults with ASD, uncertainties about the future, and their desire for the young adult to achieve his or her potential,
as well as witnessing these limitations firsthand, I developed a strong research interest regarding services for young adults with ASD. In particular, I am interested in services to promote outcomes related to postsecondary transitions from schools. Second, given my experience delivering different types of service and working with multiple providers, I have developed an interest in understanding how families make decisions regarding types of services to use, what strategies families use to seek out services, and how outcomes from services might be maximized. Third, through reading countless pages of textbooks and journal articles surrounding ‘best practices’ in service delivery, I have found myself trying to understand the nature of discrepancies between practice suggestions and types of services that are delivered in practice. Fourth, in attempting to garner these understandings, I believe there is a great need to understand families’ and service providers’ firsthand perceptions of these issues, as supported by details of their experiences and framed within their social, cultural, and historical contexts. Therefore, I have been drawn to qualitative research as a means by which to garner the in-depth understandings I desire, and as a means by which to tell families’ stories.

As a school psychology graduate student and emerging researcher and practitioner, my hope is to use findings from this study to inform my own line of work in the future. This overarching desire and my motivation for the present study are driven by my personal biases, assumptions, perspectives, and judgments including:

1. ASD is a complex and multi-faceted disorder that presents uniquely in every individual diagnosed, thus resulting in unique needs for each individual.

2. A disability should not be viewed as an issue or problem to be fixed, but rather as a unique profile of abilities to be supported and promoted through service delivery surrounding skill development.
3. Each family of an individual with ASD holds different perceptions regarding the necessity of different types and amounts of services, framed by their own perceptions of disability (whether knowingly or unknowingly).

4. Families and individuals with ASD have the right to make their own decisions regarding service use, goals for service use, and desired life outcomes for the individual with ASD, free from practitioner influence. That is, families and individuals with ASD are the experts on their own needs.

5. Families are doing the best they can and should be respected as such.

6. Practitioners should work with families to establish goals and design services that are most meaningful to the families and individuals, rather than telling families what will work for them.

7. Practitioners should work with other practitioners to promote coordinated service delivery and generalized skill use.

8. Practitioners should empower families and individuals with ASD to take control of their own service use and should include families and individuals with ASD as active members of the service delivery team.

9. Services should not stop when a child reaches young adult years.

10. Researchers should give families and individuals with ASD a voice when undertaking research to improve the quality of service delivery.

As the primary researcher driving the present study, it was my job to return to these belief statements to ensure I conducted my research through a lens free from my experiences and beliefs.
Recruitment Procedures

For the present study, I used purposeful and criterion sampling methods to recruit participants who have characteristics and experiences in line with the research question (Creswell, 2013). Following approval from the Institutional Review Board (IRB) at the University of Florida, I recruited a total of four teams for participation in the study. Specifically, I recruited one ‘team’ of participants as a pilot for the study and an additional three ‘teams’ as participants for the study. Each team included a minimum of one primary caregiver, one service provider, and one young adult with ASD.

To recruit teams, I shared study information with families and young adults with ASD through a local community organization serving individuals with ASD and related disorders throughout the lifespan. Specifically, I posted information about my study on the organization’s website and on a listserv for young adults with ASD. I also recruited at local events hosted by the organization. Once a family contacted me, I offered to answer any questions, arranged a time to meet with members of the family, obtained consent of the participant(s) present at the meeting, administered a demographic questionnaire, and conducted interviews. After completion of initial interviews, I then inquired about families’ willingness to ask their service providers about participation in the study. If they agreed, I asked the family to contact their service providers and obtain the providers’ consent to speak with me. Once providers contacted me, I then answered questions, arranged a time to meet with them, obtained their consent, administered a demographic questionnaire, and conducted interviews. By using this method, I was able to recruit providers serving the same young adult comprising the team while respecting the privacy of each member of the team.
Inclusion criteria

Specific inclusion criteria guided recruitment of participants. For the young adult, the participant must: 1) have a primary medical or educational diagnosis of ASD or a related disorder (i.e., those disorders previously classified as an Autism Spectrum Disorder: Asperger’s Disorder, Rett’s Disorder, Childhood Disintegrative Disorder, or Pervasive Developmental Disorder-Not Otherwise Specified), either as a sole diagnosis or comorbid with other diagnoses; 2) be between the ages of 14 to 25 years; 3) receive services from at least two different service providers (inside or outside school settings); and 4) receive services specifically targeting some skill or behavioral need conceptualized as directly linked to a transition-related need (e.g., a specific vocational skill, a communicative skill, an adaptive skill, a type of behavior that might be preventing access to a certain type of setting). By receiving services from at least two providers, this ensured all participants within the team could comment on collaboration between providers and this reflected a minimum level of need for services by young adults (i.e., their needs warranted at least two different types of services).

Regarding the primary caregiver, the caregiver must: 1) act as the primary caretaker, parent, or legal guardian for the young adult with ASD; and 2) actively collaborate with service providers surrounding at least one transition-related need at the time of the study. Regarding the service providers, the provider must: 1) actively collaborate with the primary caregiver of the young adult with ASD; and 2) have worked with the caregiver and young adult for at least three months at the time of the study. Providers might work in clinic, educational, community, or home settings. Providers were nominated by caregivers and therefore represented those providers who had the closet relationship with family members.
Participant characteristics

A total of four teams participated in the study: one pilot team and three participant teams that were included in the formal study. Characteristics for young adults, caregivers, and service providers across teams are provided in Table 3-1, 3-2, and 3-3, respectively. Further, information regarding self-reported collaboration is provided in Table 3-4. Information presented was primarily obtained through administration of demographic questionnaires (Appendix A), although verbal reports from interviews supplemented questionnaires in some cases. All but one caregiver participant completed demographic questionnaires, although that participant disclosed basic demographic information in her interview.

Table 3-1. Young adult characteristics.

<table>
<thead>
<tr>
<th>Team</th>
<th>Pseudonym</th>
<th>Age (years)</th>
<th>Gender</th>
<th>Race</th>
<th>Diagnosis</th>
<th>Diploma track</th>
<th>Living status</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pilot</td>
<td>Nathan</td>
<td>22</td>
<td>Male</td>
<td>Caucasian</td>
<td>ASD</td>
<td>Regular diploma</td>
<td>Home</td>
</tr>
<tr>
<td>One</td>
<td>Brandon</td>
<td>25</td>
<td>Male</td>
<td>Unknown</td>
<td>ASD</td>
<td>Regular diploma</td>
<td>Home</td>
</tr>
<tr>
<td>Two</td>
<td>Sam</td>
<td>21</td>
<td>Male</td>
<td>African American</td>
<td>ASD, cognitive delay</td>
<td>Alternate diploma</td>
<td>Home</td>
</tr>
<tr>
<td>Three</td>
<td>Jason</td>
<td>18</td>
<td>Male</td>
<td>Caucasian</td>
<td>PDD-NOS</td>
<td>Alternate diploma</td>
<td>Home</td>
</tr>
</tbody>
</table>

Table 3-2. Caregiver characteristics.

<table>
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<tr>
<th>Team</th>
<th>Pseudonym</th>
<th>Age range</th>
<th>Gender</th>
<th>Race</th>
<th>SES</th>
<th>Employment</th>
<th>Marital status</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pilot</td>
<td>Nancy</td>
<td>50-60</td>
<td>Female</td>
<td>Caucasian</td>
<td>Upper middle class</td>
<td>Homemaker</td>
<td>Married</td>
</tr>
<tr>
<td>One</td>
<td>Barbara</td>
<td>Unknown</td>
<td>Female</td>
<td>Unknown</td>
<td>Unknown</td>
<td>Nonprofit administrator</td>
<td>Divorced</td>
</tr>
<tr>
<td>Two</td>
<td>Sandra</td>
<td>50-60</td>
<td>Female</td>
<td>African American</td>
<td>Middle class</td>
<td>Self-employed Teacher</td>
<td>Divorced</td>
</tr>
<tr>
<td>Three</td>
<td>Julie</td>
<td>40-50</td>
<td>Female</td>
<td>Caucasian</td>
<td>Upper middle class</td>
<td>Instructor</td>
<td>Divorced</td>
</tr>
<tr>
<td>Three</td>
<td>James</td>
<td>40-50</td>
<td>Male</td>
<td>Caucasian</td>
<td>Upper middle class</td>
<td></td>
<td>Divorced</td>
</tr>
</tbody>
</table>
Table 3-3. Service provider characteristics.

<table>
<thead>
<tr>
<th>Team</th>
<th>Pseudonym</th>
<th>Age range</th>
<th>Gender</th>
<th>Race</th>
<th>Career</th>
<th>Years in the field</th>
<th>Years with the family</th>
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</thead>
<tbody>
<tr>
<td>Pilot</td>
<td>Nicole</td>
<td>30-40</td>
<td>Female</td>
<td>Caucasian</td>
<td>Occupational therapist</td>
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<td>10</td>
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<tr>
<td>Pilot</td>
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<td>50-60</td>
<td>Female</td>
<td>Caucasian</td>
<td>Psychiatrist</td>
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<td>14</td>
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<tr>
<td>One</td>
<td>Becky</td>
<td>20-30</td>
<td>Female</td>
<td>Bi-racial</td>
<td>Personal care assistant</td>
<td>5</td>
<td>1*</td>
</tr>
<tr>
<td>Two</td>
<td>Sally</td>
<td>20-30</td>
<td>Female</td>
<td>Caucasian</td>
<td>Special education teacher</td>
<td>3</td>
<td>1*</td>
</tr>
<tr>
<td>Three</td>
<td>Jeff</td>
<td>Unknown</td>
<td>Male</td>
<td>Caucasian</td>
<td>Associate director of service agency</td>
<td>30</td>
<td>2*</td>
</tr>
</tbody>
</table>

*In each of these cases, the provider noted knowing the family or young adult for at least 3 years prior to initiating a formal relationship with the family and young adult.

Table 3-4. Self-reported collaboration by participants.

<table>
<thead>
<tr>
<th>Team</th>
<th>Caregiver ratings</th>
<th>Provider ratings</th>
<th>Young adult ratings</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Caregiver with provider</td>
<td>Provider with providers</td>
<td>Young adult with providers</td>
</tr>
<tr>
<td>Pilot</td>
<td>Often</td>
<td>Often</td>
<td>Sometimes</td>
</tr>
<tr>
<td>One</td>
<td>Unknown</td>
<td>Unknown</td>
<td>Unknown</td>
</tr>
<tr>
<td>Two</td>
<td>Almost always</td>
<td>Almost always</td>
<td>Sometimes</td>
</tr>
<tr>
<td>Three</td>
<td>Sometimes</td>
<td>Sometimes</td>
<td>Rarely to never</td>
</tr>
</tbody>
</table>

Interview Procedures

In order to gather detailed descriptions necessary to answer the research question and sub-questions, I conducted individual semi-structured interviews with each caregiver-participant, service provider-participant, and young adult-participant. A semi-structured interview guide was adopted due to its practicality in guiding the data collection process (Appendix B). Specifically, the guide included some standardized questions while allowing participants’ flexibility to
explore their experiences in an individualized, unstructured manner (Merriam, 2009). Questions sought to elicit participants’ descriptions of their experiences with the phenomenon and the meaning they experienced with living through the phenomenon. Specific questions gathered information regarding the settings in which they experience the phenomenon, examples of their experiences, the purpose driving them to engage in the experience, the outcomes they perceive from the experience, and the thoughts, feelings, emotions, sensations, and actions that comprise their experience with the phenomenon.

For each participant, interviews were conducted at a time and location most convenient for the participant. Participants were given the option to interview in-person, by video-conferencing, or by phone. All participants elected to interview in-person. Following receipt of consent or assent, interviews were conducted by the primary researcher in participants’ homes, offices, or community settings (e.g., coffee shops). Interviews lasted 30 to 90 minutes for caregivers and providers, while interviews with young adults lasted approximately 10 to 15 minutes. For young adults, modifications to questions were made to ensure understandability of questions. For instance, questions were worded using concrete language and names of providers.

For one young adult who does not communicate via spoken language, the ‘interview’ took the form of an observation in which the young adult used pictures and gestures to demonstrate his interests and activities of his daily life to the researcher. Interviews were generally conducted individually with participants, although sometimes the young adult also sat in on the interview with his caregiver or provider. In addition, for one family, both the mother and father elected to complete the interview together. Each interview was audio-recorded as the researcher interviewed the participant.
Both while conducting interviews and immediately following completion of interviews, the researcher documented her reactions in a journal in order to aid further reflection on data obtained (Bazeley, 2013; see Appendix C for sample reflections integrated with initial reactions to interview transcripts). Next, the researcher transcribed interviews into a Microsoft Word document and entered information obtained through demographic questionnaires into a Microsoft Excel document. Transcriptions were coded for anonymity and checked by the researcher to ensure accuracy and adherence to the semi-structured interview guide. All materials were stored in secure locations and participants were reminded of their ability to contact the researcher should they have any concerns.

**Pilot Study and Iterative Development Process**

Within qualitative research, researchers should develop and test interview questions prior to finalizing the interview protocol for the study (Creswell, 2013). The purpose of this process is to ensure interview questions appropriately elicit information regarding the experiences of participants, as guided by the research questions and framework for the study. Therefore, I conducted a pilot test of the interview questions for the present study. To do so, I recruited and interviewed one team to serve as pilot participants in my study using the procedures described above. Following interviews, I solicited feedback from participants regarding the demographic questionnaires, nature of interview questions, and reactions to the interview process immediately following the process. Participants were also invited to contact me in the future, should they think of additional feedback in relation to the study.

Regarding demographic questionnaires, all participants verbally indicated their approval of questions and noted no recommendations for changes to the questionnaires. Of note, both service provider-participants did inquire about the Likert scale rating for level of current
collaboration versus lifetime collaboration. The researcher verbally explained the difference and participants indicated they understood following the verbal explanation. As a result, no changes were made to the demographic questionnaires.

Regarding reactions to interview questions and the interview process, participants universally endorsed the types of questions asked to them. The caregiver-participant stated she found interview questions to generally be understandable and helpful in guiding her to think about the transition process for her son. She only noted confusion regarding one question about “factors,” noting that the generality of wording confused her. Likewise, the young adult-participant noted he found questions understandable. For service provider-participants, both participants also stated they understood questions and did not have specific feedback. Further, both participants indicated strong agreement with the importance of types of interview questions asked, noting they believed questions asked were critically important to moving the field of service delivery for transition-age individuals with ASD forward.

In the researcher’s personal reflection on interviews through journaling, several reactions emerged as significant. First, the researcher noted that participant’s responses to questions tended to be technical in nature. For instance, the caregiver-participant often spoke of issues related to transition proper, rather than to pure process elements of planning. Likewise, service provider-participants often spoke of specific skill domains and strategies in lines with their own field of practice. Second, the researcher observed differences in the flow of conversation generated through interviews. For instance, the interviews with the caregiver-participant and one of the service provider-participants flowed very smoothly, with each participant freely speaking about topics in a detailed manner. In contrast, the other service-provider participant often paused to think before responding and then responded in a much more succinct manner. The researcher
noted that this seemed to be related to the participant’s desire to protect the identity of the family and herself as a professional. Third, the interview with the young adult-participant was very informative in highlighting considerations for future young adult-participants. The researcher had to work hard to maintain the young adult-participant’s attention during his interview, and she had to make a concerted effort to pose questions in a concrete manner. Finally, the researcher noted her own wordiness in posing questions and follow-up questions, serving as an area of improvement for the researcher herself in future interviews.

Overall, questions appeared to address each of the domains anticipated by the researcher. Participants spoke about facilitators and barriers to coordinated service delivery, their own and the roles of other participants in coordinating services, and perceived progress as a result of service delivery. Each participant spoke from the perspective of herself or himself, and considered the perspectives of the other participants. As a result, themes seemed to merge among the team, highlighting shared perceptions of factors contributing to collaboration. Following a process of peer debriefing with her advisor, the researcher determined that questions were appropriate to elicit the type of information desired for the study. No changes were made to the interview guide, although the researcher created a list of prompts for herself for conducting future interviews based on self-reflection (see Appendix D).

**Phenomenological Data Analysis**

Data analysis in qualitative research is generally conceptualized as an iterative process in which the researcher repeatedly interacts with collected data to fully abstract meaning (Creswell, 2013). Specifically, Creswell (2013) outlines general data analysis procedures for qualitative research. First, the researcher prepares and organizes data, such as in the form of transcripts from interviews. Next, the researcher codes and re-codes transcripts, eventually collapsing codes
into categories or themes. Following this, the researcher represents identified themes in writing through text, figures, and tables. Finally, the researcher contextualizes themes within the context of the framework for the study and previous literature conducted on the topic. Throughout this entire process, the researcher continually engages in a process of memoing including writing notes in the margins of field notes and transcripts, highlighting pertinent information, and reflecting on notes so as to inform codes and theme formation. The purpose of this section is to describe recommended procedures for engaging in data analysis guided by a phenomenological methodology.

Following from his description of general qualitative data analysis procedures, Creswell (2013) outlines procedures for phenomenological data analysis, grounded within general procedures. Again, the researcher begins by preparing and organizing data in the form of transcripts. Next, the researcher reads through the transcripts, and makes notes in the margins of transcripts regarding initial reflections. While engaging in this initial part of the process, the researcher should continue to engage in epoche, documenting his or her personal experiences with and preconceived notions of the phenomenon of interest. Following this, the researcher should engage in a process of reduction to reduce data segments into themes. Specific components of this process include identification of ‘significant statements’ regarding participants’ experience of the phenomenon, evaluation of significant statements through ‘horizontalization’, and engagement in ‘imaginative variation’ and reflection to arrive at overall themes. Overarching themes should describe the overall essence of the experience, including ‘what’ happened (termed a ‘textural description’) and ‘how’ the phenomenon was experienced (termed a ‘structural description’). Finally, the researcher should present the essence of the experience through text, figures, or other visual modalities.
Reduction

Reduction is the term used to describe the overarching process guiding data analysis in phenomenological research. Although reduction might be considered a ‘state of mind’ rather than a process, reduction can be operationalized as an iterative process in which the researcher engages in actions to analyze the data for the sake of research (Merriam, 2009; Moustakas, 1994; Van Manen, 2014). Specific actions contributing to reduction include identification of significant statements, horizontalization, imaginative variation, and preliminary written descriptions (Moustakas, 1994). In addition, the researcher continually reflects on and questions the structural components of the essence that is emerging, isolating all necessary components of the phenomenon (Merriam, 2009; Van Manen, 2014). Ultimately, the goal of reduction is to arrive at the essential, invariant structure of the phenomenon, which fully captures the essence of the phenomenon (Merriam, 2009).

Significant Statements

Significant statements include sentences, phrases, and quotes in the interview transcripts that provide a rich yet pre-reflective description of how participants experienced a phenomenon (Moustakas, 1994). Moustakas (1994) suggests that the researcher should highlight these statements while reading through the interview transcripts and while writing supplemental notes and reflections regarding meaning in the margins of the paper next to the statements. These statements were used to develop descriptions of the structural elements of the phenomenon as analysis progresses, including details about the context and setting of the experiences (Moustakas, 1994).
**Horizontalization**

Horizontalization describes the process by which a researcher creates a list of significant statements obtained from the interview transcripts (Moustakas, 1994). The researcher ‘lays out’ all the identified significant statements in a list, avoiding overlapping or repetitive statements to the extent possible (Merriam, 2009; Moustakas, 1994). Then, the researcher considers each statement as bearing equal weight, or contributing equal meaning, to the understanding of the experience (Merriam, 2009; Moustakas, 1994). Finally, the researcher organizes the statements into themes or clusters, also known as ‘meaning units’ (Merriam, 2009; Moustakas, 1994). This latter step of the process occurs as a result of techniques described below.

**Imaginative Variation**

Imaginative variation describes the process by which a researcher varies use of significant statements to support the emerging themes (Merriam, 2009; Van Manen, 1990). The researcher varies both the statements themselves as well as his or her personal perspectives regarding the statements (Merriam, 2009; Van Manen, 1990). A researcher engages in this process of viewing data from ‘different angles’ to ensure that he or she has captured the true, invariant structures comprising an experience (Dukes, 1984; Merriam, 2009). Specifically, the researcher should ensure that he or she has captured the essential elements of the phenomenon, including those structural components necessary for an understanding of the phenomenon to be captured in full (Van Manen, 1990). The researcher should also ensure incidental elements and extraneous details are excluded from the description of the phenomenon (Van Manen, 1990). The researcher should take the following steps to complete the process of imaginative variation: include supporting examples from multiple participants, change or delete elements used in the description of the phenomenon to see if the meaning holds, determine what about the meaning
changes when elements are varied, recruit another researcher to identify themes and supporting examples to evaluate alignment between researchers, and elicit feedback from participants to confirm all aspects of the experience are captured (Dukes, 1984; Van Manen, 1990).

Reflection

Reflection can be viewed as both the overarching and final step in the reduction process of data analysis. That is, the researcher should engage in reflection on the final identified essence, in addition to ongoing reflection as the essence emerges (Van Manen, 1990). The purpose of reflection is to grasp the essential meaning of the phenomenon, including all of its necessary structural components and themes comprising the essence (Van Manen, 1990). As described by Van Manen (2014), five dimensions guide the reflection that occurs as part of the reduction: 1) ‘eidos’ or ‘whatness,’ which describes the grasping of the essential meaning of the phenomenon; 2) ‘ways of being,’ which describes the ‘being of’ or meaning of the phenomenon; 3) ‘alterity,’ which describes those elements that are not of the phenomenon; 4) ‘self-giveness,’ which describes how the phenomenon gives itself to the person experiencing it, free from consciousness; and 5) ‘inception’ or ‘originary meaning,’ which describes both the opening of oneself to and actual experience of the phenomenon, as if it were experienced for the first time. This last step should naturally occur, rather than being pursued, and it should lead to original insights into the phenomenon.

Van Manen (1990) offers additional guidelines for reflection to ensure the researcher has arrived at the phenomenon. He encourages the researcher to ask ‘what is a theme’ and consider what the point of the experience is, to acknowledge that themes are broadly encompassed within a text rather than stated at a specific point, and to acknowledge that themes will be simplifications of the true experience, inevitably limiting descriptions of the phenomenon. He
encourages the researcher to consider how the themes came about, including the researcher’s openness to themes, desire to make sense of the data, and ability to make insights and sense of the data. Finally, he reminds the researcher to continue to relate emerging themes to the overarching phenomenon, viewing the themes as elements that describe the phenomenon as a whole. Van Manen also warns the researcher that the process of reflection is more difficult than the type of reflection humans engage in during daily life; the researcher must engage in reflection and explication of themes in a manner which is not typical in everyday life.

Written Descriptions

Once the researcher has completed the process of reduction and believes he or she has arrived at the essential elements and overall essence of the phenomenon, he or she should then engage in the process of producing a written description of the phenomenon. Van Manen (1990) points out that the multi-dimensional and multi-layered nature of the essence is most effectively communicated through a written description of the phenomenon. The description should include examples and details about the context and setting to illuminate the structural elements (the ‘how’) and textural elements (the ‘what’) of the phenomenon (Moustakas, 1994; Van Manen, 1990). Further, the description should describe meaning units and themes comprising the phenomenon (Moustakas, 1994; Van Manen, 1990). Together, these descriptions should result in a composite description of the phenomenon that depicts its essence for all participants (Moustakas, 1994).

Data Analysis Procedures for the Current Study

The section describes data analysis procedures that were employed in the present study. These procedures generally followed those outlined in the previous section, as guided by a phenomenological framework. In addition, regular peer debriefing with my advisor was
integrated throughout the analysis process. A visual flowchart is provided in Appendix E to demonstrate my process.

First, I read through hard copies of interview transcriptions, writing down my initial reactions, thoughts, and reflections regarding obtained information. In general, I considered these reactions, thoughts, and reflections in tandem with my written reactions I journaled following each of the interviews (see Appendix C for the combined sample). As I engaged in this process of journaling and reflecting, I also revisited my beliefs, biases, assumptions, perspectives, and judgements, in order to remain open to participants’ reported experiences.

Second, I engaged in two iterations of the reduction process, highlighting significant statements and providing preliminary labels (i.e., codes) to describe the statements (see Appendix F for a sample). Specifically, I conducted the first iteration of the reduction process for each participant, so as to remain open to unique ideas presented by each participant. Following the first iteration, I conducted a second iteration to ensure my personal agreement between statements and labels utilized in my first iteration. After the second iteration, I obtained feedback from my advisor in order to facilitate rigor of my reduction process.

Third, I engaged in multiple iterations of horizontalization and imaginative variation to consider all significant statements identified during the reduction process together and to begin to identify overarching themes. This third stage of data analysis was not linear in nature, instead consisting of multiple iterations of considering codes together, reflecting on codes together, obtaining peer review from my advisor, varying my use of codes and groupings into themes, applying examples of significant statements into emerging categories of themes, and revising of themes. This process continued for some time, as my thoughts surrounding meaning units emerging from the study evolved (see Appendix G for samples). This process continued until I
felt confident my data were saturated for meaning and emerging themes had been considered from all potential angles and perspectives.

The final stage of my data analysis process consisted of producing written descriptions of the essential elements of the phenomenon of collaboration that emerged from my study. To facilitate this process, I began by producing a written outline of my chapter focused on written descriptions (i.e., the results chapter). I outlined broad ideas comprising each element (i.e., domain of themes) while including significant statements (i.e., quotations and examples) to support each domain and sub-domain. I continued to engage in reflection and make edits as I saw fit, and I continued to obtain peer feedback from my advisor. I engaged in multiple iterations of writing, reflecting, and revising until I felt confident in the written description of the phenomenon I had produced.

**Rigor in Qualitative Research**

As part of conducting empirical research, qualitative researchers must convince consumers that a study is credible and that results of the study are accurate and trustworthy (Creswell, 2013; Creswell & Miller, 2000; Golafshani, 2003; Merriam, 2009). This establishment of rigor is particularly important in empirical qualitative studies, given that the researcher drives the research process (i.e., determines research questions, situates questions within a theoretical framework and methodology, collects and analyzes data, writes ‘the story’ in the final manuscript; Brantlinger, Jimenez, Klinger, Pugach, & Richardson, 2005). However, researchers have debated whether the concepts of reliability and validity, as they apply to quantitative research, are appropriate criteria by which to evaluate qualitative research (Creswell & Miller, 2000; Golafshani, 2003). To address this concern, researchers have adopted the terms ‘consistency’, ‘dependability’, ‘credibility’, and ‘transferability’ to implicate these same
Considerations for qualitative research (Brantlinger et al., 2005; Creswell, 2013; Creswell & Miller, 2000; Golafshani, 2003; Merriam, 2009). In addition, researchers have proposed specific strategies to establish the rigor of qualitative studies (Brantlinger et al., 2005; Creswell, 2013; Creswell & Miller, 2000; Golafshani, 2003; Merriam, 2009). Each of these terms and strategies is outlined below. A review of quality indicators for qualitative studies is also provided, along with a review of specific considerations for evaluating rigor in phenomenological studies.

**Reliability: Consistency/Dependability**

Within quantitative research, reliability refers to the replicability or repeatability of results or observations obtained within a study (Golafshani, 2003). Within qualitative research, researchers use terms such as ‘consistency’ or ‘dependability’ to refer to this same general concept (Lincoln & Guba, 1985; Merriam, 2009). However, researchers note that reliability, in the quantitative sense, is particularly non-applicable to qualitative research (Golafshani, 2003; Merriam, 2009). Given that qualitative research intends to elicit humans’ descriptions or interpretations of their non-static world and experiences, one would not expect to obtain the exact same results should a study be repeated (Merriam, 2009). This is particularly true for phenomenological studies (Van Manen, 2014). As a result, qualitative ‘reliability’ is conceptualized as the extent to which results arise from data collection strategies (Merriam, 2009). The primary strategy researchers employ to demonstrate this is through audit trails, although some researchers also suggest use of interrater reliability (Brantlinger et al., 2005; Creswell & Miller, 2000; Lincoln & Guba, 1985; Merriam, 2009).

**Audit trails**

In an audit trail, a researcher describes all research activities and decisions comprising the study in order to make the process transparent for the consumer (Creswell & Miller, 2000). To
do so, the researcher maintains a running journal or log of his or her activities, thoughts, questions, reflections, decisions, interpretations, and acknowledgement of biases throughout the data collection, analysis, and writing phases of the study (Creswell & Miller, 2000; Lincoln & Guba, 1985; Merriam, 2009). The journal includes a chronology of when all parts of the research process were completed, as well as field notes, memos, and preliminary themes (Bartlinger et al., 2005; Creswell & Miller, 2000; Lincoln & Guba, 1985). As a result, consumers can orient themselves as if they were part of the research process, determine whether the researcher spent sufficient time engaging in the process to produce dependable results, evaluate decisions regarding emerging themes, and assess whether researcher biases influenced data interpretation (Brantlinger et al., 2005; Creswell & Miller, 2000). Consumers might include individuals solicited by the researcher to conduct formal reviews or individuals reading the study in the future (Creswell & Miller, 2000).

**Interrater reliability**

To establish interrater reliability, a researcher works collaboratively with at least one other researcher to analyze data (Brantlinger et al., 2005; Creswell, 2013). The researchers each independently analyze the data source, such as assigning codes to interview transcripts (Brantlinger et al., 2005; Creswell, 2013). The researchers then compare their codes throughout all coding iterations, calculating their percent agreement of code use (Creswell, 2013). To facilitate the process, researchers might establish a code book in which code meanings are described (Creswell, 2013). The researchers also discuss emerging themes to ensure agreement regarding findings (Brantlinger et al., 2005; Creswell, 2013). Through use of this strategy, a researcher can demonstrate that personal biases did not impact theme development or study findings (Brantlinger et al., 2005).
**Internal Validity: Credibility**

Within quantitative research, internal validity refers to the accuracy of the type of measurement system used and the appropriateness of the measurement system for assessing the dependent variable of interest (Golafshani 2003). Within qualitative research, this concept is referred to as ‘credibility’ and generally refers to the extent to which the researcher measures what he or she intends to measure and the extent to which findings capture the participants’ true experiences (Merriam, 2009). A number of strategies to achieve these objectives exist within qualitative research and are discussed below. Creswell (2013) recommends that a researcher adopt at least two of the strategies when conducting a qualitative study.

**Triangulation**

One strategy to establish credibility within a study is triangulation, or the use of multiple data sources, methods, investigators, or theories to confirm obtained data and findings (Brantlinger et al., 2005; Creswell, 2013; Creswell & Miller, 2000; Merriam, 2009). Specifically, four types of triangulation can be employed: 1) data triangulation, which refers to use of multiple data sources (e.g., multiple participants); 2) methodological triangulation, which refers to use of multiple methods (e.g., interviews, observations, document analyses); 3) investigator triangulation, which refers to use of several researchers or peer debriefers (discussed below); and 4) theory triangulation, which refers to use of multiple theoretical perspectives to interpret the obtained data (Brantlinger et al., 2005; Creswell & Miller, 2000). As a result of this triangulation, the researcher can demonstrate that findings converge across all the sources, adding confidence that results of a study are credible and accurate (Brantlinger et al., 2005; Creswell & Miller, 2000).
**Disconfirming evidence/negative case analysis**

A second strategy to establish credibility is often referred to as disconfirming evidence or negative case analysis (Brantlinger et al., 2005; Creswell, 2013; Creswell & Miller, 2000). This strategy refers to the process by which a researcher establishes preliminary themes or categories based on data collected in the study, and then subsequently looks for data that contradicts the emerging themes or categories (Brantlinger et al., 2005; Creswell, 2013; Creswell & Miller, 2000). If the researcher identified non-exemplars, he or she continues to refine themes and categories until all data fit within the themes (Creswell, 2013). Creswell and Miller (2000) point out that this strategy can be complicated to implement and requires researcher skill, but that this strategy is well-suited to address the complexity of human experiences.

**Researcher reflexivity**

A third strategy to establish credibility is researcher reflexivity (Brantlinger et al., 2005; Creswell, 2013; Creswell & Miller, 2000; Merriam, 2009). In researcher reflexivity, a researcher reflects on and discloses his or her biases, dispositions, assumptions, beliefs, and values that might impact the research process (Brantlinger et al., 2005; Creswell, 2013; Creswell & Miller, 2000; Merriam, 2009). These beliefs might be influenced by the researcher’s social, cultural, and historical context (Creswell & Miller, 2000). After examining these beliefs, the researcher should then bracket, or suspend, the beliefs so they no longer impact the research (Creswell & Miller, 2000).

**Member checks**

A fourth strategy to establish credibility is member checks, a process through which the researcher solicits feedback regarding findings from study participants (Brantlinger et al., 2005; Creswell, 2013; Creswell & Miller, 2000; Merriam, 2009). Specifically, participants are invited
to comment on the accuracy and credibility of findings (Bartlinger et al., 2005; Creswell, 2013). Member checks usually occur at two levels: 1) first level, in which participants provide feedback on interview transcripts and observational field notes; and 2) second level, in which participants provide feedback on the identified themes and interpretations (Brantlinger et al., 2005; Creswell & Miller, 2000). Specifically, the researcher elicits the participants’ feedback on whether themes make sense, whether there were any misunderstandings, whether any information is missing, whether the language used makes sense, whether the evidence supports the themes, and whether the overall description is accurate (Creswell, 2013; Creswell & Miller, 2000; Merriam, 2009). The researcher should document this feedback and incorporate the participants’ comments into the final manuscript (Creswell & Miller, 2000). In addition to member checks, Creswell and Miller (2000) also suggest that the researcher might include participants as ‘co-researchers’ in the process, giving them greater roles and additional credit for their contributions to the study.

**Prolonged field engagement**

A fifth strategy to establish credibility is prolonged field engagement, referring to repeated data collection (Brantlinger et al., 2005; Creswell & Miller, 2000; Merriam, 2009). Specifically, the researcher continues to conduct interviews and observations until data saturation is achieved (Brantlinger et al., 2005; Merriam, 2009). That is, the researcher collects data until participants present no new information, the researcher feels there is no new meaning to be gathered, and the researcher feels that he or she has enough information to produce rich, thick descriptions (Brantlinger et al., 2005; Merriam, 2009). As described by Creswell and Miller (2000), this also serves as a method by which to build comfort and trust with participants.
**Peer debriefing/review**

A sixth strategy to establish credibility is often referred to as peer debriefing or peer review (Brantlinger et al., 2005; Creswell, 2013; Creswell & Miller, 2000; Merriam, 2009). In this strategy, a peer or colleague of the researcher who is familiar with the topic of the study provides ongoing support and feedback regarding the research process (Brantlinger et al., 2005; Creswell, 2013; Creswell & Miller, 2000; Merriam, 2009). Specifically, the individual asks questions about meaning and interpretations, challenges the researcher’s assumptions, pushes the researcher through important methodological steps of the process, and evaluates whether evidence supports findings (Brantlinger et al., 2005; Creswell & Miller, 2000). These sessions are documented and feedback is incorporated into the findings (Creswell, 2013). Merriam (2009) notes that a graduate student’s doctoral committee members function as the peer reviewers for a dissertation study.

**External audits**

An external audit is a final strategy to establish credibility of a study (Brantlinger et al., 2005; Creswell, 2013). An external auditor performs the same duties as a peer reviewer, except that the individual has no connection to the study (Brantlinger et al., 2005; Creswell, 2013).

**External Validity: Transferability**

Within quantitative research, external validity refers to the extent to which a study’s findings generalize from the study sample to the population of interest (Merriam, 2009). However, qualitative research does not aim to make broad explanations or generalizations to a large population (Merriam, 2009). Therefore, qualitative researchers use the term ‘transferability’ to refer to this quantitative concept (Merriam, 2009). Transferability is conceptualized as the extent to which findings of a study transfer to experiences of an individual
living in very similar context and with very similar characteristics (Merriam, 2009). As Merriam (2009) points out, the burden of establishing this transferability is the consumer’s task, rather than that of the researcher conducting the study. Instead, the researcher’s responsibility is to provide thick, rich descriptions of study participants so this transferability is possible.

The primary strategy used to establish transferability in a study is the researcher’s production of thick, rich descriptions (Brantlinger et al., 2005; Creswell, 2013; Creswell & Miller, 2000; Merriam, 2009). A researcher should write these rich, thick descriptions as the part of the final manuscript (Brantlinger et al., 2005; Creswell, 2013; Creswell & Miller, 2000; Merriam, 2009). The descriptions should include highly descriptive details of participants, their settings, and themes, and they should be supported by use of quotes and field notes (Brantlinger et al., 2005; Creswell, 2013; Creswell & Miller, 2000; Merriam, 2009). As a result of reading these thick, rich descriptions, the consumer should feel as if he or she is living through the experience, the consumer should be able to make decisions with ease regarding transferability of findings, and the consumer should feel confident in the researcher’s findings based on the evidence provided in the descriptions (Brantlinger et al., 2005; Creswell, 2013; Creswell & Miller, 2000).

Quality Indicators

Brantlinger and colleagues (2005) outline quality indicators that can also be used to evaluate the rigor of the methods used in a study. They note that each indicator should be viewed in light of the study’s research question and theoretical framework. Quality indicators for interview studies and qualitative data analysis are reviewed below due to their applicability to the current study.
Interviews

For interview studies, quality indicators include: 1) “appropriate participants are selected (purposefully identified, effectively recruited, adequate number, representative of population of interest)”; 2) “interview questions are reasonable (clearly worded, not leading, appropriate and sufficient for exploring domains of interest)”; 3) “adequate mechanisms are used to record and transcribe interviews”; 4) “participants are represented sensitively and fairly in the report”; and 5) “sound measures are used to ensure confidentiality” (Brantlinger et al., 2005; p. 202).

Data analysis

For the data analysis portion of the study, quality indicators include: 1) “results are sorted and coded in a systematic and meaningful way”; 2) “sufficient rationale is provided for what was (or was not) included in the report”; 3) “documentation of methods used to establish trustworthiness and credibility are clear”; 4) “reflection about the researcher’s personal position/perspectives are provided”; 5) “conclusions are substantiated by sufficient quotations from participants, field notes of observations, and evidence of documentation inspection”; and 6) “connections are made with related research” (Brantlinger et al., 2005; p. 202).

Rigor in Phenomenological Studies

In regard to phenomenological studies specifically, researchers have offered suggestions for criteria by which to evaluate a phenomenological study for rigor. For instance, Creswell (2013) notes that one should consider the researcher’s understanding of phenomenology as a methodology, whether the phenomenon studied was clearly articulated, whether data analysis procedures were appropriate, whether the overall essence of the phenomenon was conveyed with a clear description of the experience and the context, and whether the author’s reflexivity was clearly portrayed. Likewise, Van Manen (2014) indicates that one should consider whether the
researcher asked a valid phenomenological question, whether data collected are appropriately
descriptive and free from biases, whether the study is based on phenomenological literature,
whether data analysis procedures were appropriate and based on reduction, and whether the
researcher portrayed an understanding of the essence of the experience studied. Van Manen
(2014) also notes that a researcher conducting a phenomenology should consider two forms of
‘generalizations’ that might result from the study: 1) existential generalization, or the recurring
aspects of a phenomenon that might be universal; and 2) singular generalization, or that which is
either similar or unique about the studied experience with a universal essence.

Rigor in the Current Study

Both throughout and following data collection and analysis procedures, I made concerted
efforts to demonstrate the rigor of my findings by employing strategies to establish the
consistency, dependability, credibility, and transferability of findings. In line with
aforementioned strategies, I employed several of these strategies. To establish consistency and
dependability, I kept an audit trail as part of my ongoing memoing throughout the study,
documenting all activities comprising the study. Activities comprising my data collection and
analysis processes were described in previous sections, and samples of my activities are visually
depicted in Appendices C to G.

To establish credibility of findings I utilized several methods. First, I triangulated
findings among participants comprising each team to ensure consistency of data and themes
surrounding each team. Further, I considered emerging findings in line with current research on
collaboration and service delivery for adolescents or young adults with ASD. Second, I
considered disconfirming evidence through my iterative imaginative variation process, grouping
significant statements in various manners and informing groupings by exemplars that did not fit
into potential domains of themes. Third, I engaged in ongoing researcher reflexivity by revisiting my epoche and conducting memoing throughout the study, to ensure I remained open to emerging themes. Fourth, I conducted member checks by eliciting feedback from participants both following pilot interviews and following the formal phase of data collection. Participants noted no disagreements with themes and thus no revisions were necessary. Fifth, I solicited peer review throughout my data collection and analysis processes by regularly consulting with my advisor and making revisions as needed.

Finally, I sought to establish transferability of my findings and adhere to overarching quality indicators for qualitative research when collecting and analyzing my data. To establish transferability, I provided rich, thick descriptions of participant characteristics in my results chapter, as supported by questionnaire data. I also provided rich, thick descriptions of emerging themes, including supporting themes with quotes, examples, and anecdotes from interview data. Regarding overarching quality indicators for rigor, I purposefully selected participants, ensured appropriateness of interview questions by soliciting feedback from my participants and dissertation committee members, adopted consistent mechanisms to record and transcribe interviews, attempted to represent participants fairly in my written descriptions, and ensured confidentiality of my participants. Further, I attempted to conduct a systematic and well-described analysis of data, documenting my methods, reflections, support for findings, and rigor. Finally, I drew connections to existing research in my discussion chapter.
CHAPTER 4
RESULTS

The present study employed a qualitative phenomenological research methodology to answer the following research question: What are the lived experiences of caregivers of, service providers for, and young adults with ASD in collaborating to coordinate services to meet the transition-related needs of the young adult? The following sub-questions were posed to further guide this inquiry: 1) What factors influence collaboration? 2) How do participants perceive their roles in collaboration? 3) How do participants describe progress toward outcomes resulting from collaboration?

Three major domains of themes emerged from the data, each comprised by sub-themes. Two major domains emerged as central to describing the target phenomenon, including: 1) role elements shared among participants and 2) driving elements that make collaboration possible. In addition, a third major theme related to time elements pervaded across all themes, informing participants’ efforts and experiences with collaboration. The three major themes and their sub-themes are described in detail in this chapter. (See Figure 4-1).

Figure 4-1. Domains and sub-domains of themes.
Domain 1: Role Elements

Stakeholders’ descriptions of their own and other stakeholders’ roles in collaboration emerged as critical to participants’ understanding of the phenomenon of collaboration. That is, caregivers, service providers, and young adults each described their own and others’ roles in collaborative relationships in certain ways. As part of these roles, participants recognized and described characteristics that were mutually demonstrated by each participant within a given collaborative team. In turn, participants’ descriptions conveyed the sense that these shared characteristics enabled team members to adopt certain roles and work together to meet the needs of the young adult. The following role descriptors emerged and are described in detail below: 1) visionaries and goal-setters, 2) initiators, 3) leaders and decision-makers, 4) educators, and 5) connectors. Characteristics comprising each of these roles are described in the following sub-sections.

Visionaries and Goal-Setters

The first major role descriptor to emerge among participants was that of ‘visionaries’ and ‘goal-setters.’ Caregivers, service providers, and young adults each noted their own and others’ assumption of this role. Participants described how each member of the team held goals for the young adult, and they each envisioned how services would drive achievement of the goals forward. Despite individuals having unique visions, team members ultimately leveraged a shared understanding of needs and goals to develop visions (see driving elements section for further discussion). In this way, the role of each member of the team as a visionary within collaborative teams emerged as one key role element.
Caregivers as visionaries and goal-setters

For caregivers, their visions and goals for the young adults often were informed by their knowledge about their young adult children, their own values and goals, and the goals communicated or expressed to them by their children. Visions and goals for their children spanned across educational, daily living, and vocational domains. For instance, caregivers noted goals such as “we got the academic ones, and I don’t want to ever stop doing that” (Barbara), “our goals for him are to go as far educational-wise as he can” (Julie), “I want him living away from home with a roommate and participating in his community” (Sandra), “develop his skills and give him that independence and take him right to voc rehab and get him a job” (Sandra), “I think it’s an achievable goal for him to be able to provide for himself financially” (James), and “if you sat and talked with him, he wants to run his own business” (Barbara). Caregivers also described their visions for how different types of services might make achievement of these goals possible. As stated by James:

And I think that if this [community college] thing works out the way I’m hoping it will, he’ll be exposed to other jobs that he doesn’t even know he wants to do. I think he would be an excellent electronics technician. You know, because he just…once you show him a path he repeats it perfectly and then he detects the tiniest of, you know, out of whack things and knows exactly where they came from. It’s kind of amazing.

In this example, James leveraged his own knowledge of Jason’s capabilities and the knowledge of available services shared with him by providers in Jason’s life to develop a vision of how Jason could achieve vocational goals desired by both Jason and his parents. Thus, caregivers acted as important visionaries and goal-setters for their children, bringing these visions to the collaborative teams.
Providers as visionaries and goal-setters

Likewise, providers communicated visions and goals for the young adults, founded in their professional knowledge, their personal knowledge about the young adults, and knowledge provided to them by the young adults’ caregivers. These visions and goals, too, spanned across educational, daily living, and vocational demands. Jeff provided a description of his vision for Jason based on his professional opinion regarding Jason’s strengths and areas of need, “For him, he’s got the physical capabilities I think. I don’t know if he has the resilience yet to be a worker and that’s something…just physical resilience that he probably needs to develop.” This vision, in turn, informed the nature of services and guidance he provided to the family. Similarly, Becky articulated her goals for Brandon, formulated based on her professional opinion of important goals for him, “my goal with him is for him to exercise everyday” and “I’m working on his speech so like instead of him answering ‘what,’ [he will say] ‘please repeat that.’ And using his words to speak instead of just gesture.” She also indicated how she adopted the goals of Brandon and Barbara as her own, and developed her own strategies to promote progress toward the vision for the young adult:

I think there’s still a lot for him to learn management-wise and his money-wise. Like if he had his own website he would still need to have somebody with him like when he’s doing sales or when he has a sale and he has to go through the process of shipping it out and collecting the money and where does it go.

In this example, she discussed the goal for Brandon and Barbara to establish a greeting card business. Informed by this goal, she developed her own vision of how a specific skill (i.e., money management) would make achievement of the goal possible.
**Young adults as visionaries and goal-setters**

In addition, the young adults in each of the teams also expressed their visions and goals when interviewed and observed. For instance, Jason noted his goal to pursue education and training in technology. As a result, his vision was to obtain a sequence of education to achieve his goal, “Go to [elementary school], [middle school], [high school]. Oh yeah [community college].” As articulated by both Jason and his parents, Jason indicated this educational sequence would enable him to achieve his career. Brandon described a similar vision for his educational sequence that would, in turn, enable him to achieve his goal of working in graphic art. Finally, Sam showed the researcher items and pictures in response to questions about his interests and goals. For example, when asked about his interests and goals, he pointed the researcher to his folded clothes, clean closet, and breakfast he helped prepare. As indicated by Sandra, Sam’s favorite activities include cleaning and organizing, and he desires to pursue an independent life and career in cleaning or organizing. Therefore, Sam’s actions were interpreted as demonstrating his own goals and visions. In sum, the role of each participant as a visionary and goal-setter emerged as a key element of collaboration surrounding postsecondary transitions.

**Initiators**

The second major role descriptor to emerge among participants was that of ‘initiators.’ This particular role descriptor was most often attributed to caregivers and providers, with caregivers and providers demonstrating initiative on behalf of the young adult and in their everyday lives. For example, participants described how they and other members of the team initiated actions to meet the young adults’ needs across their daily lives and in the context of postsecondary transitions. Through initiating actions, participants actively sought to build relationships and form teams, advocate for the young adults, and take concrete steps to push
collaboration and progress forward. Further, participants described characteristics held by themselves and others that made their roles as initiators possible. Participants described themselves and others as motivated, committed, driven, strong-willed, persistent, and self-directed, making their efforts over time both possible and fruitful.

**Caregivers as initiators**

Regarding the role of caregivers as initiators, key elements emerged. Both caregivers and providers described the importance of caregivers taking active steps to build relationships with providers, advocate for their children, and remain persistent in their efforts. Sandra described how she pushed others to ensure development of collaborative relationships, in order to facilitate Sam’s progress in school, “I’ve been a busy body I’m telling you! I knocked down doors and I got in to meet people and I formed relationships and I opened my home.” Her self-initiated actions, in turn, set the tone for future collaboration and progress throughout Sam’s life.

Likewise, Julie and James noted the importance of reaching out to various providers and remaining persistent in their efforts to build relationships, in order to ensure Jason’s success into adulthood. Julie, James, and Jeff each credited Julie and James for their efforts and willingness to be actively involved in Jason’s life, including building relationships on his behalf. As stated by Julie:

> Well we’re [mom and dad] both very involved. We’re very involved in Jason’s life and we want to see him succeed and we want to be there for him. So we attend everything we need to attend and they see us at these functions and at these meetings and they see how much we’ve done with him and for him and I think that makes a huge difference.

In addition, Barbara described her ongoing questioning of Brandon’s current functioning, pointing collaborative teams to the progress he could be making. By pointing to the need for
high expectations for Brandon, her role as an initiator pushed Brandon’s progress forward.

Providers as initiators

Similar ideas emerged when describing the role of providers as initiators, and members of the teams each described the importance of this initiative of providers in making forward progress and collaboration possible. For instance, Sally noted the importance of other providers in school settings acting as initiators on behalf of students, in order to ensure young adults’ success across systems of service delivery, such as in schools:

The biggest advice I can give [to other providers] is continue advocating and fighting for your students… If you know that your student qualifies for a service when they graduate or this is what they need to have a successful life when they leave their school system, just advocate for them.

In this example, Sally encouraged other providers to push accepted norms so students can reach their maximum potential in adulthood. Regarding formation and maintenance of collaborative relationships, Becky noted how her own independent actions and initiative facilitated her relationship with Barbara, “Usually I’m on top of it where I can just know what’s supposed to happen.” Both she and Barbara went on to explain how Barbara respects and appreciates this initiative. In turn, service delivery was more efficient for Brandon, facilitating quicker progress toward adult goals possible for him. Finally, Jeff provided insight regarding how even one provider can act as the key person to make collaboration possible. If just one member of the collaborative team holds the independent drive to bring providers and caregivers together, collaboration and progress can be possible for the young adult. Therefore, participants’ roles as initiators emerged as another key role element.
Leaders and Decision-Makers

The third major role element to emerge among participants included that of ‘leaders’ and ‘decision-makers.’ Importantly, all participants described caregivers and young adults as the ultimate leaders within collaborative teams, making important decisions about the young adults’ futures. Providers noted they contributed to decisions but emphasized following the desires and decisions of the caregivers and young adults. For instance, caregivers managed and facilitated care and made decisions about services to access based on their visions and goals. Further, members of the collaborative teams took concerted steps to ensure young adults were actively involved as leaders and decision-makers throughout the process, with their decisions at the center of team decision-making. Thus, collaborative teams made forward movement based on leadership and decisions of team members.

Caregivers as leaders and decision-makers

Caregivers actively described their own roles as leaders and decision-makers, and these roles were also attributed to them by service providers. Each caregiver reported providing leadership in the context of postsecondary transitions, as well as their lifelong assumption of the role of overseers of their children’s lives. For example, Barbara directly described herself as the “CEO” of her son’s life: “And so I made myself the CEO of Brandon’s education. So I am the CEO of Brandon’s life. And I manage just about everything that goes on in his life.” Becky echoed the role of Barbara as the overarching decision-maker in Brandon’s life and leader of the team. Further, caregivers provided examples of the specific decisions they made as leaders throughout their children’s lives, including how these decisions played a central role in collaborative relationships. For example, in two of the teams, both the caregivers and providers of the young adults discussed how the caregivers made decisions regarding when to pull their
children out of school, where they wanted their children to live, and what types of jobs might be ideally suited to their children. Providers noted respecting these decisions and building their efforts around articulated desires.

**Young adults as leaders and decision-makers**

Participants also described how the young adults’ roles as leaders and decision-makers existed as the driving force behind the decisions and leadership roles caregivers adopted, making them leaders in their own right. For instance, Jeff noted how Jason has the decision of who to include on collaborative teams working with him, in order to inform decisions about his life, “So the futures planning is all person-centered. It’s him. So he invites people he wants to come to that meeting.” Julie also discussed how she and James make their decisions based on Jason’s desires. In one specific example, they talked about how their decision to pull Jason from school and to enroll him in community college was, in fact, Jason’s decision:

Then with him graduating this year we had the option of keeping him in the program until he was 21 years old. But, which, initially I thought that was the way that he wanted to go but he has been saying he wants to go to [community college]. So we just looked in to that and seems like he will be able to take some adult ed classes for special ed. So hopefully in the fall he’ll be enrolled in some of those classes.

Sandra extended this sentiment by discussing how she follows Sam’s desires, even if she does not fully agree with him. She described how Sam wants to live with an outside caretaker and remain unemployed. Although she did not agree with his decision, she framed his desire in light of similar decisions made by his same-age peers.

In addition to larger life decisions, each provider and young adult discussed the day-to-day decisions the young adult makes. For example, both Brandon and Becky noted Brandon
chooses activities he does each day, given he is no longer in school. As stated by Becky, “Decisions that he makes is where he’s doing his exercise and what library he wants to go to. So the location of what he’s doing is his decision.” Likewise, Jason made decisions within his vocational support program based on his interests, “Yeah I decide what I work towards.” Therefore, assumption of roles as leaders and decision-makers emerged as important in facilitating efforts of collaborative teams.

**Educators**

The fourth major role descriptor to emerge among participants was that of ‘educators.’ Caregivers and providers described educating themselves and others within the teams, as well as others outside the teams. Specifically, they educated themselves on global issues related to ASD and postsecondary transitions, and they educated others on aspects unique to each young adult. To act as educators, participants leveraged their general knowledge and awareness of issues pertinent to the young adult, and they acknowledged gaps that existed in their own knowledge, seeking to fill gaps and obtain further education. In addition, they educated others as a way of empowering others to better meet the needs of the young adults, and they directly empowered the young adults to take control of their own futures via educating them. This demonstrated the importance of participants’ assumption of educator roles in collaborative teams.

**Caregivers as educators**

Caregivers often described steps they had taken to educate themselves and others, in order to facilitate their young adult children’s transitions into adulthood. Barbara and Sandra each noted informal and formal steps they took to educate themselves. For instance, Barbara described herself as a researcher regarding types of services that might meet Brandon’s needs, “I’m a big researcher with doing stuff. I don’t just like say hey Brandon is going to do this. I
have to know about something before I get involved.” She further reflected on her belief that it is her job to seek out information, learning to act as a self-educator rather than relying on information to be handed to her. Sandra described seeking formal higher education to help her appropriately address mental health needs of Sam, above and beyond his ‘ASD-specific’ needs:

So I’m in grad school right now getting a master’s in mental health. I’ve got to find out more about that. I figure I know as much as anyone about the autism but I need to know more about the mental health issues.

She believed that she needed formal education to ensure that she, as a mother, could be as informed as possible about all of Sam’s needs.

Caregivers also talked about how they educate other members of collaborative teams, ensuring providers have sufficient knowledge of their sons, their unique needs, and their capabilities. For instance, Sandra described her actions to ensure Sam was appropriately challenged in school, based on her own knowledge of Sam’s capabilities, “But you can teach him anything. Just about anything. And that’s what I’ve been trying to tell them at school. You can teach him a trade. He can work. Because he can focus, he can function, he can work.”

Likewise, Barbara discussed educating Brandon’s personal care assistants on tasks and needs typical to Brandon’s daily life. In these ways, the caregivers promoted collaboration by educating providers and ensuring time spent collaborating was meaningful to the young adults’ progress.

Providers as educators

Both caregivers and service providers noted the role providers assume as educators within collaborative relationships, largely based on their professional knowledge and their knowledge of the young adults. For instance, providers across all teams gave examples of the
types of education they provide for families and other professionals, including educating caregivers about available resources and appropriate resources given their children’s specific needs, training school personnel on topics related to ASD and postsecondary transitions, communicating updates or changes in needs for the young adult to other providers, and teaching other professionals in the community about responding to the needs of individuals with ASD more broadly. Becky described how she taught another professional about Brandon’s needs, in order to ensure his timely progress in a vocational skills program, “It was just telling them that they need to talk slower and give him more time to process. Just explaining how they should communicate with him.” For her, even this simple example of education proved fruitful for Brandon. Julie also summarized the educational role of the provider she works with as part of her Jason’s team, “Jeff has been working with us for a few years. Basically you know, answering questions, giving us advice, things like that.” In this example, Julie communicated valuing the educational role of Jeff and looking to him as a source of trusted knowledge.

**Young adults as future educators**

Finally, both caregivers and providers indicated how they viewed their roles as educators of the young adult as a means to empower the young adult to take control of their own futures, acting as their own educators in the future. For instance, Sandra described how she has acted as Sam’s voice his entire life but has shifted her focus to teaching Sam to act as his own advocate. As an educator, she is teaching him how and when to use his voice to communicate about his needs, “They’re exposed to other people and I can tell other people exactly how to communicate and what certain things mean. You know, then I tell them develop it yourself now. And you have to work with them so that they understand you.” She went on to describe how she provides structured teaching so Sam has ample opportunities to communicate about his daily needs into
adulthood. She provided the simple example of prompting him to express types of foods he needs to buy in the grocery store. James echoed a similar sentiment, advising Jason to be a self-advocate in order to take control of his own future, “You can do it and never doubt yourself. Demand an opportunity…nicely. Don’t take no for an answer. Keep smiling and don’t take no for an answer.” In addition, Jeff indicated how he directs young adults to job search websites and takes concerted steps to teach advocacy skills to young adults, using his role as an educator to empower young adults to make vocational decisions. Thus, caregivers and providers’ roles as educators manifested themselves in various ways, each providing the foundation for collaboration and progress for the young adult.

Connectors

The fifth major role element to emerge among participants was that of ‘connectors’ between one another as well as with other families and professionals. In turn, they formed formal and informal support networks, enabling them to seek supports for themselves and act as supports for others. Caregivers and providers described how they purposefully sought connections, reaping resources and support as a result. Formal supports often included connections with co-workers and other professionals, and informal supports included connections between families. The role of participants as connectors existed as the foundation for collaboration and progress toward adulthood for the young adults as a result.

Caregivers as connectors

Caregivers discussed the nature of formal networks they built with providers and the informal networks they built with other families, offering their support to families with similar experiences to their own. For Barbara and Sandra, their professional careers enabled them to connect with other professionals and readily rely on professionals as sources of support when
needs arose. For instance, Barbara described how working for a disability-related organization enabled her to be in constant consultation with professionals and learning about new strategies on an ongoing basis to the benefit of Brandon, “And I mean he has like probably the most benefits from [organization] than anybody because I’m right there and I know everything that is going on and so I can implement all this stuff with him.” Likewise, Sandra talked about her close relationship with the leader of vocational rehabilitation services, a connection that she built that enables her to obtain quick answers about available services for her son:

I happen to have a direct line to the head of voc rehab. So I can go up and say okay explain it to me one more time [name] and how is this supposed to go. Make sure I got this before I’m supposed to walk in the door with him.

For both of these mothers, the formal supports acted as crucial networks in their sons’ lives as they transitioned to adulthood, and they expressed the belief that they will be able to utilize information and supports obtained through networks to drive collaboration forward.

Regarding informal supports, caregivers described seeking out other families for support and offering support to other families, in turn. For instance, caregivers noted the importance of knowledge and emotional support they were able to obtain from families who had previously worked with collaborative teams in the context of transitions, learning from and leaning on those families. In addition, caregivers expressed an element of ‘paying forward’ support to other caregivers, based on lessons they learned. For Sandra, her ability to connect with other families and offer support based on lessons learned in Sam’s life was an important role she adopted. Specifically, she noted helping families create visual supports in their homes during her free time, “I’ve gone into homes and I’ve done the same things for other people.”
Providers as connectors

Likewise, providers described the importance of their role as connectors in collaborative relationships, enabling them to establish formal and informal supports on behalf of families and for themselves. For example, Jeff noted the role of formal supports in his job as a provider, enabling him to connect with providers and connect providers to families. Specifically, he characterized his role as an orbiter between stakeholders in planning processes, “Sometimes we orbiter and we get between…I’ve been between family members or between family members and school personnel.” He went on to note the importance of this role and how the role enables effective collaboration and building of networks on behalf of families. Regarding informal supports, Jeff emphasized his belief that connecting families to informal supports is just as important as connecting them to formal supports. He offered the following advice to families, indicating the key role of family members and providers as connectors:

Some families are open and willing to reach out to either family members or friends, church members, or neighbors…and then there are agency people that are in their lives, professionals. So in the planning process what helps is when families, I think, access and start building a team around their person in transition.

Overall, providers and caregivers described their own and others’ roles as connectors, ensuring the multi-faceted needs of the young adults and their family members are met as collaboration occurs and the young adults transition into adulthood.

Domain 2: Driving Elements

The second major domain to emerge as critical to a description of the phenomenon included stakeholders’ descriptions of the elements driving collaboration. That is, caregivers, service providers, and young adults each described elements that enabled collaboration to be
effective and productive. Unlike role elements that were maintained individually by participants, driving elements included those actions taken and recognized collectively on the part of each member within a collaborative team. Specific driving elements included the following: 1) team members’ shared understanding of each member of the team; 2) team members’ shared goals, visions, and hope for the young adult; 3) team members’ adoption of strategies to drive relationships forward; 4) team members’ ongoing flexibility and engagement in problem-solving; and 5) team members’ shared experience of collaboration. Of note, participants also described barriers within the context of each element, and the steps they had taken to overcome barriers. As a result, discussion of barriers is embedded in each of the following sub-sections. Each driving element is described in detail below.

**Team Members’ Shared Understanding of Each Team Member**

The first major element to emerge among participants included team members’ descriptions of their shared understanding of the strengths, capabilities, needs, values, and desires of each of the other members of the team. Specifically, participants described how the understanding of these aspects transcended across young adults, caregivers, and providers. In turn, this shared understanding enabled ongoing collaboration, mutual understanding and respectful relationships, and shared problem-solving. Further, participants acknowledged that a lack of shared understanding acted as a barrier to productive collaborative relationships. In turn, they sought to address existing barriers as a team and overcome barriers. Therefore, team members’ shared understanding of one another served as an important driving element in relationships.

**Shared understanding of young adults**

Regarding young adults, teams each described a shared understanding of young adults’ personality characteristics, perceived capabilities, communication styles, and areas of need. For
participants, the young adult within each of the teams had certain personality characteristics that were regarded as strengths for the young adults and acted as the glue bringing team members together. For instance, young adults were described as “delightful,” “sociable,” “nice,” “kind,” “happy,” “easy-going,” “friendly” or “a friend,” “motivated,” “talented,” “capable,” “a quick learner,” “conscientious,” “affectionate,” “aware,” “insightful,” “persistent,” “polite,” and “welcoming.” Team members described “loving” their interactions with one another on account of young adults’ personality characteristics. Barbara articulated how Brandon’s strengths brought collaborative teams together throughout his life:

Brandon just has the aura about him even though he doesn’t communicate with people.

He has this way about him that people just fall in love with him. He just... he’s nice, he’s kind, you know. He’s not aggressive or demanding or anything. He goes with the flow.

Likewise, other members of teams described young adults’ demeanors, personalities, and attitudes globally as strengths of the young adults that rallied caregivers and providers to work together on their behalf. Following from a discussion of strengths, participants also noted shared understanding of young adults’ capabilities, including centering their efforts in working toward future goals on the shared knowledge of capabilities. For example, Sally stated, “So the school is trying to set him up with vocational rehab services because he is capable of working when he graduates.” Both she and Sandra voiced a shared understanding of the need to push Sam to fulfill his capabilities, founded on the strengths exhibited by Sam.

As part of this shared understanding of young adults, participants discussed a shared understanding of how young adults communicate their needs, feelings, wants, and desires. Caregivers and providers emphasized how they facilitate the young adults’ ‘voices,’ despite the young adults engaging in minimal verbal communication. They noted actions to facilitate this
element of voice are based on their long-standing knowledge of what the young adult likes and desires, nonverbal cues the young adult might give to indicate desires, and willingness to give the young adult time to express himself. For instance, Barbara described “you have to play the role of the parent and the person” in order to act as a voice for her son. This sentiment was echoed by Sandra and Sally, who noted that teachers and parents must act as advocates for students who do not engage in verbal language. Likewise, Becky articulated the importance of giving Brandon time to communicate his thoughts, “With him it’s patience and communication and understanding what he wants…sometimes it takes some time for him to tell you.” She went on to describe how she has improved at reading his body language over the time she has worked with him, and she noted making a conscientious effort to ask Brandon for his opinion and give him adequate time to respond.

Similarly, Sandra indicated how she watches Sam to understand his goals, desires, and needs. For example, when describing Sam’s role in formulating future goals, she stated:

You have to watch him to see what it is he likes to do. He can’t just tell you. But he can’t tell you, no not really. But you can watch him and see what he enjoys. You see him cleaning the kitchen. You see him doing the dishes and putting them away. You see him, you know, cleaning his room that’s what you see. He doesn’t like messiness or dirt or…he’s very clean.

After providing this information, she was further observed to facilitate Sam’s voice by guiding Sam in showing the researcher his favorite items, in order to represent his future interests and the process by which she obtains his opinion. Based on observations of Sam’s behavior, she and Sam’s providers worked together to help Sam achieve his goal of working as a cleaner as an adult. In addition, Jason, in tandem with his parents, described how he relies on his parents to
express his goals and desires in meetings with his providers. He validated information by stating yes or nodding his head, trusting in his parents’ and providers’ shared understanding of his goals and the way in which he can most effectively communicate.

Finally, participants described a shared understanding of areas of need for the young adults; these needs informed efforts adopted by each member of the teams. In addition to communication needs noted previously, young adults presented with unique needs related to certain learning areas, sensory needs, psychosocial needs, and independent living skills. For instance, Julie, James, and Jeff mutually discussed needs for Jason surrounding social skills and insight. Jeff stated, “He’s very exploitable and someone could take advantage of Jason because of how nice he is.” For this team, this shared understanding informed the team’s actions to connect Jason with social skills services and target conversational skills as a necessary part of the transition to adulthood. Likewise, Sandra and Sally noted Sam’s heavy-handedness and prompt dependency, and how these needs impact his ability to work and live independently. As stated by Sally, “He can’t do certain things because he needs so many prompts.” Sandra also noted, “I think we’re all on the same page with that. We all don’t know where this prompt dependency thing comes from.” In turn, acknowledgement of these needs across all teams resulted in concerted efforts on the part of participants to address needs as a collaborative team. Participants discussed engagement in shared problem-solving, described in further detail in a later section, and creativity on the part of team members to meet the young adults’ needs. As a result, the young adults’ progress toward adulthood could be promoted through collaboration.

**Shared understanding of caregivers and families**

Regarding caregivers and family members, participants within teams described a shared understanding of families’ values, familial structures, and caregivers’ strengths and needs. This
shared understanding facilitated relationships and allowed providers to work with caregivers in a meaningful, respectful, and productive manner. For Sandra, she endorsed providers who ask her questions and adopt her perspective, in order to center efforts on her values, “That providers should try to see through our eyes. And try to understand how we feel.” Sally adopted a similar stance on perspective-taking, noting the personal emphasis she places on understanding the structure of the home environment during the transition process:

Umm knowing that, okay when this student graduates they are going to live at home, and that’s going to be their supported environment, so what can we do in their final months at (school) to prepare them for that? Because it’s great here, my classroom is very structured and it’s very routined, but when they go home it’s very difficult for families to structure every minute of their day, 7 days a week. So how can we prepare our kids for, not every day is going to be structured when you get home.

For Sally, she acknowledged the limitations of planning in school and the importance of collaboration on promoting an understanding of the home environment young adults will enter. Participants also extended on these sentiments by describing their shared understanding of caregivers’ strengths and needs. For instance, Jeff highlighted the strengths of the caregivers within the team, describing their “capacities” and independence in facilitating efforts on behalf of Jason. In general, Jeff noted how he customizes his personal efforts based on the individual strengths and needs of families:

This whole thing about teaching a man to fish umm versus giving them a fish... You know, have you ever heard that? You know, for the longest time, and it really is inadequate...we always said we would teach a man to fish so that they would have skills to enable them. But there was a problem with that...a lot of people don’t have a fishing
pole. And if they don’t have a fishing pole they’re not going to be able to fish. So it
doesn’t matter how much you train them.

For Jeff, he considers the resource families bring with them in collaborative relationships. He
then builds and expands upon these resources to empower the family in advocating for their
needs and developing future collaborative relationships to meet their needs. In each of these
ways, shared understanding of caregivers facilitate collaboration and progress on behalf of the
young adults as they transition to adulthood.

**Shared understanding of providers**

Participants also described a shared understanding of providers’ strengths, life
circumstances, and distinct roles. In a reciprocal manner to shared understanding of caregivers,
shared understanding of providers allowed caregivers to work with providers in a meaningful,
respectful, and productive manner. For instance, caregivers and young adults described strengths
of providers that enabled productive collaboration on behalf of the young adults. Within teams,
providers were described as “helpful,” “cool,” “funny,” “creative,” “nice,” “friendly,” “open,”
“receptive,” “informative,” “positive,” “well-organized,” and “goofy.” All participants described
the passion that providers have for their jobs, enabling them to work well in collaborative
relationships. Becky and Sally each noted the personal passion they respectively bring to their
jobs, “It’s a really rewarding experience working with individuals with special needs. And you
really have to feel lucky to do it” and “I just fell in love with the students.” This passion was
mutually recognized and valued by all participants.

In addition to recognition of strengths, participants also acknowledged life circumstances
of providers and the distinct roles of providers in collaborative relationships. For example,
Becky described how she values that Barbara acknowledges her personal life circumstances and
works around these circumstances, “Especially now that I’m pregnant too, she tries not to give me too much (laughs).” For her, she continued working in a productive manner within the team despite limits in the action she can take due to her pregnancy. Participants also indicated the importance of identifying distinct roles for each provider within collaborative teams, based on shared knowledge of providers’ training and capabilities. For instance, Barbara described working with her sons’ providers to understand job duties they are able to fill, and then determine roles based on this understanding. She specifically described working with Brandon’s massage therapist to define the massage therapist’s role, the other providers’ roles, and how they could all work together to meet Brandon’s needs:

The massage therapist and I just sat down and kind of carved out a little bit of a different role for [provider] during that time where the three of them are going to sit down and talk about what parts they’re working on and why.

In this example, Barbara took concerted steps to understand the providers’ capabilities and promote collaboration among each member of the collaborative team. Further, Jeff extended ideas about understanding of roles by expressing the importance of defining roles and obtaining a commitment from each member of collaborative teams to fulfill their roles. He stated, “You do action planning where people start making commitments on what they’re going to help with and what resources they can bring to the person.” For him, collaboration was only possible once all team members fully understood one another, the families, and the young adults, and committed to their roles. In sum, shared understanding of each member of the team existed as critical for all participants.
Barriers to shared understanding

Participants identified different types of barriers that they have experienced in their collaborative relationships and steps they have taken to overcome barriers. Each of these barriers primarily revolved around caregivers and providers holding different expectations for the young adults, based upon a lack of shared understanding of the young adults’ abilities and capabilities. For instance, Sandra, Julie, and James each described instances in which they felt their young adult children were capable of skills beyond those targeted by providers. Specifically, Julie and James noted Jason is working on manual labor tasks through his vocational programming, yet they are frustrated because they believe he can obtain a more advanced job. Similarly, Sandra described her frustration when Sam works on tasks at school he has already accomplished at home:

And they said to me at school they can tell he already knows how to clean and he enjoys the cooking class. Well hello, he knows how to cook. And I didn’t teach him microwave, he knows how to microwave. But that’s not what I taught him. I taught him this is an egg. And this is how you crack that egg. So he knows how to crack an egg.

For each of these caregivers, these frustrations further translated into differing perspectives from providers regarding progress for the young adult. Both sets of caregivers expressed their frustration regarding providers’ focus on certain percentage of task completion as exemplifying progress. Sandra articulated this frustration:

They’re (school personnel) like well how do we know he’s met the goal? I said just keep going around in a circle. Don’t do the same thing over and over and over and over. He needs 70%, he needs 80%...trust me, if you’ve shown it to him and he did it, then he knows how to do it. And you will lose him if you keep going over and over and over
saying this was not 70%, this was…he doesn’t care about the percentages. He’s got that.

You’ve got to move on to the next thing. And he will retrieve that when he needs it.

For these caregivers and providers, their understanding of how the young adults demonstrate their knowledge and abilities differed, acting as a barrier to shared understanding within the team. However, all caregivers and providers described the lessons learned from barriers encountered throughout the young adults’ lives and expressed overall satisfaction with the collaborative relationships they have achieved for their young adult children.

**Shared Goals, Visions, and Hopes for the Young Adult**

The second major element to emerge among participants included team members’ articulation of shared goals, visions, and hope for the young adult. These shared goals, visions, and hope followed from each team member’s shared understanding of the young adult and one another and each team member’s adoptions of communicative strategies to ensure explicit discussion of goals, visions, and hope (strategies described in detail in the next sub-section). In turn, shared goals, visions, and hope acted as the impetus for collaborative efforts and ensured team members worked toward the same objectives in their collaborative relationships. Several facets comprised this shared understanding, including a shared understanding of the exact goals for the young adult, a shared vision for the appropriateness of goals given the young adult’s age as well steps that would enable the young adult to achieve his goal, and shared hope for success and achievement of goals. However, participants also described instances in which a lack of shared goals, visions, and hope acted as a barrier to collaboration, noting the importance of overcoming barriers to engage in productive collaboration. Each of these facets is described further below.
Shared goals

Regarding shared goals, participants explicitly voiced the same goals for the young adult in a given team, enabling effective collaboration on behalf of the young adults. For instance, Brandon, Barbara, and Becky each articulated engaging in art, taking community college classes, developing life skills, independent communication, and living a happy life as goals for Brandon. Further, Becky noted the importance of explicit communication regarding goals or adaptations to goals, “Share what goals you have for your child with that person [provider] on a daily basis.” In her opinion, caregivers should be proactive about sharing goals on behalf of young adults in collaborative relationships. For Sam, Sandra, and Sally, goals shared for Sam included increases in independent living skills and assertiveness. Sandra shared how she works with Sam’s providers to ensure ongoing progress toward the goal of assertiveness:

Assertiveness, to be able to be assertive, is what we’re working on right now. For him to be able to speak for himself. Because he knows what he wants but we don’t. So trying to get him to be able to speak for himself. That’s one of the number one goals. You know, it’s like starting over. Use those words. You have them, use them. They will get you things if you use them. So that’s how we’ve been collaborating now, based on the goal and collaborating. Working on the assertiveness.

For her, a clear, shared understanding of the goal for Sam, including the rationale for the goal, was key to ensuring all members of the collaborative team took concerted steps to facilitate the goal. Finally, Jason, Julie, James, and Jeff stated goals for Jason, including attending community college, striving for independent living, and developing social and communication skills. Within this team, Jeff specifically pointed to formulation of the goal based on the team members’ shared
understanding of the values of Jason and his family members, pointing to the interplay between a shared understanding of team members and shared goals for a young adult.

**Shared visions**

Regarding shared visions for the young adults, team members described the necessity of formulating a vision based on expectations of what is appropriate for typically-developing individuals of the same age, as well as developing a shared vision of steps necessary to enable the young adult to achieve his goals. Team members evaluated the appropriateness of visions and goals using an age-appropriate framework, setting high expectations for the young adults founded on this rationale. Across teams, caregivers and providers noted developing visions based on considering the typical independence, activities, and goals of young adults of the same age. For instance, Sandra stated, “I believe every child should leave home, just the way I did. You know and get out there to the best of their ability and then come home.” For her, treating Sam “as autism first” and limiting his independence was unacceptable, especially when formulating a vision of what his adult life would look like.

Further, caregivers and providers discussed the importance of letting the young adults act as their own visionaries, given their age. As stated by Becky, “With him it’s respecting he is an adult and that he does make his own decisions.” For members of this team, Brandon acted as the central force in formulating his vision. In turn, team members respected his decisions given that he is an adult, and they adopted steps to enable him to achieve his goals based on the vision. In addition, Jeff discussed how he leverages a vision of what is appropriate for clients based on remembering that his clients are people first:

As concerned with autism, it is true that there is not one piece of technology that’s only appropriate for a person with autism. So, there’s not. We don’t develop…there’s no
technologies that are just for autism. So for the professionals and for the people that are going to be the support people, you have to really understand that they’re people…they’re brothers, they’re daughters and sons, they’re cousins, they are next-door neighbors, and they are friends... They are students, they are congregation members. And seeing them as this person first, that this disability lens they see the world through is just how they access the world and they operate on the world. And when we engineer it in ways that make it understandable, in perceptual processes, and then teach them appropriate judgments…which is, that’s the big black hole of autism support.

As Jeff described, he uses this understanding as the basis to guide family members and young adults in developing visions and goals, pushing them to consider age-appropriate goals despite discomfort that might arise.

Team members also discussed how their shared visions inform steps to take to ensure the young adults reach their goals, as a product of collaborative relationships. For example, caregivers and providers in each of the teams talked about specific strategies they adopt or activities they use to guide the young adults toward achievement of their goals. For Brandon, a major goal articulated by the team members included developing artistic skills and creating a company in which he could sell greeting cards to earn money. Based on this shared goal, Barbara and Becky helped facilitate the young adult’s participation in community college classes, creation of small projects to sell for profit, and showing of his products as art displays. Barbara extended the description of collaboration based on the shared vision by discussing how Brandon’s community college professor also played a role in facilitating movement toward his goal, as another member of the collaborative team:
She set it up where him and another young artist who has autism had their artwork displayed in the gallery at [community college]…so we got to go see that. She helps them sell their artwork at the farmer’s market, you know. She’s just, that’s the kind of role she plays.

In Brandon’s case, each provider worked with Barbara to discuss the vision for Brandon and assume roles to leverage progress toward goals. The caregivers and providers in the other teams echoed similar ideas related to shared visions and movement toward goals. For instance, Sally noted how she formulated teaching plans for her students’ final months in school based on goals for their living situations post-school. Likewise, Jeff discussed how he works with families and young adults to determine achievable work and social skills, such as working to enable Jason to achieve his goal of obtaining competitive employment. In each of these cases, shared visions are critical to achievement of goals and desired outcomes for the young adults.

**Shared hope**

Finally, participants articulated the importance of maintaining a shared sense of hope when formulating and working toward shared visions and goals. As part of this shared hope, participants indicated they continue to hold on to hope for success, and they actively use orientation toward hope and success as the foundation for collaborative work. For instance, when describing an essential element of collaborative work in her experience, Sandra indicated, “You respect and build a working relationship. We’re working together for his success. And that’s always been what I used.” For her, she sees hope for success as a key component of team-building and collaboration. Within team 4, Jeff and Jason each noted the importance of hope shared by the young adult, as well as by his parents and other providers. Specifically, Jason
voiced his hope for future success, and he indicated this hope is shared by his family. Jeff also voiced hope in terms of orienting Jason toward success:

With that kind of progress, it would build a confidence in him and it would build a desire in him to learn something new or something more or give him some pride, that kind of thing. So that’s the kind of progress I would rely on.

For Jeff, hope extended beyond just the hope voiced by caregivers and providers; hope is something that is demonstrated by the young adult and should be viewed as an important outcome of collaboration. By sharing this hope, teams can adopt meaningful visions and goals that make achievement of success possible.

**Barriers to shared goals, visions, and hope.**

In addition to describing the shared goals, visions, and hope that make collaborative relationships fruitful, participants discussed how a lack of shared goals, vision, and hope acted as a major barrier to collaboration. Specifically, participants described instances in which their goals, vision, and hope did not align, and they offered a rationale for why this discrepancy existed. For nearly all of the caregivers, they voiced frustration regarding a lack of alignment between goals formulated in the school systems versus goals formulated by the family for adulthood. As stated by Julie, “I think other people have based his success on like we said, academic goals. Whereas for us, yeah academic goals are great, or at least for me, that’s great but I wanted the communication skills to be there.” Sandra echoed a similar sentiment, stating:

Well why didn’t you train him? Or teach him? I don’t like the word train. Teach him the things I asked you to. You know, job skills and things like that. And they [school personnel] said we have to do academics. And I said what academics? I don’t, he’s not going to go to college. He’s just not.
From each of these caregiver’s perspectives, communication and job skills were more important than academic goals to enable the young adults to achieve their long-term goals. Each caregiver voiced frustration with time spent on academic goals, when they believed daily living skills would offer more long-term benefit to their young adult children. However, caregivers acknowledged that school personnel are in charge of school goals, acknowledging the rationale for the focus on academic skills. Becky also discussed the specific barrier that exists when providers do not hold a shared vision of the necessary steps to enable young adults to achieve their goals. In turn, providers may work on contradicting skills that stunt forward progress. Overall, participants acknowledged barriers that might exist and must be overcome, but shared goals, vision, and hope are key to collaboration and successful transitions to adulthood for young adults with ASD.

**Strategies to Drive Relationships Forward**

The third major element to emerge among participants included team members’ descriptions of the actions they took to facilitate collaboration. That is, team members noted strategies they personally adopted to ensure ongoing collaboration, as well as strategies in place systemically that enabled collaboration and provided a guide for collaborative practice. On a personal level, team members engaged in conversations, met with one another, and utilized written means to maintain collaboration, and they communicated dedication to collaboration and used their time collaborating in a purposeful manner. On a systemic level, team members operated within systems that used specific models for collaboration, goal-setting, and accessing supports. However, participants also described the barriers that existed at personal and systemic levels, including how barriers impacted their ability to collaborate. Participants’ experiences of strategies to facilitate or hinder collaboration are described below.
Personal strategies adopted

When describing actions they personally adopted to facilitate collaboration, participants pointed to both concrete actions they took as well as intangible strategies adopted. For instance, participants across all teams indicated they planned meetings with team members and established certain patterns regarding when and how to communicate with one another. For team members, this often included a combination of the following strategies: 1) using journals, home notes, log-in sheets, and emails as a means to communicate; 2) establishing a pattern of communicating with one another on a daily, weekly, or monthly basis; and 3) inviting team members to meetings and independently setting up meetings. Becky noted the schedule of communication she had adopted with Barbara, “We usually coordinate in the morning. She’ll tell me updates or anything like that when I see her in the morning.” For them, this system of communication facilitated ongoing communication at an appropriate time interval for Brandon. Sandra noted her role in actively inviting team members to her house to ensure collaboration, “I kind of opened the doors. I used to invite everyone to my house. All the school people and all the [organization] people.” For her, setting the tone for collaboration was effective, and her personal efforts established a pattern of service for Sam. In addition, both Sandra and Sally discussed the home-school log they established to ensure ongoing communication. As stated by Sandra:

With school we have a communication log that goes back and forth. If there’s something in particular, like when school starts you meet the new teacher and they give you a sheet. Umm a Q and A if you will to write down things about your child and things you want to see them doing and things they do at home. And then you sit and try to tie those things in with what they’re actually doing at school. So for instance we’ve both been trying to get him less prompt-dependent. But that’s not working. So she will tell me what she’s tried.
And I’ll try it and let her know what the results are. I’ll try something and let her know.

For instance, she didn’t realize that when he’s out of focus all she has to do is ask him why he came to school. Why do we come to school? We come to school to… And I said he’ll finish it. And she went, oh! So when he gets out of focus she’ll use that phrase because that’s something I use at home. Because if I have to ask him something, he starts telling me that right away. I go, oh, so someone acted up today. We go to school to work? So why didn’t you. It’s not funny? She goes, I’ll notice he’ll tell me when he’s doing something that’s not funny. So we share those kinds of things back and forth. How to communicate, how to get him to stop doing certain kinds of things, how to stop doing certain kinds of things. So that’s pretty much how we collaborate at school.

In this example, she described the importance of this strategy in ensuring ongoing communication regarding issues immediately relevant to Sam. The system was adopted by Sandra and Sally based on a shared understanding of what would work best for them, and it enabled ongoing communication and collaboration to ensure Sam’s progress.

Beyond concrete strategies adopted by participants, caregivers and providers also noted intangible qualities that enable concrete strategies to work in collaborative relationships. Specifically, each participant talked about the importance of dedication and purposefulness when engaging in strategies. Participants engaged in strategies that demonstrated their dedication to ongoing contact, their willingness to exceed their role expectations for the benefit of the young adults, and their purposefulness in their time spent collaborating and the individuals invited to be a part of the collaborative relationships. Julie and James described how, “He [young adult] barely missed a week since he was 2 years old until about 2 years ago.” They further noted their belief that providers recognized and valued their unwavering commitment to appointments and
meetings over the course of Jason’s life, showing their dedication to collaboration. Julie also acknowledged that providers often must use their personal time to collaborative effectively, “And a lot of them, they do it in their free time, you know. Like they meet with us on their personal time, it’s their weekend.” Team members noted that if providers are not able to spend their work time collaborating, they sometimes must work outside the scope of their work to facilitate collaboration.

In addition, team members indicated they use their time together in a purposeful manner and they choose members of teams in a purposeful manner, to ensure the best use of each person’s time. Specifically, Jeff noted how his collaboration with Jason, Julie, and James is “intermittent” yet “well-placed.” In order to effectively collaborate for as many young adults as possible, he must navigate relationships using this purposefulness. Similarly, Becky discussed how her time spent collaborating is limited, yet she makes the most of even the 5 minutes she has to talk with Barbara:

We’ll have an exchange of maybe like 5 minutes where I update him on his mood and how he’s been doing today and anything she needs to know like if he has money or anything because he likes to spend his money like crazy. So we just watch that for him. And then…I would just show her if there’s anything new that I’ve already done that she hasn’t done.

For this team, the 5 minutes per day spent communicating was key for exchanging information about Brando. Barbara and Sandra further extended on ideas about purposefulness by describing their actions to select team members based on their qualities and their fit with the young adult and existing team members. As stated by Barbara:
But I really like the team we have right now. And I think that I pick the team, like when I hired and did interviews, not the first interview, I interview somebody first and then if I get a good feel for them, I’ll introduce them to Becky and Brandon. So, and so I do that on purpose.

Sandra also stated, “They [providers] met me before they met him and they were picked specifically for him.” Therefore, for each team member, purposefulness in time spent collaborating and selection of individuals with whom to collaborate proved to be key to collaborative efforts.

**Systemic supports**

When describing systemic supports in place to facilitate collaboration, participants highlighted strategies supported by organizations, funding structures, and policies and laws that enable collaboration to occur within teams. Specifically, participants provided examples related to the processes put in place by providers’ organizations to facilitate collaboration, processes for setting and evaluating progress toward goals, and available supports for accessing community resources. For Sam, these processes were established by the school district and supported by district-wide and state-wide funding structures. In line with educational law, Sam’s educational team was required to hold certain meetings to discuss progress and to document progress toward goals. For Jason, Julie and James discussed their experiences with vocational rehabilitation services, based on their understanding of the structure put in place by vocational rehabilitation. Jeff also noted specific structures put in place by his organization to facilitate collaboration and mutual understanding among collaborative teams. For instance, he described processes to prepare families for meetings with other professionals and to ensure collaborative teams’ shared understanding of needs and goals for young adults:
We’ll do pre-IEP meetings with families and we try to get with the educators…they don’t always make time available. So at the very least we meet with families. And we do informal assessments and figure out, help them figure out what the priorities are. And so we have some frameworks to do that with.

For this provider, established frameworks enacted by his organization are critical to efficiency in his job and the type of supports he can provide to families and other providers.

**Barriers to strategy use**

In contrast to personal actions and systemic supports that enable collaboration, participants also described barriers that exist to collaboration at both personal and systemic levels. At the personal level, participants indicated that communication breakdowns, time, and busyness of team members acted as barriers to productive collaborative relationships. For Becky, collaboration eventually fell apart with another provider due to the complexity and inconsistency of communication between the providers and Brandon:

> It kind of fell off the wagon after a while just for the inconsistency of communication between all three of us. Because she would email through him and then I would just get CC’ed on it and then I wouldn’t have…I wouldn’t be with him in the afternoon when he actually got the email back so it just…it would prolong it.

In this case, each provider desired to work together but communication became too complicated for the collaboration to continue. Sally extended this idea by stating her perspective that ongoing communication on the part of caregivers is just as important as communication between providers. Anytime a line of communication breaks down, a barrier to collaboration will exist. Providers, in particular, also noted the busyness of their jobs and the little time they often have to spend with young adult and their caregivers as barriers to collaboration. Becky described how
she holds multiple jobs, and she is only able to see Brandon for a limited period of time each morning before Brandon goes to school or transitions to another provider. In these ways, personal factors acted as barriers to collaboration and progress.

Finally, systemic barriers also acted as obstacles to productive collaboration, placing constraints on the capacities in which participants could operate. Participants attributed systemic barriers to bureaucracy, governmental and educational laws, a lack of availability of community resources, funding structures, a lack of appropriately trained of providers, and organizational structures. For instance, Barbara acknowledged the role of bureaucracy in limiting the amount of collaboration that is possible when young adults are still in school, “You know a lot of it is just bureaucracy, the way that the government works. Like with funding and the way that school systems work.” In addition to encountering this barrier during Brandon’s formal schooling years, Barbara noted how bureaucracy and a lack of funds continued to impact his participation at the community college level. Similarly, Sandra and Sally discussed how the Sally is limited in the types of services she can provide and the amount of collaboration in which she can engage due to educational policies and a lack of community resources. Sally described limitations to her scope of practice and collaboration with parents and caregivers while young adults are in school, “But again without mom or his guardian present we can only go so far. So it is limited to what we can do for our students unfortunately.” Further, her ability to support post-secondary transitions is impacted by the community resources available for young adults when they do transition out of school, “It’s hard in [city] because there’s not…we have all these services for them when they’re at [school] but then once they leave [school], especially our ASD population, there’s nothing…there’s not a lot for them.” That is, from her perspective, she does not have the ability to collaborate with adult service providers, given that they do not exist in the first place.
Likewise, Julie, James, and Jeff voiced similar frustrations about limitations to collaboration due to policies and resources, as well as limitations posed by funding structures and a lack of trained professionals to appropriately support young adults as they transition to adulthood. As stated by Julie, “A lot of the budgets are limited and they cut back on people and staffing so there’s not a lot of people to maybe go out there and see what’s available. It seems like there are more and more students who need it but less and less staffing and budget for it.” She recognized the need for services but the systemic limitation placed on caregivers and providers to leverage services to meet the needs of young adults. James described his perceptions of a lack of appropriate training of providers, further contributing to systemic barriers that exist:

It seems like ESE providers at all levels are, as you can imagine, under-funded…umm overwhelmed. And still kind of trying to find their way. Still kind of unsure how to attack these. And I imagine part of that is, you know, once you’ve met one autistic kid you’ve met one autistic kid, right? You know, part of that also is probably the newness of the whole condition. But they all seem like they’re not quite ready for primetime services.

In addition, Jeff noted how his caseload size and the caseload size of his co-workers act as ongoing barriers to more active collaboration with clients, “We’re in 14 counties and we have 3,500 families that we support…3,500. Families roll in and out.” As a result, the providers in his organization do the best they can to efficiently support as many families and outside providers as possible. Overall, participants acknowledged the personal and systemic barriers that impact their ability to achieve certain goals and visions, yet they noted continued effort to pursue collaboration based on their role qualities and understanding of what is best to meet the needs of families, young adults, and providers.
Flexibility and Engagement in Problem-Solving

The fourth major element to emerge among participants related to team members’ ongoing flexibility and engagement in problem-solving in the face of issues or barriers that arose. Specifically, participants described how team members demonstrated personal and professional flexibility when the needs and trajectories of the young adults changed, services ended or were deemed no longer appropriate, role adaptations on the part of caregivers and providers were necessary, and uncertainty or setbacks arose. Further, team members noted working together to problem-solve strategies to address needs and barriers and remaining committed to problem-solving. In this way, team members worked together flexibly to problem-solve strategies for any barriers that arose, working for the benefit of the young adults. Thus, team members’ flexibility and engagement in problem-solving emerged as an essential element to collaboration and are described below. Of note, discussion of barriers is embedded in the sub-sections below, given that flexibility and problem-solving served as actions to directly address barriers.

Ongoing flexibility

In terms of flexibility, caregivers and providers discussed the necessity of acknowledging changes in the young adults’ needs, trajectories, and services over time, particularly when the young adults reached high school. For some of the young adults, the transition to high school sparked deeper conversations about what was realistic for the young adult, given the proximity to adulthood and the present reality for the young adult. For instance, Julie and James noted changing Jason’s course of study when he reached high school, as a result of working with collaborative teams to determine how to best meet his needs and prepare him for the future. As stated by Julie, “It was around, I think it was 8th grade…he graduated middle school with a regular diploma. It was when he entered high school that they put him on the alternative track.”
She went on to explain that the family and providers realized this would be the best course of study for Jason, in order to provide him the vocational and social skills to achieve realistic adult outcomes. Caregivers also reflected on the importance of acknowledging when services were no longer appropriate for their children, and accepting that some services end and they must move forward. For Barbara, this acceptance occurred in terms of accepting the limitations of vocational rehabilitation services:

Vocational rehabilitation he's a client of them. They were paying for someone to go to umm to umm, school, but since we're not seeking a degree anymore they stopped paying for that so we have to figure out what they're going to do.

In this case, Brandon was struggling to succeed in community college classes. As a result of his changing needs, the nature of his services changed. In turn, this placed Barbara in a situation in which she had to respond in a flexible manner and problem-solve with the young adult’s other providers to ensure his ongoing progress in adulthood. Sandra, Julie, and James echoed similar sentiments when describing their recognition that school and speech-language therapy services were no longer benefitting Sam and Jason, respectively. In both of their cases, they looked to other types of services to better meet their children’s needs, with providers in agreement regarding the shift.

Flexibility also took the form of accepting changes in each team member’s role, based on the needs of the young adults and one another. For instance, in Brandon's case, role release occurred in the form of Barbara delegating more decision-making responsibilities to the young adult’s personal care assistants. As stated by Barbara:
Beck will, she knows us well enough. Like just wanted to let you know I started doing with Brandon. And I’m like yeah that’s great…So they feel secure enough in their position to make…to be self-directed and I love that.

In this case, both Barbara and Becky acknowledged their satisfaction with this role shift, founded on Barbara’s acceptance that she could no longer be the sole decision-maker on behalf of Brandon. This shift was founded on respect and understanding formed within the team, and trust in the decisions of Becky. In Sam’s case, the opposite shift occurred in which Sally acknowledged the limits of her role with Sam’s pending transition out of high school. As stated by Sandra, “We’ll take it from here. You know, it’s for me to prepare myself now to take it.” In this quote, Sandra refers to the mutual understanding she held with Sally that Sandra can act as his life skills teacher in the future. In Jason’s case participants described several types of role shifts, including Jeff educating and empowering Julie and James to take control of Jason’s vocational services, as well as Jason assuming a self-advocacy role and relying less on his parents and providers. In each of these cases, the role shift was founded on a shared understanding of the needs and capabilities of each team member, possible through collaboration. Further, the close-knit relationship and level of contact between team members impacted the role shift, as well as the age of the young adult.

In addition, caregivers and providers acknowledged the importance of remaining flexible when uncertainty or setbacks arose. In these instances, flexibility took the forms of making adaptations and remaining steadfast in the face of uncertainty, as well as remaining open to new experiences as the young adult progressed. For example, Julie, James, and Jeff described uncertainty that had recently arisen for Jason, in terms of determining what types of services
could best meet his current vocational needs and acknowledging the limitations of available services. As described by Julie:

We don’t really know what he needs so maybe that’s also, we don’t know who to contact or no one has been able to tell us what he needs based on how they know him or where to send us in that direction. So we’re kind of in that gray area…what do we do next? So we just have to keep trying different things.

In his case, Julie, James, and Jeff stated their ongoing commitment to meet his needs and develop a vision of how to achieve vocational goals, even in the face of the uncertainty he encountered. They also noted revising all plans they had based on Jason’s stated goal of attending community college, responding flexibly to his needs and committing to helping him achieve his new goal. When describing Sam’s recent emergence of prompt dependence and therefore decreased independence, Sandra stated, “I could see the whole thing was coming unglued but I held fast.” In her eyes, she knew Sam was regressing in terms of his skills, but she refused to give up on his trajectory and capabilities. In turn, she looked to providers to engage in mutual problem-solving regarding how to best meet his current needs. Becky also acknowledged the importance of remaining open when encountering uncertainty or setbacks, in order for team members to open themselves to new possibilities for young adults:

Be open-minded to new things for that person to try. Don’t feel like that one time they couldn’t do it so they shouldn’t do it anymore. Have them try again and again until…Or just have them try multiple times rather than just trying it once and giving up on them.

For this team, openness in terms of flexibility and consideration of new options was a key practice to ensure Brandon’s growth. Team members noted that progress sometimes takes time, remaining flexible even when they were unsure regarding the effectiveness of certain practices.
Ongoing problem-solving

Finally, participants described the need for ongoing problem-solving to address the needs of young adults and other team members in a flexible fashion. Their problem-solving took the form of collaboration to determine available services and appropriate strategies given the needs of the team and young adults, including how services and strategies might meet or fail to meet the young adult’s needs. For example, Barbara provided a detailed description of her problem-solving process with the young adult’s community college professor:

[Name of professor] and I were talking about maybe having him taking some classes in graphic arts. The problem with that is that I can’t get him in, I can’t just get him in to a graphic art class. The degree is so, it’s like, oh my god, you almost have to be a doctor to get this degree, lot’s of math in there… Anyway, we know he can’t get that, we just want him to audit a class. Umm he audited one a couple of years ago and it was during the summer and the professor had no idea, it was online, and so they have no idea who they’re dealing with and so it didn’t work out. So we’re trying to think of how we can kind of work on that.

In Brandon’s case, Barbara and his professor were working together to brainstorm how Brandon might meet his goal of being a graphic designer, whether the goal was appropriate given the complexity of the classes and degree, achievable steps Brandon could take while problem-solving continued, and their ongoing commitment to continue discussion regarding steps to achieve the goal. Members of other teams described similar processes in which they laid out potential options, talked about pro’s and con’s of options based on their shared understanding of the young adults’ needs, and agreed to continue engaging in the conversations as they attempted to implement the different strategies. For Same, this took the form of discussions between
Sandra, Sally, and outside provider regarding strategies to decrease Sam’s prompt dependency. For instance, they discussed use of visual supports in the home and strategies Sandra had tried at home that could be incorporated in the classroom. For Jason, Jeff described an example in which the team brainstormed transportation options for Jason:

I talked with Jason and Julie about this…I said, you know, to get around how do you plan on doing this? So your options are walking, bicycle, bus, Uber, taxi, drive, helicopter (laughs). Umm you know skateboard, skates…anyway. They opted riding for the city bus and I know his mom has done that with him and has taught him.

In this case, the team was able to reach a consensus and try out the strategy to determine its efficacy. For all participants, ongoing flexibility and problem-solving was a key element of collaboration, ensuring ongoing progress for the young adults.

**Team Members’ Shared Experience of Collaboration**

The fifth major element to emerge among participants included team members’ descriptions of their shared experience of collaboration with other members of the teams. Specifically, participants referenced their overarching experience of the phenomenon of collaboration using certain descriptors, and these descriptors were mutually used by members of given teams. They described experiences with successful and productive collaboration as well as experiences with barriers to collaboration, such as those noted throughout the current domain. By experiencing collaboration in a shared manner, participants were able to arrive at shared understandings, goals, visions, hope, use of strategies, flexibility, and problem-solving. They were able to recognize roles of one another and to look to the past, present, and future (described in the next domain). In turn, a shared experience of collaboration existed as critical to driving collaboration forward.
Experience of successful collaboration

Participants described varied aspects of their experience with successful collaboration, including the manner in which they experienced collaboration as an overarching phenomenon and their relationships with other members of collaborative relationships. They used adjectives describing both the positive and difficult experiential aspects of successful collaboration, and they adopted similes to provide comparisons as means of explaining the phenomenon. Among the adjectives adopted by participants, both caregivers and providers described collaboration as “helpful,” “beautiful,” “a blessing,” “wonderful,” and “fantastic.” They described “loving” their interactions with other members of collaborative teams, such as in the relationship between Brandon and his community college professor. As stated by Barbara, “And now he loves (emphasis) her. And so he always says she’s his favorite fan. And she says I am your favorite fan Brandon.” In this example, Barbara described one provider’s experience of loving collaboration with Brandon. Jason’s collaborative team experienced collaboration in a similar manner. As stated by Jeff, “It’s fantastic to be able to work with a family like that.” In his case, he experienced collaboration with the family and Jason as fantastic and an enjoyable experience.

To further describe their experiences with successful collaboration, participants provided similes to illustrate their experiences. For instance, Jeff described collaboration as a celebration of the person, “Basically you celebrate the person as a…you do it as a party and a celebration of the person.” In his eyes, collaboration can be most fully appreciated and successful when experienced as a party or celebration centered on young adults’ strengths and goals. In addition, Sandra and Jeff each employed similes to point to both the experience of and outcomes from collaboration. For example, Sandra stated, “But I’ve always found that collaboration and working with is the only way to fly. It’s the only way to fly because otherwise you’re going to
spend all your time arguing.” Similarly, Jeff compared collaboration to other approaches, “And when we get educators as part of that team, it makes it a lot (emphasis) better.” For each of these participants, the experience of collaboration is much more enjoyable, exciting, and productive than attempting other routes of achieving adult outcomes for the young adults. As a result, they are motivated to continue engaging in collaboration on behalf of the young adults.

Finally, participants noted difficulties that typify the collaborative experience, even when collaboration is going well. This idea was strongly communicated across each of the teams, with participants acknowledging the reality that successful collaboration requires work. For instance, participants provided the following descriptors when discussing the experience of collaboration: “hard,” “difficult,” “tough,” “not easy,” “not always successful,” and “hard to engineer.” However, they also pointed to the experience of continually “trying” to make collaboration and partnerships work on an ongoing basis. For them, successful collaboration is an ongoing process that must be continually maneuvered in tandem with other team members, in order to produce desired outcomes for the young adults.

**Experience of barriers to collaboration**

Following from their descriptions of experiences with successful collaboration, participants also discussed experiences with barriers to collaboration. All caregivers and providers provided at least one example or descriptor of a barrier to collaboration experienced in their lives, noting their emotions, thoughts, and reactions to the barriers. For instance, Barbara illustrated the varied aspects of a negative experience with a past provider whom she felt gave her false information. She discussed the experience in terms of “a lot of money wasted,” “a lot of time wasted,” “a lot of aggravation,” “I felt very angry,” “there was a sense of dishonesty,” and “it was very disappointing.” Caregivers and providers across the other teams also noted
difficulties with barriers that arose or failed attempts to collaborate, describing, “the breakdown as difficult, “setbacks as hard to see,” “a lack of collaboration as awful,” and “the relationship as non-productive.” In a specific example, Julie and James described a breakdown of communication and collaboration with a provider as a “source of frustration and annoyance.” They went on to delineate aspects of the frustration and annoyance, including “especially when we have different goals,” “when communication completely breaks down,” and “when Jason is not appropriately challenged.” Overall, when describing their experience with collaboration, participants described overarching experiential aspects related to elements of successful collaboration and barriers to collaboration. By developing this shared understanding, participants navigated their relationships and worked together on behalf of the young adults, promoting progress toward adulthood.

**Domain 3: Time Elements**

The third major domain to emerge as critical to a description of the phenomenon included stakeholders’ pervasive description of time. That is, when describing their experiences with collaboration, caregivers and service providers referred to time elements that impacted that their experiences. For instance, caregivers and providers often framed descriptions of collaborative efforts in terms of their past experiences, and their reflection and growth from those past experiences. They talked about their present realities, including accepting those realities and using the present realities as an impetus for forward movement. In addition, they discussed the key role of foresight and looking to the future to frame current efforts, including when considering skill development, coordination of care, and outcomes from collaboration. Each of these elements of time in relation to collaboration is described in detail in this section.
The Past: Longevity and Reflection

Caregivers and providers often referred to the past when describing their experiences with collaboration, highlighting the important role of longevity of experiences and lessons learned from past experiences in informing their current collaborative efforts. That is, caregivers and providers described longstanding experiences with collaboration and with working in the field of service delivery, informing their current efforts. In addition, caregivers and providers reflected on lessons learned from positive and negative experiences in their lifetimes, also informing their efforts and understanding of various aspects of collaboration in the present. Each of these aspects of the past are described below.

Longevity

In regard to longevity, caregivers and providers described their longstanding experiences in coordinating care, working with providers and families, and using young adults’ interests and desires as a guide for their efforts and collaboration. For caregivers, they noted their ongoing dedication to collaborate with their children’s providers throughout their lives. For instance, Sandra described her ongoing communication with her son’s early providers, setting the tone for her future collaborative efforts:

I’m still in contact with, well not Sam’s teacher because he started school here, but [Sam’s brother; also diagnosed with ASD]’s teacher in [state], I’m still in touch with them. And he’s 23. So I’ve always had that open line of communication.

In this case, she continues to rely on past providers as a source of support, and she relies on her past experiences to inform her current efforts. Further, caregivers and young adults described how the young adults’ interests have historically guided their efforts and continue to do so when seeking services and providers with whom to collaborate. For example, Jason, Julie, and James
described their dedication to following Jason’s educational desires throughout his life, informing the types of services and supports they sought for him. This trend continues at present, as the family seeks support from outside organizations to make Jason’s desire to attend community college a reality.

For providers, both caregivers and providers noted the impact that years of experience in the field have on the providers’ abilities to effectively collaborate at present and work with the respective young adults. For instance, Becky established a relationship with Brandon nearly six years prior to the date she participated in the study, despite only having worked intensively with him for two years. Both Becky and Barbara described the longstanding relationship as important in enabling Becky’s work with Barbara and Brandon. As stated by Barbara, “She’s been with me for almost two years but her husband was Brandon’s caregiver for two years. So they’ve known Brandon forever…I think it’s key, it makes the machine run smoother.” A similar pattern existed in the other two teams as well. Sally developed a relationship with Sam five years prior to becoming his teacher. She conducted therapeutic horseback riding sessions with him, in part inspiring her to become a teacher and serve Sam and young adults in a new capacity. For Jeff, he established a relationship with Jason and his family early in Jason’s life, purely by chance. He described:

It’s kind of an unusual circumstance because they lived in my neighborhood. They lived down the block from me. So I would see Jason when he was very young. And my kids, we’re friendly with their older, with some of the older kids. And when did I first really…I would see Jason at some of our events and I would talk to his parents in the neighborhood because they knew who I was. And then really I guess professionally we only started working together maybe two years ago.
In each of these cases, the families and providers were able to build an understanding and trust over time between one another and with the young adult. Further, providers noted that general longevity in their field provided them the knowledge to best meet the needs of the young adults and families in each of these teams, as well as the needs of other young adults and families served. In each of these ways, longevity led to successful collaboration at the time of transition.

Reflection

Participants pointed to the key role of reflection and learning from past experiences in informing their current collaborative efforts. Specifically, participants described learning from both positive experiences and barriers in the past, including building upon lessons learned from experience to frame current progress and remembering that they were able to successfully overcome barriers in the past. Participants also alluded to the lessons they learned from the past, including using the lessons to inform their current efforts and acknowledging their successes even when they did not feel confident in their actions at the time. To each participant, especially caregivers, learning proved key to their current collaborative efforts.

Regarding learning from positive experiences, caregivers described certain actions they took, strategies they adopted, and relationships they built that taught them how to successfully navigate collaborative services in their children’s transition-age years. For example, Sandra described learning how to set goals and evaluate mastery with Sam and his providers. Although not a typical provider, she told a story about working with Sam and his barber to determine a plan in which Sam could get progressively longer haircuts and use coping strategies for his anxiety when getting haircuts. Following details about her story, she stated, “We set a goal. You know, whatever that goal may be. It was to sit through a haircut, to sit still through a haircut. And that’s mastered.” As a result of this collaborative experience, Sam also learned
how to communicate his needs, an important skill he could use in adulthood. In Jason’s team, Julie described successful relationships she built with the school system in the past, noting the difference the relationships made in Jason’s development. In turn, she took and continues to take lessons learned from the relationships to navigate her current relationships.

In addition to learning from positive experiences, caregivers and providers described the importance of learning from negative experiences, such as learning from strategies to successfully overcome barriers in the past. For instance, Barbara provided an example in which she overcame a negative relationship with one of Brandon’s occupational therapists at a young age. She believed she was deceived by the occupational therapist; however, she learned to look for characteristics she does not desire in providers and red flags regarding promises about outcomes from services, informing her current efforts. Sandra described a time in Sam’s life when he began having seizures unexpectedly. She experienced the event as scary and was uncertain how to respond at the time, but Sam overcame the seizures through her work with his providers. Currently, Sam is experiencing newfound sensory and independent living needs, marking a departure from his prior abilities. However, Sandra described feeling confident in her ability to navigate these needs in a similar manner to her ability to work Sam’s providers to manage his seizures. Julie discussed an experience in which Jason, Julie, and James struggled to work with school staff when Jason was in elementary school. At the time, he was experiencing behavioral and emotion regulation difficulties. However, he matured and entered a new school, overcoming the early difficulties. Julie and James used this lesson to frame their ability to work with current providers, especially those with whom establishing a relationship is more challenging.
Finally, caregivers reflected on the global lessons they learned throughout their children’s lives as they discussed their current collaborative efforts. For caregivers, they acknowledged that their best learning occurred with the passage of time and new experiences, and their reflection on past events enable them to see the effectiveness of strategies they employed. Barbara offered her general sentiment regarding her own learning over Brandon’s life, in response to a question regarding how she knows what actions to take when navigating collaborative relationships:

In the very beginning, you know, I mean now 25 years or later or whatever…he was diagnosed when he was 2 so it’s 22, 23 years later umm… I was clueless when it first started and overtime, with just the experience… Those are all things I’ve learned to do with him over 25 years.

Sandra extended this idea by stating her realization that reflection enables her to see what she did in the past and learn from it, “And so I never really recognized all the things I did until I looked back on them. And now you’re asking me about them and I’m thinking wow I did do something.” She also talked about the key role of reflecting in tandem with providers, particularly those who have known Sam for a long time. In this way, both the caregivers and providers learned from their actions in tandem, taking part in the reflective process together as a way to deepen their relationship:

But when you go back and you tell it to someone else, you see all the things even clearer than you did when you were actually in it. And so we do a lot of that talking, like what it used to be like and what Sam used to do. And we laugh about it. We share those stories with [provider] and she shares hers with me.
For her, this shared reflection served as an important learning experience, an ability to grow from the past, and an ability to experience joy in the present. Based on longstanding experiences and lessons learned, participants were able to orient themselves to the present and look to the future when collaborating on behalf of the young adults.

**The Present: Acceptance of Reality**

In conjunction with references to the past, participants made continual references to their experiences within the present. Specifically, caregivers and providers discussed their experiences with accepting reality as it occurs, including accepting the young adults’ present needs, accepting their own lives, letting go of the past, choosing actions based on the present, revising visions and goals as needed, and accepting the time that reality assumes. They accepted these present realities within their respective teams, communicating their own experiences with one another and sharing in experiences that arose. From this acceptance of reality, team members then developed a plan for continued forward movement, looking to the future as a guide. As such, the experience of the present in collaborative relationships emerged as a critical element.

Each of the team members described their own experiences with accepting the present reality both individually and as a team, and responding as a team to the reality. Most often these descriptors centered on changing needs and accepting setbacks, in order to meet the young adults where they were in that present moment. For example, Barbara described her experience with accepting reality through collaboration with Brandon’s community college professor. Specifically, she worked with the professor to re-evaluate appropriate goals for Brandon:

We just sat down about a month and a half ago and decided that we might try to pursue a different avenue…he’s just not…I think he’s either getting bored with it or the...
accommodations aren’t enough to support him in that environment. He’s learning but not learning at a pace fast enough with trying to keep up to get the GED requirements.

For the team, they had to consider whether pursuit of coursework in graphic design was appropriate for Brandon, given the complexity of the classes and his stunted learning in the classes. The reality was not one they wanted to accept, but they realized it was necessary for Brandon. Based on acceptance of reality, they developed a plan for realistic classes for Brandon to take in the future and a plan for continued engagement in artistic activities.

For Sam’s team, similar examples emerged as Sandra and Sally planned for Sam’s transition out of formal schooling. Both Sandra and Sally discussed examples related to Sam’s recent emergence of prompt dependency, decreased engagement in independent living skills, and increased engagement in sensory seeking activities. For instance, Sally stated:

Because when he did start the school year he was very independent and he does do very well with cleaning skills, he does well with wiping tables and cleaning dishes. But then over the year he has gotten very heavy-handed so we don’t give him dishes to wash.

She further described her attempts to problem-solve with Sandra to determine the appropriate course of action, “So it’s just, trying to find a job that he is capable of working…what kind of job can he perform?” Through collaboration, Sandra and Sally discussed steps to adopt to address Sam’s needs in the moment. For example, Sandra reverted to using old strategies such as visual aids and schedules, Sally modified the tasks and supports for Sam in school, Sally modified IEP goals with Sandra, and Sandra ultimately decided to pull Sam from high school due to lack of perceived progress. In each of these situations, participants accepted the reality for the young adult and reacted accordingly with one another.
For Jason’s team, acceptance of reality took the form of acknowledging Jason’s current needs, his likely trajectory, and supports that were or were not available. Both James and Julie described arriving at their present reality as a product of their past experiences. Julie described, “I think there was more care available for him when he was younger. More services available.” James added to this sentiment by stating, “Well yeah because the possibilities were so much broader. Because as he gets older the possibilities narrow down. So certainly your track options are different, right, that’s more limited.” For them, they had to accept that fewer adult services exist than child services, in order to promote Jason’s vocational and independent living goals. They communicated a sense of disappointment in the system, but they voiced an acceptance of what is available. From there, they worked with Jeff to access available resources, continuing to pursue resources into the future.

Across all teams, participants also indicated their acceptance of the time that present reality assumes, particularly in regard to the pace of progress the young adults make in the present. For example, Barbara described the amount of time collaborating and coordinating care takes to meet the needs of Brandon, “It’s a 24/7 job.” She also discussed her acceptance of the slow-moving nature of progress in the present:

It is slow. And I think because we’re inventing the wheel as we go along. And so you know, we’ll try something and we’ll go ehh that didn’t work so well. And with [young adult] I know that we need to give it, not just a week or two…because he’s trying to get the concept of what we’re trying to have him do.

For her, she accepted that progress and changes in the moment take time, assuming more than just a fleeting moment. Sally described a similar phenomenon in regard to the present reality of progress. She stated, “Progress for him right now is, we take it on a day to day basis…because
of his ability level, we base his progress on a day to day basis.” For Sam’s team, Sandra and Sam’s providers mutually accept that time is an important element in their efforts. Likewise, Jeff endorsed the notion of time that exists when considering progress as a result of collaboration. Specifically, he described how, to the outside observer, Jason might be able to make quick progress. However, progress takes time and reality assumes a prolonged stretch of time. He stated:

The family has been doing this with him forever and this is a family with significant capacities also. You know, they put him in good situations. And they’ve had resources to be able to meet his needs. And look where he is and it’s taken this long.

For each of these teams, acceptance of the present reality and the time it assumes was a key facet in terms of their engagement in collaboration and mutual understanding of the needs of the young adult during the transition period.

The Future: Activation of Foresight and ‘Seeing’ Progress

Following from a description of the past and present, participants also continually referred to their overarching orientation toward the future. This future orientation included activating foresight to collaborate effectively and ‘seeing’ forward movement and progress. Each caregiver and provider acknowledged the critical importance of maintaining an orientation to the future, particularly in relation to thinking about ongoing progress and plans when the caregiver is no longer able to spearhead efforts or the provider is no longer serving the young adult. Further, each participant discussed the importance of ‘seeing’ young adults’ progress and the progress of the teams, as a way of remaining oriented toward the future. By looking to the future, teams could effectively engage in collaboration and ensure ongoing progress for the young adults.
Activation of foresight

Regarding activation of foresight, caregivers and providers discussed the importance of early orientation to the future and consideration of a time when caregivers and providers are no longer able to collaborate on behalf of the young adult. By remaining oriented to the future, concerted efforts can be adopted to ensure ongoing care coordination and a high quality of life for the young adults in the future. Regarding an early orientation to the future, caregivers and providers discussed the necessity of activating foresight from the time the young adult is a child. Barbara referred to this idea when she stated:

What I think is that they don’t start preparing soon enough. You know people say to me how long have you been thinking about him doing these things. I said probably since, you know, I got over the shock of he’s autistic. So, you know, realistically 10, 13, those ages. So really start ahead. And it…always look at it, nothing is set in stone. You know, things are going to change, but at least have an idea of where you’re going to go.

In this statement, Barbara indicated she began considering Brandon’s future from the time he was first diagnosed with ASD. Despite activating foresight early, however, she also remained open to accepting present realities as they emerged, revising her foresight as needed. In a similar manner, Sally echoed the importance of early foresight and planning, expressing her frustration when this does not occur, “Unfortunately we do have some parents that I guess don’t want to accept the reality that their 20…their child will be turning 22 very quickly.” In her experience, a lack of orientation toward the future hinders forward progress and collaboration for young adults.

Following from this sentiment, caregivers and providers described the necessity of considering a time when the caregivers and providers are no longer present to collaborate on behalf of the young adult. Although the reality is difficult to accept, participants emphasized the
importance of keeping this reality in mind when collaborating. Sandra articulated this foresight in terms of considering the skills Sam and his brother will need to live a safe and healthy life without her in the future. In describing her foresight, she first described her general acknowledgement of a time when she is longer around:

It’s a scary thing too knowing that one of these days I won’t be around. And so you constantly try to prepare them for when I’m not going to be here. But you never know when that’s going to be… You take yourself out of it and you look in and see what you would want them to know and what you would want to protect them from and how you can take them to be independent. That’s what I did with these guys.

From this statement, she then talked about her specific considerations for the skills that will likely promote Sam’s quality of life and his brother’s quality of life in the future:

Okay, find all the things that could possibly put them in harms way and do your best to teach them those. Now I know not everybody can, you know I have people whose kids are just laying there and what do you do in that instance? You do the best that you can, you know. And you start with the end in mind and you pull yourself out of the picture.

For Sandra, teaching independent living skills to Sam and her other son was a priority, informed by her orientation to skills he will need to live a life without her.

Barbara and Becky extended on these ideas by discussing their attempts to coordinate care with the future in mind. Barbara described her specific actions to coordinate Brandon’s care over time, should she or a provider no longer be in his life. She described her strategy in the following manner:

I’m managing it in a fashion, the way that I have set it up is that if something happened to me someone could jump in, could look through my files and things that I’ve written... I
want everybody to have their piece of the puzzle, so to speak, or puzzle piece to, you know, to make the whole picture. So that if one little piece is gone the whole entire thing doesn’t fall apart. That other pieces are there to be able to keep together.

For her, she wanted to ensure development of a plan in which either her son’s current providers or future providers have a sustainable skeleton for care coordination. She actively works on the plan at present, using feedback from providers and foresight to ensure development of the optimal plan. Becky also noted how she considers a time when she will no longer be working with Brandon, ensuring his future providers can build upon her efforts, “Try and look long-term rather than just short-term. Even past your time that you plan to work with that individual.” In her case, she desired to lay the foundation for future efforts in her work with Brandon and Barbara, in the case that she is no longer working with Brandon.

In addition, Jeff extended on ideas related to foresight by describing the necessity of providers looking to a time they are no longer able to serve families, in order to inform the type of legacy they desire to leave in their work. He indicated, “I feel like one of my legacies I want to do here is lay out a system to get the most people that we work with, give them access to employment.” For him, collaboration and work with families enabled him to understand systemic issues related to postsecondary transitions, in turn orienting him toward his own terminal goals. By activating foresight and considering his legacy on a large-scale, he adopts steps and strategies to ensure numerous families can continue to successfully collaborate and navigate postsecondary transitions in the future.

‘Seeing’ progress

Finally, participants described the importance they place on remaining oriented to the future in terms of ‘seeing’ progress obtained within teams and demonstrated by young adults. By
continually holding in mind past experiences, current realities, and future visions for teams and young adults, team members can remain open to progress as it occurs and see progress into the future. For instance, caregivers noted how they must ‘keep their eyes open’ to ‘see’ progress that is occurring and envision progress that can occur. Sandra described orienting herself to Sam’s future progress in terms of her past learning about Sam’s progress. She stated, “Sam has always been one to break that mold” [in regard to norms imposed on him by the world]…“And little things pop out to let you know he’s listening and he’s thinking and that’s all progress.” In this example, she described a conversation between herself and another provider, including Sam’s later reaction that demonstrated he was listening and in agreement with their problem-solving. By learning from this experience, she is able to develop a better vision for Sam’s progress in the future. Barbara and James echoed similar experiences. Barbara stated, “I mean some things surprise us” and James described, “I’ll go a step further, he’s exceeded every expectation that we’ve ever set for him.” In each of these cases, the caregivers reiterated the experience of opening themselves to their sons’ capabilities and progress toward adulthood goals. Through this opening of themselves, they envision promising futures for their young adult children.

Further, participants discussed their experiences of celebration when thinking about progress and looking toward the future. For instance, the caregivers and providers in the teams described experiencing forward movement and visions as “huge,” “excitement,” “awesome,” “fabulous,” and “great.” Jason described his own experiences with progress as “so cool” and “exciting.” In addition, Barbara pointed to celebratory aspects of progress, “I’m always happy and you know, celebrate moving forward.” In this way, she is able to maintain a sense of excitement when considering the future and what is possible for her young adult son. Across each of the teams, the participants described the experience of joy in progress that can occur when collaborative
team members open themselves to progress in unison. In turn, shared visions of progress into the future drove successful collaboration, enabling team members to share in the phenomenon of collaboration.
CHAPTER 5
DISCUSSION

As ASD diagnoses increase, demands are placed on families and service providers to deliver services aligned with the multi-faceted needs of individuals with ASD and their family members, particularly those transitioning into adulthood (Pringle et al., 2012; Shattuck et al., 2011; Taylor & Henninger, 2015). As a result, there is a critical need to understand practices that might facilitate efficient and responsive delivery of care. Current research and policy points to collaborative service delivery as an essential practice to ensure delivery of appropriate services for young adults with ASD and their family members, and to increase efficiency of service delivery for providers (Lubetsky et al., 2014). However, empirical research on collaborative service delivery to coordinate services for individuals with ASD transitioning into adulthood remains limited (Noonan et al., 2008; Smith & Anderson, 2014). Therefore, investigation of elements contributing to collaborative service delivery is imperative to ensure positive outcomes for young adults with ASD.

The purpose of this study was to examine the lived experiences of young adults with ASD, their family members, and their service providers in collaborating to coordinate services to meet the postsecondary transition-related needs of the young adult. A total of three collaborative teams participated in this study, including one young adult with ASD per team, one to two primary caregivers per team, and one service provider per team. This study utilized a phenomenological methodology to examine participants’ shared, lived experience of collaboration (Creswell, 2013; Merriam, 2009). Results of this study provide insight into key elements of successful collaboration shared in common for the three participating teams.

First, team members adopted roles within collaborative relationships, acknowledging both their own and other team members’ shared assumptions of the roles. Specifically, team
members each formulated goals (i.e., goal-setters) and developed visions of how services would drive achievement of goals (i.e., visionaries). They each initiated actions to establish relationships and connect to services (i.e., initiators). They each made decisions about service use (i.e., decision-makers) and acted as leaders both within relationships and when coordinating care (i.e., leaders). In addition, they each educated themselves and one another about issues related to ASD, the young adults, and available services (i.e., educators), and they connected themselves and others to formal and informal supports (i.e., connectors). For each role, the shared assumption of roles among team members emerged as critical across all three teams.

Second, team members described elements of collaborative relationships that foster effective collaboration and allow team members to overcome barriers contacted when collaborating. Specifically, team members each adopted actions informed by a shared understanding of each team member’s abilities, needs, and values (i.e., shared understanding), and team members held and adopted actions informed by shared goals for the young adults, shared visions of services to drive achievement of goals, and shared hope for outcomes for the young adults (i.e., shared goals, visions, and hope). Team members’ collaboration was driven by adoption of shared communicative strategies as well as systemic supports in place to facilitate collaboration (i.e., adoption of strategies). Team members approached situations in a flexible manner while engaging in ongoing problem-solving (i.e., ongoing flexibility and engagement in problem-solving). In addition, team members experienced both successes and challenges in collaboration in a similar manner, such as experiencing feelings of celebration surrounding the young adult and collaboration or experiencing feelings of frustration surrounding challenges (i.e., shared experience of collaboration). Each of these elements interacted and facilitated other elements, resulting in a dynamic process of collaboration shared among all teams.
Finally, all participating teams described their roles and the driving elements for collaborative relationships in the context of time and history. That is, participants reflected on lessons from the past, experiences in the present, and visions of the future when describing elements of collaboration during the postsecondary transition period. When describing the past, team members noted the role of their longstanding experiences with collaboration and systems of service delivery, as well as the lessons they learned from reflecting on past experiences. In tandem with learning from the past, team members described opening themselves to the present reality and accepting that reality, whether positive or negative. In addition, team members remained oriented to the future at all times, activating foresight to conceptualize how collaboration and service delivery would be linked to goals and adult outcomes for the young adults. Simultaneously, they remained open to progress occurring, allowing them to ‘see’ the progress of the young adult toward adulthood. Overall, this critical transition period in the young adults’ lives served as an impetus for reflection related to time for participants when describing collaboration.

In the remainder of the chapter, I discuss each of the study findings described above in relation to existing research and theoretical models regarding collaboration. I also discuss study findings in relation to the theoretical framework for the study, including ways in which the current study can inform the theoretical framework. In addition, I discuss limitations of the current study, implications for future research, and implications for practice. Each of these domains is discussed in detail below.

**Team Members’ Roles in Collaboration**

In line with previous research, participants described their overlapping roles within collaborative teams. Although consistent with previous research in some respects, findings
largely expanded upon existing research by attributing varied roles to caregivers, providers, and young adults when collaborating. Roles identified in the present study included: 1) visionaries and goal-setters, 2) initiators, 3) leaders and decision-makers, 4) educators, and 5) connectors. Broadly, caregivers of early-childhood to young adult-age individuals with ASD assume roles as information-sharers, observers and learners of skills, decision-makers, and advocates for services, although caregivers often note taking a backseat role when coordinating services (Bezdek et al., 2010; Carbone et al., 2010; Coogle et al., 2013; Coogle & Hanline, 2014). Providers adopt roles as information-sharers, facilitators of various services, and deliverers of services aligned with their specialized skills (Auert et al., 2012; Carbone et al., 2010; Coogle et al., 2013). Finally, research indicates individuals with ASD are not actively involved in planning services (Dyke et al., 2015; Turcotte et al., 2015).

Regarding team members’ roles as visionaries and goal-setters, initiators, and leaders and decision-makers, study findings are consistent with existing research pointing to the value of similar roles among caregivers and providers. For instance, existing studies targeting postsecondary transition-age individuals with ASD highlight the role of families in informing necessary supports, developing plans, setting goals, acting as advocates, and coordinating care for adolescents or young adults with ASD, and the role of providers in adopting roles in line with their areas of expertise (Cai & Richdale, 2016; Cheak-Zamora et al., 2015; Dyke et al., 2015; Ferguson et al., 2015; Hendricks & Wehman, 2009; Lee & Carter, 2012; Newsome, 2000). Specifically, Ferguson and colleagues (2015) and Wehman and colleagues (2012) pointed to the key role of shared goal-setting among a variety of team members, given each team member’s unique role and perspective within the teams. In their studies, teams of providers worked together to garner the perspectives of caregivers, set goals for skill development (e.g., job skills,
social skills, daily living skills), implement interventions, and evaluate outcomes. Similar to the present study, team members acknowledged share roles among caregivers and providers particularly in relation to goal-setting. However, the present study further expanded on roles by attributing additional roles as initiators, leaders, and decision-makers to caregivers in tandem with providers. The difference in findings is likely due to the varied design of the studies, in that the present study specifically examined caregivers’ firsthand perspectives rather than evaluating intervention efforts from providers’ perspectives.

Study findings are also consistent with previous research pointing to caregivers’ and providers’ views of themselves as educators and connectors. Regarding their role as educators, existing studies demonstrate that providers are viewed as experts in issues related to ASD, well-trained in collaboration, and able to share information with caregivers (Golnik et al., 2009; Mackintosh et al., 2012). In addition, providers are often viewed as experts within their respective fields, adopting roles aligned with their expertise (Ferguson et al., 2015; Wehman et al., 2012). These findings are consistent with the present study, in that participants described providers’ roles in educating caregivers, young adults, one another, and individuals outside the teams about topics related to general ASD service delivery. However, the study also extended on the research by attributing a similar role to caregivers, contributing to a form of role release between caregivers and providers in which they assumed roles of educators as one another. In addition, existing research points to the key role of team members in connecting themselves and other team members to supports. For instance, research shows caregivers value access to formal and informal supports (Moodie-Dyer et al., 2014; Symon, 2001), caregivers value when providers connect them to community supports (Kuhlthau et al., 2015; Tucker & Schwartz, 2013), and providers value professional relationship-building (Havlicek et al., 2015). Similar
findings emerged in the present study in regard to caregivers’ and providers’ roles in connecting caregivers specifically to formal and informal supports.

The present study also expanded upon existing literature in several other important ways. In general, a paucity of research exists examining team members’ shared roles in collaboration surrounding transition-age adolescents or young adults with ASD, particularly from the perspectives of multiple team members. For example, research reviewed above primarily considered roles of caregivers or providers in isolation, with limited commentary by participants on other team members’ roles on the same collaborative teams. Further, no studies considered the roles of or obtained firsthand information from young adults with ASD on collaborative teams. In the current study, role elements were described by and attributed to each team member within a collaborative team. Specifically, caregivers, providers, and young adults each assumed roles as visionaries, goal-setters, and educators. Further, caregivers and providers assumed roles as initiators and connectors, and caregivers and young adults assumed roles as leaders and decision-makers. Overall, these findings depart from existing studies that indicate caregivers may take a backseat role on collaborative teams (e.g., Bezdek et al., 2010; Mackintosh et al., 2012; Minnes & Steiner, 2009) and that adolescents or young adults with ASD serve very limited roles on teams (e.g., Dyke et al., 2015; Turcotte et al., 2015). In contrast, the present study pointed to the role of obtaining firsthand perspectives from young adults using accessible communication modalities.

Further, findings from the present study expanded upon the exact nature of team members’ roles in collaborative teams. For instance, although previous research highlighted the roles of caregivers as goal-setters, initiators, and leaders and the role of providers as educators to some degree, the present study expanded upon the nuances of roles for all team members. In
regard to their roles as visionaries and goal-setters, team members in the present study identified facets that enable them to assume roles as visionaries and goal-setters. For example, team members leveraged their knowledge about the respective young adult, and providers built upon their professional knowledge to formulate services matched to need in order to set goals and determine visions. In terms of their roles as initiators, team members described characteristics (e.g., committed, motivated, persistent, self-directed) that enabled team members to act as initiators. As leaders and decision-makers, team members looked to both caregivers and young adults to ultimately facilitate the roles and decisions of teams. Finally, in regard to their roles as educators, team members specifically described their roles as educators of the young adults, in order to empower the young adults to take active roles in planning their futures and educating others. The discrepancy between existing studies and the present study is likely due the design of the present study, which obtained in-depth, firsthand information from all participants regarding the phenomenon of collaboration. As a result, the present study represents an importance extension to existing research (e.g., Cheak-Zamora et al., 2015; Dyke et al., 2013).

**Elements Driving Collaboration**

When describing their experiences with collaboration, participants described the following driving elements that enabled collaboration to be effective and productive, especially when overcoming barriers: 1) shared understanding of each member of the team; 2) shared goals, visions, and hope for the young adult; 3) adoption of strategies to drive relationships forward; 4) ongoing flexibility and engagement in problem-solving; and 5) shared experience of collaboration. Like role elements, these driving elements both overlapped and expanded upon existing research related to facilitators and barriers within collaborative teams.
Shared Understanding

For the most part, team members’ descriptions of other team members aligned with existing research. For example, the necessity of aligning services with the needs and symptomology of the individual with ASD and the values, economic supports, and social supports available to families, especially during the postsecondary transition period has been well-described in the literature (Chappel & Somers, 2010; Lee & Carter, 2012; Jensen & Spannagel, 2011). Similarly, team members in the present study acknowledged the importance of understanding each team member’s strengths, capabilities, needs, values, personality characteristics, role, and desires in order to engage in ongoing collaboration, assume meaningful relationships, and engage in problem-solving together.

However, participants in the present study also acknowledged the importance of incorporating understanding of providers’ characteristics, thereby considering all team members’ characteristics as part of collaborative teams. This discrepancy is likely due to participants’ close relationships with providers in the present study, in that participants had longstanding relationships with providers and formulated trust and understanding due to the nature of relationships rather by service delivery type. Further, participants in the present study identified barriers that might exist to sharing an understanding of all team members’ characteristics, such as misaligned expectations for team members and a misunderstanding of team members’ abilities. This finding aligns with existing research that points to barriers such as a lack of appropriate consideration of families’ needs and devaluing of the role of families on collaborative teams (Bezdek et al., 2010; Moodie-Dyer et al., 2014; Tucker & Schwartz, 2013). Overall, both prior research and the current study point to the importance of continually building a shared understanding in order to overcome barriers to collaboration.
Shared Goals, Visions, and Hope

Findings from the present study about goals, visions, and hope for the young adults expanded upon existing research in a number of ways. Existing research in this domain emphasizes the value caregivers place on being invited to share goals with collaborative teams (e.g., Tucker & Schwartz, 2013) and the types of goals likely to be shared for transition-age adolescents or young adults with ASD (e.g., self-advocacy skills, social skills, vocational skills, independent living skills; Chappel & Sommers, 2010; Lee & Carter, 2012). However, the present study more explicitly delineated driving elements to developing shared goals, visions, and hope. For instance, team members described the importance of articulating shared goals for the young adult within teams, outlining shared visions of steps or services to enable the young adult to achieve goals, formulating visions informed by considering what is age-appropriate for the young adult, and sharing a sense of hope for goals and the future. These shared goals, visions, and hope were likely impacted by their joint assumption of roles as goal-setters, visionaries, leaders, and decision-makers. In addition, both existing research and the present study point to barriers that might exist when goals, visions, and hope do not align, and the necessity of taking concerted steps to overcome barriers.

Strategies to Drive Relationships

Participants in the present study described strategies, actions, and systemic supports that are similar in nature to strategies identified in existing research. In general, previous research has most extensively focused on overt strategies to drive collaboration forward such as clear communication, frequent communication, providers inviting caregivers’ input, planning of meetings, funding structures, adequate staffing, time, location of services, supportive policies, supportive organizational structures, supportive leaders within organizations, availability of a
point person for collaboration, formal organizational structures, and availability of assessments to track progress (Atkinson et al., 2007; Cooper et al., 2016; Ferguson et al., 2015; Havlicek et al., 2015; Kuhlthau et al., 2015; Moodie-Dyer et al., 2014; Noon et al., 2008; Tucker & Schwartz, 2013). Intangible aspects driving relationships forward such as trust, respect, commitment, shared philosophies, and role clarity also have been a focus of previous research (Atkinson et al., 2007; Cooper et al., 2016; Ferguson et al., 2015; Havlicek et al., 2015). In addition, existing research points to numerous barriers closely related to the unavailability or lack of use of the strategies listed above (e.g., Cooper et al., 2016). Specifically in relation to transition-age individuals with ASD, separate child and adult systems of care, abrupt transitions related to a lack of proper planning, a lack of trained providers, and confusion about funding structures act as major barriers to collaboration (Havlicek et al., 2015). The present study identified similar facilitators and barriers to coordinated care from the perspective of each team member, adding further evidence related to specific strategies driving or hindering collaborative relationships.

**Flexibility and Engagement in Problem-Solving**

Findings from this study both aligned with and expanded upon existing research regarding flexibility and problem-solving within collaboration. Specifically, previous research points to the role of flexibility and problem-solving in facilitating collaboration, especially from providers’ perspectives. Research indicates collaborative relationships during the postsecondary transition time period are characterized by problem-solving to overcome barriers, changing roles of providers, and relationships that evolve based on the adolescent’s or young adult’s needs (Havlicek et al., 2015; Noonan et al., 2008; Petri, 2010). The present study expanded upon these findings by incorporating caregiver and young adult perspectives and by further considering
factors that might necessitate flexibility and problems-solving. For example, changes in needs or roles of team members, changes in availability or appropriateness of services, alterations in trajectories of the young adults, and setbacks or uncertainties in skill development or collaboration necessitated flexibility and problem-solving. Further, team members in the present study highlighted their ability to engage in problem-solving as a result of remaining flexible and maintaining hope for the young adults, expanding upon existing research.

**Shared Experience of Collaboration**

In the current study, participants described their shared experiences of collaboration, including experiences of successful collaboration as well as instances in which collaboration was difficult or failed to succeed. Specifically, they used adjectives that pointed to their shared orientation to the positive aspects of collaboration (e.g., “wonderful,” “a celebration”), the difficult aspects of successful collaboration (e.g., “tough”), and the shared experiences of barriers to collaboration (e.g., time wasted, sense of dishonesty, disappointment). By sharing in collaborative experiences, participants were able to approach their roles, build upon driving elements, and orient themselves to time in a shared manner, enabling productive collaboration. Although no similar experiential elements were identified in extant literature, researchers have pointed to the ability of shared discourse to diminish medical dominance and equalize power relationships among providers from a theoretical perspective (Haddara & Lingard, 2013). In the current study, shared experiential elements can be conceptualized as a form of shared discourse that enabled team members to engage in collaboration characterized by equal relationships. That is, each team member experienced collaboration as a team member, rather than as a separate entity (e.g., a caregiver, a young adult, a provider).
Collaboration in the Context of Time

Finally, when describing their experiences with collaboration, participants described an overarching element of time pervading all role elements and driving elements. First, caregivers and providers described their longstanding experiences with coordinating care, operating within systems of service delivery, and adopting efforts informed by the young adults’ needs and goals. In addition, they noted learning valuable lessons based on reflecting on their past experiences, including positive experiences and barriers they overcame. Second, caregivers and providers indicated an openness to the present, including accepting the young adults’ present needs, accepting their own lives, letting go of the past, choosing actions based on the present, revising visions and goals as needed, and accepting the time that reality assumes. Team members worked together in a cohesive manner by opening themselves to their shared present realities. Third, caregivers and providers described a general orientation to the future, including activating foresight to plan services early in the young adults’ lives and to plan for a time when caregivers or providers are no longer able to coordinate services for the young adult. In addition, caregivers and providers noted the importance of orienting themselves to and celebrating the progress of the young adults when thinking about the future.

This domain primarily expands on existing research, although some research in relation to time exists. For instance, in regard to the past, one study examining coordination of care for young children with ASD described the impact of caregivers’ expectations from prior experiences in informing current expectations for intervention services (Auert et al., 2012). In regard to the present and future, Jensen and Spannagel (2011) proposed a model for service use informed by a child’s reaction to and progress from services both in the present and when considering a family’s trajectory of service use. Also in regard to the future, various researchers
have recommended early planning for postsecondary transitions from high school, such as beginning planning at least three to four years before the adolescent leaves high school (Chappel & Sommers, 2010; Lee & Carter, 2012). Similarly, findings from the present study point to caregivers’ consideration of growth and development as a result of both previous and current service use, as well as caregivers’ foresight prior to the young adults’ transition to adulthood.

Although some existing research points to time elements when coordinating services, time elements emerged as a major theme in the present study. Specifically, time emerged as a fluid and pervasive element within collaboration for transition-age young adults with ASD, impacting all efforts of the collaborative teams. The significance of the passage of time likely was exacerbated by the nature of the transition faced by the caregivers and young adults, particularly in relation to feelings of uncertainty and worry that can accompany the transition (Cheak-Zamora et al., 2015; Dyke et al., 2015; Newsome, 2000). That is, the transition period to adulthood likely sets the occasion for active reflection and newfound consideration of present realities and future visions and hope. Overall, findings indicate that collaborative experiences in this time period cannot be discussed without consideration of where team members have been, where they are in the present moment, and where they are looking to go in the future.

**Overarching Models for Collaboration**

An overarching model describing the shared, lived experience of collaborative service delivery for transition-age young adults with ASD emerged from the study. This model incorporates the perspectives of caregivers, young adults, and providers comprising collaborative teams, and the model was consistent for members within teams and across teams. It both builds and expands upon existing models of collaboration, offering important implications for collaboration surrounding transition-age individuals with ASD.
Collaboration in the Present Study: Roles, Driving Elements, and Time

The model emerging from the present study is fluid in nature with role elements, driving elements, and time elements impacting and informing one another. For instance, a given team member adopts certain roles when collaborating (e.g., a caregiver sets a goal for the young adult and seeks out services based on a vision of what will make attainment of the goal possible). The team member recognizes he or she holds those roles, and other team members recognize those roles in the team members as well as in themselves (e.g., a provider recognizes the caregiver as a goal-setter, the provider voices his or her opinion on services that make attainment of the goal possible, and the provider and caregiver look for the young adults’ opinion). Given his or her role, the team member then engages in certain actions to ensure ongoing collaboration and ongoing maintenance of roles. In tandem, other team members also engage in the actions, contributing to the shared nature of actions (e.g., the caregiver considers the young adults’ strengths and needs when determining what services are appropriate, the caregiver regularly communicates with providers to ensure all team members share the same understanding and goal, team members problem-solve attainment of the goal especially in the face of challenges).

Finally, team members reflect on experiences from the past, view the present in a certain manner, and look to the future to inform their roles or actions (e.g., the caregiver may remember working toward a similar goal in the past and seek out different services based on lessons learned, and the caregiver accepts barriers that arise day-to-day while remaining oriented to the terminal goal). Other team members blend their own unique learning histories, acceptance of reality, and ideas for the future with the given team member through collaboration, such as through use of driving elements (e.g., providers contribute what they have learned and remain open the caregivers’ and young adults’ present realities and future goals, made possible by a
shared understanding and ongoing communication). In this way, the full essence of collaboration is realized for the teams. Overall, the present model reflects collaboration existing within working teams, likely reflecting a phenomenon that would be experienced by teams comprised of various team members collaborating to meet the needs of a young adult with ASD.

**Existing Models for Collaboration**

A number of theoretical models for partnerships and interdisciplinary collaboration are present within existing literature, with similarities and difference to the model emerging from the current study. For example, Brookman-Freeze and Koegel’s (2004) model outlines elements similar in nature to the driving elements emerging from the present study, including shared goals, shared expertise, shared responsibility, an understanding of the family, ongoing problem-solving, and use of a strengths-based approach. Further, Summers and colleagues’ (2005) model focuses on those intangible elements existing between the provider and child and the provider and caregiver (e.g., respect, trust, commitment). Given each model’s focus on two-way partnerships (i.e., caregiver-provider; caregiver-child), additional elements likely emerged in the present study due to consideration of each stakeholder in relation to one another in the context of collaboration (i.e., caregiver-provider-young adult).

Three interdisciplinary models for collaboration relate to the present study. First, Bronstein’s Model for Interdisciplinary Collaboration is a widely cited model for collaboration with the social work literature (Bronstein, 2003; Petri, 2010). In the Bronstein model (2003), elements comprising collaboration include providers’ understanding of each provider’s role, providers’ characteristics or values that inform their roles, providers’ education of one another in terms of appropriate goals and tasks, providers’ ability to work in an interdependent manner,
providers’ respect of one another, providers’ flexibility in collaboration, providers’ shared ownership of goals, structural and systemic factors in place supporting collaboration, and providers’ reflection on and growth from lessons learned in collaboration. Similar to the current study, the Bronstein model broadly highlights a number of role elements, driving elements, and time elements that inform interdisciplinary collaboration. However, Bronstein’s model views elements in terms of elements either internal or external to teams, as opposed to the proposed model for the present study which considers elements as intertwined. Further, Bronstein only considered elements specific to collaboration between providers, rather than in relation to elements shared among providers, caregivers, and individuals with ASD. Overall, the proposed model in the current study demonstrates an application of some elements common to Bronstein’s model but as applied to collaborative teams surrounding transition-age young adults with ASD.

Second, the Medical Home Model is a widely cited model for collaboration throughout medical service delivery (AAP, 2002; Russa et al., 2015). The Medical Home Model largely implicates multiple providers working to ensure families’ and children’s needs exist as the center of collaborative efforts (AAP, 2002; Gabovitch & Curtin, 2009). This model for collaboration is related to the present study, in that both models arguably target individuals with complex needs entrenched in multiple systems of care. Further, both the Medical Home Model and the present study point to the importance of a shared understanding of the child and caregiver existing at the center of collaborative efforts. However, unlike the Medical Home Model, the present study details role elements, other driving elements, and time elements that inform collaborative service delivery, and by demonstrating applicability of a shared understanding for collaborative service delivery for young adults with ASD. In turn, the present model might inform serviced delivered
within the Medical Home Model, especially when considering complex medical needs of adolescents and young adults with ASD who will be transitioning to adulthood.

Third, a model for interprofessional collaboration based on existing literature includes Careau and colleagues’ Continuum of Interprofessional Collaborative Practice in Health and Social Care (2015). In their model, Careau and colleagues highlight elements related to incorporation of families’ and children’s needs, changes in roles and services based on changing needs, response to changes in a flexible manner, formation of authentic relationships, the role of providers as experts and information-sharers, and factors that impact providers’ interdependence versus independence (2015). Thus, this model points to certain elements that are similar to role elements (i.e., educators), driving elements (i.e., shared understanding, flexibility and problem-solving), and time elements (i.e., the present) in the current study. However, the current study extends on their model by considering the perspectives of caregivers, providers, and individuals with ASD, beyond just the perspectives of providers. Further, the current model points to additional elements of collaboration, likely a product of multiple perspectives and the specific nature of collaboration for young adults with ASD. Overall, the current model relates to and extends on existing models for collaboration in a number of ways, particularly in relation to extensions surrounding collaboration for transition-age young adults with ASD.

**Findings in Relation to the Theoretical Framework**

The framework for the present study is broadly based on Bronfenbrenner’s ecological systems model and conceptualizes families as dynamic systems that operate bi-directionally to their environmental systems (Cox & Paley, 1997). In addition, the framework offers direct implications for families that include a child with a disability and for families accessing support services, such as the families participating in the current study. Finally, the model can be
broadly applied to consider collaborative practices to best meet the needs of families, particularly those families with a child with a disability. Study findings are discussed in relation to each of these aspects below.

**Bronfenbrenner’s Ecological Systems Model**

Broadly, findings from the study directly align with Bronfenbrenner’s wider ecological systems model (1979). Emerging findings explicate the systems in which all participants operate, with system variables influencing participants’ experiences and responses. For instance, for a given caregiver, findings directly linked the caregiver to his or her young adult child and to the young adult’s providers (i.e., microsystem) while also considering the relation between the young adult child and his or her providers (i.e., mesosystem). The caregiver described his or her experiences in relation to local organizations, available social or vocational supports, and available transportation (i.e., exosystem). Further, the caregiver described the impact of policies, educational systems, adult systems, his or her beliefs about age-appropriateness of goal-setting, and his or her unique learning history on collaboration, as well as his or her current expectations for, practices of, and experiences with collaboration (i.e., macrosystem). Finally, the caregiver referenced the pervasive nature of time when considering his or her experiences and acknowledged changes in services and his or her own expectations with passing time (i.e., the chronosystem). All participants referenced these factors to some degree. In addition, study findings also implicate historical structures and other cultural, religious, and philosophical structures that provide a foundation for participants’ experiences with collaboration.

**Family Systems Framework**

Variables related to the family unit, particularly in relation to the impact of the young adult with ASD on the family, informed emerging experiences and findings. In line with the
family systems framework, the family unit emerged as a key variable to consider in light of collaborative practices (e.g., Davies & Cicchetti, 2004). Specifically, caregivers and young adults with ASD operated as family units in relation to providers and broader systems of care to access services to meet the young adults’ and families’ needs. The needs of the family units changed with the transition of the young adults with ASD to adulthood, causing a shift in the structure of the units. This shift could be understood in relation to the internal and external subsystems within and around the units (Cox & Paley, 1997; Cridland et al., 2014; Davies & Cicchetti, 2004). For example, the young adults assumed an active role in collaborating to coordinate services and establishing goals, shifting the internal subsystems. In regard to external subsystems, unique driving elements and barriers emerged to collaboration during this time period, given the complex needs of young adults with ASD transitioning to adulthood. Ultimately, shifts in the family units and subsystems drove hope for the young adults, access to services, achievement of collaboration, development of skills for the young adults, and the functioning of the families.

In line with proposed applications to service delivery (e.g., Powers, 1991) and a family systems intervention model (Dunst et al., 1998; Dunst & Trivette, 2009; Trivette et al., 2010), findings from the current study offer implications for collaborative service delivery in light of the broader family systems framework. In the current study, collaboration and access to services directly impacted caregivers and young adults within family units. When collaborating to coordinate services, team members broadly considered family’s needs, values, abilities, visions, goals, hope, and any barriers that existed (Powers, 1991). In this way, caregivers and young adults were connected to services appropriately targeting family’s needs in light of the broader systems of their lives. In addition, providers and families worked together to achieve balanced
power and open lines of communication when collaborating together, seeking to achieve
homeostasis across systems for the young adults (Fine, 1985; Wehman, 1998). Finally, although
outcomes were not directly assessed, team members voiced hope, access to support systems,
education and empowerment of one another, and future aspirations that point to positive
outcomes from collaboration and service delivery, particularly for the young adults with ASD
(e.g., Dunst et al., 2009; Morgan, 1988; Powers, 1991).

Limitations

Several limitations existed in the present study and serve as areas to target in future
research. First, the present study included young adult males with ASD (i.e., ages 18 to 25)
rather than sampling experiences across transition-age individuals with ASD (i.e., ages 14 to 25)
or across gender. Experiences might be different for younger adolescents (e.g., ages 14 to 18)
early in the postsecondary transition process or for females, offering additional or differing
insights from those emerging in the present study. Second, the present study highlighted the
experiences of families that were purposefully selected for their connection to resources and
relative success with collaboration. Incorporation of families of various socioeconomic and
cultural backgrounds with varying levels of access to resources and support networks would
likely provide information regarding experiences beyond those discussed in this study. While
this study focused on successful collaborative teams in order to identify promising practices, a
corollary study examining less successful collaborative teams might add to our understanding of
factors that foster and interfere with effective practice.

Third, although participants implicated wider societal, political, economic, and cultural
factors impacting their experiences with collaboration, the present study did not directly assess
these factors. Participants’ perceptions of broader societal systems impacting their experiences
would like to provide a more nuanced understanding of their present experiences, and offer wide implications for policy and practice. Fourth, the present study did not explore perceived outcomes from collaboration, given that participants were entrenched in the process of collaboration at the time of participation. Assessment of outcomes from collaboration would like point to the relationship between experiences and outcomes, informing practice.

**Implications for Future Research**

Given extant literature, study findings, and study limitations, a number of important areas exist for future research. First, future research should incorporate the perspectives of collaborative teams coordinating services for adolescents and young adults of varying ages and for adolescents and young adults with varying medical and psychiatric needs. In this way, future studies can highlight the nature of service use for individuals at various stages of development as well as for individuals presenting with varied, complex needs (e.g., Taylor & Henninger, 2015).

Second, future studies should incorporate families of varying socioeconomic and cultural backgrounds. As related to Trivette and colleagues’ family systems intervention model (2010), studies should seek to identify those families most in need of services, using collaboration as a framework to connect families to services.

Third, future studies should clarify and test models of collaboration to more closely highlight practice recommendations based on real-life experiences of collaborative teams for individuals with ASD. In line with recommendations from prior research, the need exists to clarify terms used when referring to collaboration (e.g., Perreault & Careau, 2012) and to operationalize collaboration across settings and teams (e.g., Careau et al., 2015). The present study used the term collaboration to refer to service coordination between caregivers, providers, and young adults with ASD, providing one example of a way to conceptualize collaboration...
surrounding this time period. Fourth, although the present study elicited some perceptions of progress through collaboration, future research should further examine processes to assess for progress through collaboration and to gauge outcomes from collaboration. Existing research highlights positive outcomes that can result from collaboration (e.g., Bezdek et al., 2010; Bronstein, 2003; Cooper et al., 2016; Hendricks & Wehman, 2009; Noonan et al., 2008; Petri, 2010). However, studies should seek to specifically link desired outcomes to collaborative practices, and to examine the nature of outcomes using longitudinal designs.

Finally, a broad, overarching need for research examining experiences with collaboration for postsecondary transition-age individuals with ASD continues to exist. Despite numerous writings regarding recommendations for collaborative practice in general, a paucity of research exists to understand collaboration practices in this time period. Future research should continue examining team members’ experiences, challenges, needs, and strengths, while incorporating the views of adolescents and young adults with ASD. As described in previous research (e.g., Dyke et al., 2015), this type of research offers critically important implications for practice, with the potential to improve life outcomes for individuals with ASD. Once a sufficient understanding of factors that promote successful collaboration is established, large quantitative studies should be conducted to further evaluate practices linked to outcomes for adults with ASD.

**Implications for Future Practice**

Based on study findings, a number of implications exist for future practice. First, study findings point to important practices to leverage prior to the transition of individuals with ASD out of high school. If service providers take concerted efforts prior to the transition period to facilitate the roles of caregivers and adolescents with ASD on collaborative teams, develop in-depth understandings of families, engage caregivers and adolescents in goal-setting and planning
for service use and goal-setting, agree on communicative strategies to utilize with families and other providers, engage in ongoing problem-solving, and push families to think ahead about plans, then teams are likely to be successful in collaborating to promote outcomes for young adults. In order to achieve these goals, organizations could adopt specific practices to facilitate open communication between providers and families, allocate time to collaborative teaming between families and providers as well as between providers, and facilitate discussion about families’ strengths, needs, values, and goals. Further, providers could hold workshops or trainings for families to disseminate information and inform families of their roles in collaboration. With these practices, providers can overcome their own professional limitations and efficiently deliver services to families in a responsive manner, consistent with previous research (e.g., Cooper et al., 2016; O’Reilly et al., 2014; Siklos & Kern, 2006).

If caregivers actively participate on collaborative teams, communicate about their needs and goals, educate providers about their children, engage in ongoing communication with providers, develop reciprocal understandings of providers, and take active steps to facilitate adolescents’ involvement on collaborative teams prior to the transition out of high school, then teams are likely to be successful in collaborating to promote outcomes for young adults. Further, if caregivers reflect on past experiences and open themselves to the possibilities for their children with ASD, while remaining open to day-to-day challenges that might present themselves through collaboration and the transition period, then collaboration is likely to be facilitated. To promote these roles and processes, community organizations and schools might hold workshops to inform caregivers of their roles and best practices, ensuring appropriate dissemination of information to caregivers. In this way, caregivers can develop appropriate plans early for their children with ASD, with the potential to overcome barriers, alleviate stress, and promote young adult outcomes.
for their children (e.g., Chappel & Sommers, 2010; Hendricks & Wehman, 2009; Lee & Carter, 2012; Noonan et al., 2008).

For individuals with ASD, preliminary research suggests the critical need for including adolescents or young adults with ASD on collaborative teams. However, the present study points to the key roles of young adults on collaborative teams as leaders, decision-makers, and information-providers, as well as strategies to facilitate adolescents’ or young adults’ voices on teams. In practice, caregivers and providers should determine the best means for young adults to express their own needs and goals, allowing the young adults to express themselves on teams. Further, young adults should actively participate in planning processes, with appropriate accommodations and procedures utilized to place the young adult at the center of planning efforts. Finally, the strengths and progress of young adults with ASD should be celebrated in the context of collaboration and postsecondary transitions, allowing the individuals with ASD to celebrate their own roles and progress from collaboration. In this way, practices can alleviate stressors for young adults and give them the skills to advocate throughout the future (Chappel & Sommers, 2010; Lee & Carter, 2012).

In addition, study findings support broader implications for policies and adult services for individuals with ASD. Overall, the study highlights the critical role of collaboration in addressing the potential medical, psychiatric, and adult living needs of the 1 in 59 children transitioning into adulthood in the next decade in a coordinated manner (CDC, 2018; Doshi-Velez et al., 2014; Pringle et al., 2012). Specifically, elements of collaboration emerging from the study offer promise for addressing demands placed on adult systems of service delivery by connecting families to appropriate services early, facilitating outcomes for young adults with ASD, and streamlining practice for providers (Ganz, 2007; Moodie-Dyer et al., 2014; Shattuck et
Further, study findings point to policy implications regarding family-centered, coordinated, and responsive service delivery, both for pre-transition-age adolescents as well as adults with ASD (e.g., Lubetsky et al., 2014). While there remains a critical need for additional research and examination of practice, findings from this study offer practical recommendations to improve current practice and promote achievement of the ‘good life’ for adults with ASD (Dyke et al., 2015).
APPENDIX A
DEMOGRAPHIC QUESTIONNAIRES, BY PARTICIPANT TYPE

Caregivers:

1. What is your relationship to the young adult? (i.e., parent, grandparent, etc.)
   ____________________________________________________________

2. What is your age? ________________________________

3. How would you describe your ethnicity/race? ___________________________________

4. What is the highest level of education you have achieved? ______________________

5. What is your employment status? ______________________________________

6. How would you describe your family’s socioeconomic status? (Circle one)
   Lower Class   Lower Middle Class   Middle Class
   Upper Middle Class   Upper class

7. What is your current marriage status? _________________________________

8. How many children are in your family and what are their ages?
   ____________________________________________________________

Please answer the following questions about your child:

1. Gender? ________________________________

2. Age? ________________________________

3. Ethnicity/race? ________________________________

4. Grade? ________________________________

5. Diploma track? ________________________________

6. Does your child receive ESE services or 504 accommodations? __________________

7. Disability classification(s):
   a. Primary: ________________________________________________

217
b. Secondary: ____________________________________________________________

c. Who provided these diagnoses? ________________________________________

8. Has your family begun formal transition planning services with the school? Yes No

9. Does your child participate in these meetings? Yes No

10. For services your child receives **in school**, please check off services he/she currently receives, please list for how long, and please check off whether your child has ever received these services.

<table>
<thead>
<tr>
<th>Service</th>
<th>Currently Receive? (Check if yes)</th>
<th>How long? (List)</th>
<th>Ever received? (Check if yes)</th>
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</thead>
<tbody>
<tr>
<td>Speech/language therapy</td>
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<tr>
<td>Occupational therapy</td>
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<tr>
<td>Physical therapy</td>
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<tr>
<td>Behavioral therapy</td>
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<tr>
<td>Counseling</td>
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<tr>
<td>Vocational rehabilitation</td>
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<tr>
<td>Assistive technology</td>
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<tr>
<td>Other:</td>
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<tr>
<td>Other:</td>
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</tbody>
</table>

11. For services your child receives **outside of school**, please check off services he/she currently receives, please list for how long, and please check off whether your child has ever received these services.

<table>
<thead>
<tr>
<th>Service</th>
<th>Currently Receive? (Check if yes)</th>
<th>How long? (List)</th>
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<tr>
<td>Assistive technology</td>
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<tr>
<td>Pediatrician</td>
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</table>
12. For the following items, please place a check mark in the box (1 to 4) that best describes each statement.

<table>
<thead>
<tr>
<th></th>
<th>1: Rarely to never</th>
<th>2: Sometimes</th>
<th>3: Often</th>
<th>4: Almost Always</th>
</tr>
</thead>
<tbody>
<tr>
<td>How often do you collaborate with your child’s providers <strong>currently</strong>?</td>
<td></td>
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</tr>
<tr>
<td>How often have you collaborated with your child’s providers <strong>over his/her lifetime</strong>?</td>
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<tr>
<td>How often do your child’s providers work together <strong>currently</strong>?</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>How often have your child’s providers worked together <strong>over his/her lifetime</strong>?</td>
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<td></td>
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<tr>
<td>How often does your child participate in planning <strong>currently</strong>?</td>
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<td></td>
<td></td>
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</tr>
<tr>
<td>How often has your child participated in planning <strong>over his/her lifetime</strong>?</td>
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</tr>
</tbody>
</table>
For service providers:

1. What is your job title? ____________________________________________________

2. What is the highest level of education you have achieved? ____________________

3. What is your age? ________________________________________________________

4. How would you describe your ethnicity/race? ________________________________

5. Describe the current settings in which you work:
_______________________________________________________________________

6. Describe the types of services you provide:
_______________________________________________________________________

7. What is your current caseload size: _______________________________________

8. How many years have you worked in this field? _____________________________

9. How long have you worked with this family? ________________________________

10. Please check off any types of service providers with whom you collaborate currently to meet the family’s needs and please list for how long you have collaborated.

<table>
<thead>
<tr>
<th>Service</th>
<th>Currently Collaborate? (Check if yes)</th>
<th>How long? (List)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Speech/language therapy</td>
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<tr>
<td>Occupational therapy</td>
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<tr>
<td>Pediatrician</td>
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<tr>
<td>Personal care assistant</td>
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<tr>
<td>Other:</td>
<td></td>
<td></td>
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<tr>
<td>Other:</td>
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</tbody>
</table>

11. For the following items, please place a check mark in the box (1 to 4) that best describes each statement.
<table>
<thead>
<tr>
<th>Question</th>
<th>1: Rarely to never</th>
<th>2: Sometimes</th>
<th>3: Often</th>
<th>4: Almost Always</th>
</tr>
</thead>
<tbody>
<tr>
<td>How often do you collaborate with <em>this family</em>?</td>
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<tr>
<td>How often do you generally collaborate with <em>other families</em>?</td>
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</tr>
<tr>
<td>How often do you collaborate with <em>this family's</em> other providers?</td>
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</tr>
<tr>
<td>How often do you generally collaborate with providers of <em>other families</em>?</td>
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</tr>
<tr>
<td>How often does the <em>child in this family</em> participate in planning services?</td>
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<tr>
<td>How often do <em>children in other families</em> generally participate in planning?</td>
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</tbody>
</table>
APPENDIX B
SAMPLE INTERVIEW GUIDES, BY PARTICIPANT TYPE

Caregivers:
1. Tell me about yourself.
   a. Tell me about (name of the young adult).
   b. Tell me about the service providers working with (name) currently.
2. How long has (name) worked with each of these providers?
3. What skills is (name) working on currently?
   a. Any particular skill you are focusing on at the moment?
4. Tell me about your current relationship with (name)’s providers.
   a. How was your relationship when you first started working with those providers?
   b. Is this similar to your relationships with (name)’s providers throughout his/her entire life?
5. Tell me about (name)’s provider’s relationships with one another?
   a. How long have they interacted?
   b. What does this interaction look like?
   c. What is your role in this interaction?
6. Describe to me the process by which you and (name)’s providers plan for services together?
   a. Make decisions/changes?
   b. Describe (name)’s role in this planning, if any.
7. Tell me about a time working with the providers went really well.
   a. Thoughts/feelings you had?
   b. Actions you took?
8. Tell me about a time working with the providers did not go well.
   a. Thoughts/feelings you had?
   b. Actions you took?
9. What factors helped you build positive relationships with the providers?
   a. Have these helped you in relationships with other providers?
10. What factors stood in the way of building positive relationships with providers?
    a. Have these stood in the way of relationships with other providers?
11. How would you describe ‘progress’ – i.e., tell me what it means for (name) to make progress toward his/her goals?
    a. Thoughts/feelings you have about this?
    b. Actions you take as part of your relationship with providers to facilitate this?
    c. How does this look compared to outcomes you hope for (name) to achieve?
12. What advice would you give to caregivers seeking to coordinate services like you?
    a. Providers seeking to coordinate services with caregivers?
    b. Young adults seeking to be part of this planning process?
13. Do you have any additional comments you would like to share?
Service providers:
1. Tell me about yourself.
   a. Tell me about (name of the young adult).
   b. Tell me about (name)’s caregivers.
2. How long have you worked with (name)?
3. What skills is (name) working on currently?
   a. Any particular skill you are focusing on at the moment?
4. Tell me about your current relationship with (name) and his/her caregivers.
   a. How was your relationship when you first started working with them?
   b. Is this similar to your relationships with other clients and their families?
5. Tell me about your relationship with any other of (name)’s providers?
   a. How long have you interacted with them?
   b. What does this interaction look like?
   c. How was your relationship when you first started working with them?
   d. Is this similar to your relationships with providers of other clients?
6. Describe to me the process by which you, (name)’s caregivers, and (name)’s providers plan for services together?
   a. Make decisions/changes?
   b. Describe (name)’s role in this planning, if any.
7. Tell me about a time working with (name)’s caregivers or other providers went really well.
   a. Thoughts/feelings you had?
   b. Actions you took?
8. Tell me about a time working with (name)’s caregivers or other providers did not go well.
   a. Thoughts/feelings you had?
   b. Actions you took?
9. What factors helped you build positive relationships with the caregivers/providers?
   a. Have these helped you in relationships with other caregivers/providers?
10. What factors stood in the way of building positive relationships with caregivers/providers?
    a. Have these stood in the way of relationships with other caregivers/providers?
11. How would you describe ‘progress’ – i.e., tell me what it means for (name) to make progress toward his/her goals?
    a. Thoughts/feelings you have about this?
    b. Actions you take as part of your relationship with providers to facilitate this?
    c. How does this look compared to outcomes you hope for (name) to achieve?
12. What advice would you give to providers seeking to coordinate services like you?
    a. Caregivers seeking to coordinate services with providers?
    b. Young adults seeking to be part of this planning process?
13. Do you have any additional comments you would like to share?
**Young Adults:**

1. Tell me about yourself.
   
   a. *Alternate probes: What is your name? How old are you? What do you like to do for fun?*
   
   b. Tell me about [name for caregivers].
   
   c. Tell me about [name for service providers].

2. How long have you known [name for service providers]?

3. What kind of things do you work on with [name for service providers]?
   
   a. *Alternate probe: Your (name of caregiver) told me you work on (name of skill). How is that?*

4. How do you and [name of service providers] get along?
   
   a. What helps you get along?
   
   b. What gets in the way?
   
   c. Has it always been that way?
   
   d. Is this that the same as [name for other service providers]?

5. How does your [name of caregivers] get along with [name for service providers]?
   
   a. *Alternate probe: Do you see them talk to each other?*
   
   b. Has it always been that way?

6. Do you help decide what you want to work on with [name for service providers]?
   
   a. *Alternate probe: I hear you work on (name of skill). Did you decide to work on that?*
   
   b. What kinds of things?
   
   c. Have you ever tried to change what you were working on? How did that go?
   
   d. Did [name for caregivers] help you decide that? What about [name for service providers]?

7. Tell me about a time you helped decide what you would work on with [name for service providers].
   
   a. What did you do to make this happen?
   
   b. What were you thinking while this happened?
   
   c. What were you feeling while this happened?

8. Tell me about a time that you wanted to work on something but could not.
   
   a. What did you do during this time?
   
   b. What were you thinking during this time?
   
   c. What were you feeling during this time?

9. What are your future goals?
   
   a. *Alternate probe: what do you want to do in a few years? I hear you want to do (name of goal), tell me about that?*
   
   b. Have you gotten closer to your goals since you started working with [name for service providers]?
   
   c. What have you done to make this happen?
   
   d. What do you think about this?
   
   e. How do you feel about this?

10. As part of this study, I am hoping to help out other students like you. Any advice you would give to them?
    
    a. What about other [name for caregivers]?
    
    b. What about other [name for service providers]?

11. Anything else you would like to add?
APPENDIX C
SAMPLE REFLECTIONS AND REACTIONS TO INTERVIEWS

Study team 1
Reactions to caregiver interview 1:
- Mom is very in the know in terms of knowledge
  - Mom as an advocate - emphasizes point of getting other caregiver’s in-the-know
  - Need for other caregivers to be in the know as well
- Notes everything is son’s choice and formulated around his desires
  - Mom’s own actions facilitate this
  - Providers give assistance and reminders
  - Sense that mom values this both for herself and him
  - Activate motherly insight – step in as needed
  - Centered on belief he can do anything – and if doesn’t work the first time, try something else
- Seems to have established strong relationships with providers
  - Common objectives
  - Lists a number of facilitators (openness, respect, warmth, patience, listener, realistic goals, etc.)
- Tackles barriers as pop up (e.g., can’t meet GED requirements; needs change into puberty; can’t get certain kinds of careers)
  - Some related to ASD symptomology and co-morbid concerns
  - Barrier of time with providers
  - But make necessary adaptations; driven by flexibility
- Mom really in-control as far as getting people on same page to meet son’s needs
- Described providers/activities they facilitate in certain ways (e.g., helpful, nice, ‘cool’)
- Describe relationship in certain ways: e.g., family-like
  - Son’s characteristics bring them together
- Relat between son and providers also based on son’s char’s/mutual respect
- Day-to-day life highlights the true needs/barriers to target/overcome
- Frame a lot of examples in past vs. present – life flexibility, forming ‘the business’
- Frame son’s life as a business
  - Mom views self as just one piece (although the CEO)
  - Mom also the oil between the parts (although noted ‘loves’ when providers are self-directed)
  - External providers as advisors
  - Careful selection of providers as key
- Share responsibilities with providers
  - Shared responsibilities integrated in daily life
  - See providers as integral piece of the puzzle
  - Invite feedback and ongoing communication drive this
  - Also facil of proximity, co-worker
- Look outwards for support – e.g., community, Medicaid Waiver, other parents
- Communication between providers:
  - Facils (for CGs): value one another, communicate, formalized method (journal)
  - Mom facilitates role clarity
Mom experiences as ‘beautiful’, great, loves it
- Framed in negative exemplars seen in the past
- Some relationships as delicate so don’t push it

- Variety of types of goals, informed by the past and present
  - Comparisons to what would be expected to an individual of his age ➔ also plays into mom’s role
  - Also framed in foresight that mom not around forever

- Many elements to describe progress:
  - Think of in terms of life history and future
  - Slow; encounter setbacks
  - Requires flexibility
  - Big picture as the CEO
  - Providers see the parts they are involved with but that involvement is key to their buy in
  - Experience together as excitement, celebration

- *good at giving lots of examples
- *struck by fact that this is a mom who works 10-12 hour days, then describes daily life difficulties (e.g., son doesn’t sleep) yet still facilitating all this
- *pervasive theme of flexibility – e.g., plans change, goals changes, barriers pop up, life examples help you reframe
- *metaphors of life as a business and collaboration as a puzzle
- *stories/examples/descriptions all very much grounded in past to frame the now; also always considering in context of the future/element of foresight

Study team 2
Reactions to caregiver interview 1:
- Mom as advocate for her sons and disability community in general
  - Very in the know, knows people
  - *Consistent theme of her professional knowledge
  - Use knowledge to inform goals and types of supports to use
  - Facilitates own opportunities/opens doors
  - Pursue further education to activate more types of knowledge
  - Element of longevity of applying knowledge
  - Watches out for others

- Work with providers surrounds child’s needs, child’s desires
  - Get everyone on same page whether like it or not
  - Compare to what seen in the past
  - Recognize that it takes a village – no one has all the answers
  - Blending of roles
  - Shared need to react to needs that pop up
  - Collaboration as ‘the only way to fly’

- Mom as the leader of the team/coordinator of care, enforcer of rules for son, sharer of knowledge
  - School communicates the issues/information-sharers
• Role release to caretaker
  o Mom as mediator and interpreter based on insider knowledge of son; sets him up for success
  o Providers as future fillers of mom’s role
• Consistent element of always comparing child to TD peers – e.g., goals, day to day life, how talk to him, how let relate to siblings
  o Let child take the reigns
  o Form goals based on them; even if don’t always agree
  o Role of observation and insider knowledge in understanding his interests/desires
  o High expectations
• Mom as continuing to learn from and grow with sons
  o Reflection of her life as amazing yet difficult
  o Excitement for him as he ages
• Describe providers in certain ways (e.g., ‘blessing’)
  o Characteristics of providers relationship with son: affection, respect, longevity of relationship
  o Characteristics of her relationships with providers (when ‘good’): story-telling, retrospection, laughter, sharing, trust, respect, shared problem-solving, open communication/solicit input, information-sharing, kindness, know where parents are coming from
  o Characteristics of her relationships with providers (when ‘not good’): *different goals/beliefs/expectations in what is important – really based in age appropriateness; lack of communication; one perceiving they are expert over another
  o Facilitator: hold son at the center, purposefully choose, understanding of need for generalization, form goals based on needs, son’s characteristics, seen the benefits, recognize own limitations, ‘careful’ process; kindness/compassion
  o Expectation from day one; open doors; only way to avoid barriers
  o Element of time – it takes time
• Role of child: ask for/seek out help
• Role of formal external supports
• Barrier: financial, attention to other child, mom’s health, children’s symptomologies, resources (for providers)
  o Tackle and overcome
  o Element of flexibility
  o Element of suddenness in some cases
  o Experience as ‘annoying’; ‘frustration’ (different goals); ‘tough’ (lack of collab)
• Comparison to past (where we’ve been) and future (foresight)
  o Emphasizes point of foresight and taking herself out as middleman
  o Alludes to role of retrospect at various points
  o Current: certain barriers and needs
  o Sense of ‘realness’ (this is how it is)
  o Know when to move on
• Certain openness to whatever the outcomes might be, but while holding high expectations
• Element of comparison to other families and individuals with ASD
  o Helps frame goal and what see as own role in mom-child relationship
Progress
  • Compare to life history; hold on to goals from the past
  • Goals as impetus for forward movement – especially in sharing/collaboration
  • High expectations that they work towards
  • Add things on systematically as make progress – start small and move forward; terminal goal is the whole and son’s own control
  • Encounter setbacks as arise – okay if don’t reach goal at first
  • Progress as ‘awesome’
  • Doing ‘fine’ as acceptable
  • Open eyes to ‘see’ progress
  • Work toward ongoing expectation of TD

*Mom is a fighter
*Strong emphasis on behavioral examples
*Multiple children and life barriers but making it work
*Lots of reference to the past and where they’ve been
*Huge believer in person first, maybe I don’t agree with what you want to do but you are your own person
*Sense that she really understands her sons and what makes them click
*Brings up issue of race

Study team 3
Reactions to caregiver 1 & 2 interviews:
• Frame description of son in terms of past development/growth
• Longstanding nature of general positive experiences
  • Also in terms of son’s strengths/characteristics over lifetime
  • More available then than now
• No real negative experiences, just lack of resources
  • When describe barriers: miscommunication, lack of honesty, financial/HR on part of school, novelty of dx, don’t fully understand son, lack of understanding of parents’ goals
  • Experience as frustration
  • Some disconnect between what he’s capable of at home vs. in school
  • Parents note their role was the same – open, trusting
• Facilitators
  • Providers: openness, receptiveness, informative, interpersonal skills, genuine interest, above and beyond, committed, sensitive, caring, honesty
  • Parents: committed, take steps to facilitate opportunities
  • Child: good-natured, easy-going, friendly, thoughtful
• Experience collaboration as helpful and friendly
• Parental knowledge of son’s strengths/needs/what works for him
  • Use as impetus to move forward
  • Child trusts that parents doing the best for him
• Son’s desires as driving forces
  • Changed action plan when he changed his desire
- See his goals as fantastic or awesome
- Importance of advocacy, patience, kindness when can

- Hold high expectations for son
  - Sense of sadness/disapproval that he’s not challenged
  - Set high and okay if not totally achieved
  - Hold on to hope

- Role of providers: informants, advice-givers, organizers, facilitators, helpers
- Role of parents: facilitators of goal achievement, information sharers between parties
- Role of child: attendee, taker-in of information, provider of information
- Encountering setbacks and continuing to move forward
  - Stop services if not needed
- Long-term goals as driving forces
  - Think of needs in terms of future goals/plans

- Element of looking to others
  - What seen available for other ESE students
  - Improvements help all students
  - Connection to neurotypical peers

- Sense of uncertainty in the future – lack of resources, a grey area
  - But keep trying things, pushing forward

- Progress:
  - More tangible, ‘real-life’ linked goals vs specific academic areas
  - Also building of non-tangible life skills – e.g., confidence, pride, motivation
  - Determine goal in light of biggest area of need (communication)
  - Success defined in movement toward goal
  - Slow/non-existent in some areas
  - Celebrate when makes progress

- *Seemed much more in the moment/thick of things vs. other two more retrospective (both in thinking about the past and looking forward)
- *Seemed less like ‘fighters’ than previous 2 – not to say they aren’t actively pursuing options for their child just less of a headstrong feel
- *Closer-knit relationships in the past, now more informants
APPENDIX D
INTERVIEW PROMPTS BASED ON SELF-REFLECTION

Reminders:
- Gather narratives, anecdotes, stories, and examples of a lived experience
- Descriptions should delineate details of the experience as the individual lived it, rather than capturing the individual’s own interpretations of the experience
- Garner an understanding of the nature and meaning of the experience of interest, free from reflection
- Work to uncover pure descriptions; experiences are transformed when language is attributed to an experience or an individual attempts to recollect an experience
- Remind the participant to avoid causal explanations, generalizations, abstract interpretations, and use of idioms or other flowery language
- Revisit my own experiences so as not to color the phenomenon
- Guiding questions: “What have you experienced in terms of the phenomenon?” and “What contexts or situations have typically influenced or affected your experiences of the phenomenon?”
- Continue to gather natural descriptions and stories until data saturated
APPENDIX E
FLOWCHART OF DATA ANALYSIS PROCESS

Journaling and reflection on Interviews and transcripts; revisit beliefs, biases, assumptions

Reduction process: Phase 1

Reduction process: Phase 2

Horizontalization  Peer review
Imaginative variation  Reflection

Production of written descriptions

Peer review  Reflection
### APPENDIX F

**SAMPLE OF REDUCTION PROCESS**

<table>
<thead>
<tr>
<th>Page</th>
<th>Text</th>
</tr>
</thead>
<tbody>
<tr>
<td>387</td>
<td>C1: And so I didn’t know he liked gardening until he went last time and he really enjoyed it.</td>
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<tr>
<td>388</td>
<td>(Voice of professor) and I were talking about maybe having him taking some classes in graphics.</td>
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<tr>
<td>389</td>
<td>The problem with that is that I can’t get him in, I can’t just get him in to a graphic art class. The degree is so, it’s like, oh my god, you almost have to be a doctor to get this degree, but all</td>
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<tr>
<td>390</td>
<td>much in there… Anyway, you know he can’t get that, you just want him to audit a class. Umm he</td>
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<tr>
<td>391</td>
<td>auditioned once a couple of years ago and it was during the summer and the professor had no idea, it</td>
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<tr>
<td>392</td>
<td>was online, and they have no idea who they’re dealing with and so it didn’t work out. So</td>
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<tr>
<td>393</td>
<td>we’re trying to think of how we can kind of work on that. Umm as far as life skills, umm that’s</td>
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<td>394</td>
<td>every single day, I just hired a new caregiver and I’m getting ready to take a big trip so I’m just</td>
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<td>395</td>
<td>getting all set up with that but I have spoken to them, and one in particular, when in the</td>
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<td>396</td>
<td>afternoon, umm about working on maybe some cooking skills, so she can help him with some</td>
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<tr>
<td>397</td>
<td>cooking skills. Umm he knows how to do his own laundry… all this has to be facilitated but</td>
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<tr>
<td>398</td>
<td>doesn’t just do it on his own, you have to work with the schedule, and I don’t know if that’s just</td>
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<td>399</td>
<td>being a 25 year old man.</td>
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<td>401</td>
<td>C1: (Laughs). It’s just unse, I don’t know why he won’t do it by himself, because he won’t,</td>
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<tr>
<td>402</td>
<td>(Muffled). If just, everything takes effort, we need to keep on him. It’s the people who, well let me.</td>
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<td>403</td>
<td></td>
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<td>404</td>
<td>EK: (Laughs) Yeah.</td>
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<tr>
<td>405</td>
<td>C1: It’s a 24/7 job. But he knows how to do it, like this morning I said you need to pick up your</td>
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<tr>
<td>406</td>
<td>clothes in the bathroom, his bathroom, because I have to go in and scrub it and so I went in and</td>
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<td>407</td>
<td></td>
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<tr>
<td>408</td>
<td>PI: I mean, most families of kids with significant disabilities need to develop a team to meet their</td>
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<tr>
<td>409</td>
<td>needs. And the futures planning process is a really good way of doing that. Basically you</td>
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<td>410</td>
<td>celebrate the person as a. . . you do it as a party and a celebration of the person.</td>
</tr>
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<td>411</td>
<td>EK: Mmm.</td>
</tr>
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<td>412</td>
<td></td>
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<tr>
<td>413</td>
<td>PI: That and teaching families. Some families are open and willing to reach out to either family</td>
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<tr>
<td>414</td>
<td>members or friends, church members, or even neighbors, or umm… and then these are agency</td>
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<tr>
<td>415</td>
<td>people that are in their lives… professionals. Umm so in the planning process umm what helps is</td>
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<td>416</td>
<td>when families, I think, access and start building a team around their person in transition.</td>
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<td>417</td>
<td>EK: Sure.</td>
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<td>418</td>
<td>PI: And you never know as you do the planning process that they umm, you get and let</td>
</tr>
<tr>
<td>419</td>
<td>you get unexpected outcomes and you do action planning where people start making</td>
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<tr>
<td>420</td>
<td>commitments on what they’re going to help with and what resources they can bring to the</td>
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<tr>
<td>421</td>
<td>person.</td>
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<tr>
<td>422</td>
<td>EK: Mmm.</td>
</tr>
<tr>
<td>423</td>
<td>PI: And so, it’s helping families use sort of this umm process for umm team-building and for</td>
</tr>
</tbody>
</table>
APPENDIX G
SAMPLE OF HORIZONTALIZATION AND IMAGINATIVE VARIATION PROCESSES

Themes

Role codes:
Role of provider
- Procedural descriptors (e.g., what I do, nature of involvement)
- Job descriptors (e.g., facilitator, advisor, guide, educator, informant, one piece, supporter of other providers)
- Characteristics (e.g., initiator, advocate, knowledgeable, connected)

Role of parent
- Job descriptors (e.g., expert, informant, decision-maker, visionary, delegator, connector, leader, facilitator)
- Characteristics (e.g., advocates, go getters, initiators, knowledgeable, prioritizers)
- Knowledge and capital (e.g., professional knowledge, build networks)
- Parents as parents (e.g., understand child as a child) - ??

Adolescents/young adults
- Job descriptors (e.g., center, attendees, information-providers, leaders, decision-makers)
- Characteristics (e.g., personal characteristics)

Other supports (e.g., formal/financial, informal/families/communities)
Element of role-blurring (where to put this??)
Element of voice of the adolescent/young adult (where to put this??)

Driving elements codes:
Shared understanding of the adolescent/young adult and family
- Characteristics/needs/strengths (including adolescent knowing who they are)
- Incorporate family values
- Acting on their behalf/make the transition as easy as possible

Shared visions/goals/expectations/hope for the adolescent/young adult
- Common objectives (including adolescent/young adult knowing objectives)
- Including comparison to TD, remembering they are adults

Ongoing flexibility and adaptation
- Seek input/look to other providers and family members
- Overcome gaps, setbacks, needs (including knowing when to move on)
- Shift relationships and role release
- Shared problem-solving and doing what works
- Acknowledge barriers

Interpersonal characteristics
- E.g., respect, warmth, patience, affection, sharing, proximity, genuineness, caring, commitment, sensitivity, openness, communication, flexibility, adaptability, team player,
proactive, open to feedback, enjoyment of job, activate knowledge and training to make/work on a plan, shared problem-solving, simple involvement of providers and caregivers, shared implementation, listening/learning, open to different perspectives

- Careful selection for characteristics
- Everyone valuing everyone (e.g., it takes a village)
- Certain barriers related to characteristics

Procedural elements
- Formal systems (e.g., journals, job descriptions, etc.)
- Larger-scale systems (e.g., funding, resources, community supports)
- Purposefulness

Experiential elements:
- Collaboration descriptors (e.g., helpful, a party, a celebration of the person, fantastic, great beautiful, love it, helpful, friendly, the only way to fly; yet hard, not easy, not always successful, hard to engineer)
- Breakdown descriptors (e.g., difficult, tough, frustrating, annoying)
- Progress descriptors (e.g., exciting, celebration, awesome)
- Life journey descriptors (e.g., amazing; yet difficult)
- Adolescents/young adults as conveying a sense of contentment and liking of people in their lives

Time elements:
- Past/longevity:
  - Learn from the past/element of longevity (e.g., this didn’t work last time, let’s do something else this time; this is what things used to be like, this is where we are now; this is what I’ve seen in terms of building relationships with certain kinds of providers)
- Present/reality:
  - Remain in the present/sense of reality (e.g., holding on to beliefs such as he can do anything; let’s remember how old he is and what is expected for an individual of his age; ongoing learning and growing with child; encounter things as they occur)
- Future/foresight
  - Look to the future/foresight (e.g., where will I be and my son be in x number of years; where do we want him to be and how do we get there; who will assume my role; use to inform efforts)
- Progress:
  - Experience as slow and frustrating at times
  - Encounter setbacks and overcome
  - Terminal goal as the outcome/keep eyes on the goal to motivate ongoing effort (both tangible and intangible goals)
    - But steps also as success
- Differences between caregivers/providers
  - Big picture (caregiver) vs individual parts (providers)
  - Skill domains
- Facilitators to success
  - Oriented toward the bigger picture, time, staying on top of goal, adult as willing to do the work, adapt to overcome barriers/setbacks, hold on to hope, activate foresight
- Open eyes to ‘see’ progress
- Celebrate progress when it occurs
- Also personal/professional growth as part of the process
REFERENCE LIST


Caldwell, B. M. (1973). The importance of beginning early. In M. Karnes (Ed.), *Not all little wagons are red: The exceptional child’s early years* (pp. 2-10). Arlington, VA: Council for Exceptional Children.


BIOGRAPHICAL SKETCH

Elizabeth Klinepeter graduated with her Doctor of Philosophy in school psychology from the University of Florida in August of 2018. Prior to completing her doctoral degree, she earned her Master of Education degree in school psychology from the University of Florida in spring of 2015 and her Bachelor of Arts degree from the University of Notre Dame in spring of 2013 with a major in psychology and a minor in education, schooling, and society. Dr. Klinepeter has a long-standing interest in service delivery for children, adolescents, and young adults with intellectual and developmental disabilities (including autism spectrum disorder) and their family members. During her time at the University of Florida, Dr. Klinepeter actively provided clinical services to individuals with developmental disabilities and their family members. She conducted research in her area of interest and was a four-year Graduate School Fellow as part of her studies. She intends to pursue a career integrating clinical service delivery and research in line with her area of interest.