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TOWARDS BETTER OUTCOMES FOR FAMILIES WITH TRANSITION-AGE
YOUTH OR YOUNG ADULTS WITH ASD:
A MIXED METHODS STUDY FROM A PARENT'S PERSPECTIVE

DISSERTATION

A dissertation submitted in partial fulfillment of the
requirements for the degree of Doctor of Philosophy in the
College of Education
at the University of Kentucky

By

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ABSTRACT OF DISSERTATION

TOWARDS BETTER OUTCOMES FOR FAMILIES WITH TRANSITION-AGE YOUTH OR YOUNG ADULTS WITH ASD: A MIXED METHODS STUDY FROM A PARENT'S PERSPECTIVE

The after-high-school outcomes for individuals with autism spectrum disorder (ASD) and their families are less than desirable. The current study employed an exploratory sequential mixed methods design in order to enhance understanding of the family adaptation process during transition. First, a qualitative study was conducted in order to understand the stressors, external and internal support, coping strategies, and family adaptation outcomes during transition, from a parent's perspective, using the ABCX model. Thirteen parents of adolescents and young adults with ASD were interviewed. These parents reported a continually high level of stress due to normative strains and ASD-related demands. They clearly described the tangible, emotional, informational, and internal resources both received and needed. Parents, as active agents in their children's lives, have their own views towards transition, philosophy, and ways of coping. Even though many of them reported negative experiences, these parents also found new meanings and happiness in their lives.

Based on the literature review and the qualitative results, a quantitative study was then developed, which applied the ABCX model to understand the predictors of good parent transition outcomes and investigate the mediating mechanism between stressors and parent transition outcomes. At the indicator level, autism severity, mental health crisis/challenging behaviors, filial obligation, general social support, transition planning quality, parent-teacher alliance, parenting efficacy, problem-focused coping, avoidance-focused coping, and optimism were important predictors of the four benchmarks of parents' outcomes (i.e., parents' burden, parents' transition experience, parents' subjective health, and family quality of life). At the structural level, optimism, emotion-coping strategies, and resources mediated the relationships between stressors and parents' outcomes. Research and practical applications are discussed.

Findings across the two studies led to identification of key factors that influence the outcomes of parents of adolescents and young adults with ASD, as well as an understanding of the complex relationships among the predictors. The results build upon existing empirical and theoretical work related to the transition of families of adolescents and young adults with ASD. Recommendations for future research and clinical practices are discussed.

KEYWORDS: Autism, transition, families of adolescents and young adults with ASD, ABCX Model

Wing Hang “Venus” Wong

03/20/2018

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Thank you for teaching me how to be a good scientist-practitioner and supporting me throughout the exploration.

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Chapter 1 Introduction

Autism Spectrum Disorders

Autism spectrum disorders (ASD) are a lifelong, pervasive, developmental disorder characterized by social and communication deficits and restricted, repetitive, and stereotypical behaviors, interests, and activities (American Psychiatric Association, 2013). The Centers for Disease Control and Prevention (2014) reported that one in 68 individuals are impacted by ASD. This disorder is more prevalent among males than females, with a ratio of four to one (CDC, 2014). Individuals with ASD are also prone to have other genetic conditions. For instance, about 20% of children with ASD have a genetic condition, such as Down syndrome, fragile X syndrome, or tuberous sclerosis (National Institute of Mental Health, 2016). Other than genetic conditions, Simonoff et al. (2008) found that 70% of participants had at least one comorbid psychiatric disorder and 41% had two or more. The most common comorbid diagnoses were social anxiety disorder, attention-deficit/hyperactivity disorder, and intellectual disability.

Even though many individuals with ASD experience limitations in their daily functioning and social lives, many of them also possess exceptional strengths (National Institute of Mental Health, 2016). For instance, 44% of these individuals have above average intelligence (Christensen et al., 2016), while many of them are visual learners (Quill, 1997).

Students with ASD and Achievement Gap During Transition

Approximately 50,000 teens with Autism Spectrum Disorder (ASD) turn 18 in the United States each year (Shattuck et al., 2012). The large amount of individuals with ASD becoming adults has highlighted the urgency of preparing this group of students to

exit school and transition into adulthood. Unfortunately, the transition process and outcomes of students with ASD are less than desirable, even worse when compared to peers with other types of disabilities. For instance, students with ASD are less likely to take a leadership role in the transition process (<3%; Cameto et al., 2004) or make decisions about their transition plan (Shogren & Plotner, 2012). After high school, individuals with autism are less likely to be employed and earn less (i.e., \$9.2 hourly) compared to most of the students who were served under other categories of disabilities (e.g., emotional disturbance). Other than enrollment in secondary education and employment, independent living is also an important adult outcome. However, only 17% of individuals with autism live independently. Compared to most of the other disability categories, individuals with autism are less likely to live or finance themselves independently. Additionally, individuals with ASD partake less in the community (Cameto et al., 2004).

Families of Students with ASD

The negative transition outcomes and transition experiences do not only impact students with ASD, but also their families because a majority of individuals with ASD continuously rely on their caregivers' intensive support, even through late adolescence and into adulthood (Smith et al., 2010; Wager et al., 2007). The need for an intensive level of care of individuals with ASD put parents' health at risk. A number of studies showed that parents of children with ASD reported higher stress levels than parents of typically developing children and parents of children with other types of disabilities (Benson & Kersh, 2011; Dabrowska & Pisula, 2010; Hayes, & Watson, 2013; Higgins, Bailey, & Pearce, 2005). In the case of individuals with ASD, especially for those

categorized as lower functioning, these stressed caregivers and families are often the primary advocates for the transition process (e.g., advocating for post-secondary services, acquiring services for their child; see Ankeny, Wilkins, & Spain, 2009; Hanley-Maxwell, Pogoloff & Whitney-Thomas, 1998). However, the transition process often fails to empower caregivers and families. Cameto and colleagues (2004) found out that only less than 30% of parents of students with ASD feel that the transition planning is very helpful. Despite the high-level of reported parental participation during the transition process, more than 40% of parents reported that their child's IEP goals are determined mostly by the school (Cameto et al., 2004), indicating that parents may not be the core decision makers in the process. Even worse, some parents with students aged 17 to 18 and leaving high school had not yet received such information for transition planning (Cameto et al., 2004).

At the point of transition planning and exiting high school, parents of students with ASD generally experience a number of challenges, for instance, they are older, and facing more physical and mental health issues (see Ha, Hong, Seltzer, & Greenberg, 2008; Greenberg, Seltzer, & Greenley, 1993). Other than aging, they often experience financial hardship (Parish, Thomas, Williams, & Crossman, 2015) because the costs of long-term caring for a child with ASD are high. These common life experiences may add to the family stress during the transition period. Yet, in the current educational system, parents' experiences and family-level outcomes are often left out when gauging transition outcomes (Henninger & Taylor, 2014).

A successful transition should be based on how well the family is doing and how parents perceive the transition process (i.e., family-centered approach; Neece, Kraemer,

& Blacher, 2009). The U.S. Department of Health and Human Services (2017) particularly highlighted that “services and programs should consider the role of the family during the process of transitioning to adulthood. Understanding how to support and include families, without undermining the autonomy of the individual with ASD, is an important but complicated need.” With that being said, the transition process and goals should take family well-being into consideration. A lack of studies focusing on families’ perspectives and experiences may prevent us from having an in-depth insight in the transition process and outcomes of students with ASD and their families (Gerhardt & Lanier, 2011).

Gaps in the Literature

First, the current body of research fails to provide a detailed account of the transition process at a micro-level from a parent’s perspective. In particular, we do not have a comprehensive picture of the sequence of events, experiences, and actions associated with the transition. Without a clear, comprehensive picture of the current situation, practitioners are less likely to pinpoint areas of needs of students with ASD and their families.

Second, traditional measures of successful transition outcomes, such as competitive employment and independence, may not be appropriate for individuals with more severe disabilities (Snell-Rood, et al., 2017). Merely focusing on the traditional measures of outcomes will miss the big picture of the well-being and quality of life of young adults with ASD. For individuals with more severe disabilities, the number of services and support received is also a critical indicator of good transition outcomes.

Third, since parents often continue to be the major caregivers of children with ASD, a successful transition should also be based on how well the family is doing and how parents perceive the transition process (Neece, Kraemer, & Blacher, 2009). Yet, we have a limited understanding of the role of parents and their impact on transition planning quality, as well as the impacts of transition on caregivers' wellbeing.

Purpose and Research Questions

The dismal outcomes of ASD call for attention to research and clinical programs for this group of individuals. However, only 1% of all autism research funding is designated to studies related to aging or adulthood in autism (Roux et al, 2017). The current research project is in response to the lack of understanding of adults or young adults with ASD, as well as their aging family members.

To address the current limitations in the field, I utilized an exploratory sequential mixed methods research design to provide a detailed account of the experiences associated with the transition process from a family-centered approach and answered two board research questions: (1) What are the stressors, external and internal support, coping strategies, and parent transition outcomes from a parent's perspective?; (2) What are the predictors of parent transition outcomes?

Potential Significance

The current study will potentially have three main contributions. First, the detailed account of the transition process will provide first-hand information about family adaptation process during the transition period from high school to post-secondary activities. This information can help pinpoint the strengths and weaknesses of the current transition services and education. Second, the current study will examine the weight of

family- and student-level protective factors on family transition outcomes. The use of a family-centered approach looking at protective factors and outcomes will widen the view on potential transition services and strategies, extending support at the family level. Third, the use of a family-centered approach encourages researchers and school professionals to look at the disparities in transition outcomes of students with ASD from a broader angle focusing on the important role of parents during and after transition from high school to post-secondary activities.

Research studies have highlighted the importance for treating ASD as a life-long disorder (Farley et al., 2009), and thus and the need for better-quality adult services for this group of individuals (Howlin et al., 2013; Taylor & Seltzer, 2011). The current study has provided a new angle to look at the transition process that might lead to better adaptive outcomes for families of emerging adults with ASD.

Conceptual Framework

Little attempt has been made to apply theory to understand the outcomes of students with ASD and their families (Kirby, 2015; Taylor, 2009). Yet, the use of theory can guide the development of research questions and explain results (see Office of Behavioral and Social Sciences Research, n.d.). I applied the ABCX model to understand the outlook and predictors of family-centered transition outcomes.

Guiding Theoretical Framework

The ABCX model is a prominent model that provides an understanding of the adaptation and adjustment process during stressful events within the family structure (Lustig & Akey, 1999). It was built on Hill's ABCX model (1949; 1958) and focuses on resiliency: "the positive behavioral patterns and functional competence individuals and

the family unit demonstrate under stressful or adverse circumstances which determine the family's ability to recover by maintaining its integrity as a unit while insuring, and where necessary, restoring, the well-being of the family members and family unit as a whole" (McCubbin & McCubbin, 1996, p. 5).

The ABCX model includes three predictors (i.e., stressors, resources, and perception and coping) and one outcome variable (i.e., adaptive outcome).

A – Stressors. *A* is defined as life events or transitions that have an impact on the family system (e.g., change the interaction patterns or roles of the family members; McCubbin & Patterson, 1983). *A* also includes the cumulative effects of daily stressors over time (Lavee, McCubbin, & Patterson, 1985).

B – Resources. *B* includes resistance resources, which are defined as the family's abilities to counteract the negative effects implicated by the stressors (e.g., family's social network may help parents of children with disabilities to obtain services; informal and formal support; McCubbin & Patterson, 1983). *B* also includes adaptive resources, which are defined as the existing resources and newly developed resources following the crisis experienced by the family (Lavee et al., 1985).

C – Perception and coping strategies. *C* encompasses family definition and views on the crisis (e.g., the perceived impacts of the crisis on the family functioning; McCubbin & Patterson, 1983). *C* also captures the perception and coherence of the family, which are the family's general orientation to their situation (e.g., overall appraisal, coping strategies; Lavee et al., 1985; Florian & Dangoor, 1994).

X – Adaptive outcome. *X* represents family adaptation, which is the outcomes of the adaptation and adjustment process and a product of the “A”, “B”, and “C” components (Lavee et al., 1985).

The ABCX model has been used flexibly as a conceptual framework in different fields (e.g., Brannan, Helfinger & Foster, 2003; Han, 2003; Stuart & McGrew, 2009). In particular, many different variables have been used as the “X” outcome. For instance, family burden (Stuart & McGrew, 2009), marital satisfaction (Paynter, Riley, Beamish, Davies, & Milford, 2013), parents’ health status (Pakeham, Samios, & Sofronoff, 2005), and use of mental health services (Brannan, Heflinger & Foster, 2003) have all been used as “X” outcomes. One can see that some “X” outcome variables can also be used as “A”, “B”, and “C” components. For instance, the use of mental health services was treated as an outcome variable in Brannan and colleagues (2003), but it was treated as a resource (B) received by the family in other ABCX studies (e.g., Bristol, 1987; Minnes, Woodford, & Passey, 2007). To give another example, caregiver’s psychological well-being/distress has been extensively used as an outcome variable (e.g., Pakenham, Sofronoff, & Samios, 2004; Pakenham et al., 2005); yet, Brannan and colleagues (2003) used it as one of the resource components (B). There is not an absolute way to use the ABCX model. More importantly, the application of the ABCX model is based on research questions, logical reasoning, and the match between the potential variables and the definitions of the “A”, “B”, “C”, and “X” components. Thus, the ABCX model only gives a general definition to the “A”, “B”, “C”, and “X” components, but it does not specify what constructs should represent these components.

Guiding Philosophical Position

From a larger standpoint, the current study utilized a pragmatist philosophical position. Pragmatists believe that knowledge can be innately true or constructed. Different forms, perception, and understanding of knowledge stem from the combination of action and reflection (Biesta, 2010). According to the pragmatist position, research questions are often the determinants of the methodology chosen (Creswell & Plano Clark, 2011). Such an approach is particularly useful when the research questions do not lean toward either the positivist or interpretive philosophy (Ihuah & Eaton, 2013). This also allows the flexible use of research approaches (e.g., deductive, inductive) and research strategies (e.g., quantitative, qualitative). Pragmatists also focus on real-life problems and aim to make an impact upon daily issues (Maxcy, 2003).

I believe that issues related to families of adolescents and adults with ASD are real problems experienced across countries as suggested by the literature. Current knowledge about how to better serve families of transition-age youth is based on objective (e.g., evidence-based practices verified by research studies) and subjective factors (e.g., how parents view those evidence-based practices). Thus, both deductive and inductive methods would provide value to an inquiry of the experiences of families of transition-age youth with ASD and the predictors of family outcomes. Indeed, the use of qualitative and quantitative methods would provide a rich and solid foundation of our understanding in such an inquiry.

Chapter 2 Review of Literature

The body of literature on the transition experience of students with ASD and their families is growing rapidly, but remains sparse compared to research about young children with ASD. The current literature review will provide readers with an overview on literature about the transition from high school to postsecondary activities, as well as the experiences of individuals with ASD and their parents during the transition process.

In particular, the current study can be broken down into two parts. The first section will provide a general review of the literature with regard to legislation, the transition outcomes of individuals with ASD and their family members, and issues related to the transition process. The second section will include a systematic review about the available published evidence regarding the use of the ABCX model for individuals with ASD and their families. This review aims to understand the predictors and outcomes (X) used for individuals with ASD and their families that are organized according to the constructs of the ABCX model. Together, the first section of the literature review will provide an in-depth overview of the current issues experienced by families of transition-age youth with ASD, while the second section will give specific insight into the use of the ABCX model with this population.

Part One: General Review

Important Transition Legislations

Many students with disabilities are served under either the Individuals with Disabilities Education Improvement Act (IDEA) or Section 504 of the Rehabilitation Act of 1973. These laws not only ensure the entitlement of students with disabilities to quality transition services, but also structure the landscape of what and how services are

delivered. This section will focus on discussing the application of these two laws and other relevant standards on transition.

Individuals with Disabilities Education Improvement Act (IDEA). The process of transition happens frequently in life and results in changes that might lead either to growth or deterioration (Schlossberg, 2011). Transition from high school to post-secondary activity is one such transition (Heck-Sorter, 2013). In the United States, the transition experiences of students with disabilities and their families are largely influenced by public policy. The most far-reaching legislation is the Individuals with Disabilities Education Improvement Act (IDEA, 2004). IDEA entitles all children and youth with disabilities, aged three through 21, a free and appropriate public education (FAPE) in the least restrictive environment (LRE) (IDEA, 2004). In IDEA 2004 (2014), transition services are defined as, “a coordinated set of activities for a child with a disability that is designed to be within a results-oriented process, that is focused on improving the academic and functional achievement of the child with a disability to facilitate the child’s movement from school to post-school activities, including postsecondary education, vocational education, integrated employment (including supported employment), continuing and adult education, adult services, independent living, or community participation.” These services should be, “based on the individual child’s needs, the child’s strengths, preferences, and interests, and includes instruction, related services, community experiences, the development of employment and other post-school adult living objectives, and, if appropriate, acquisition of daily living skills and functional vocational evaluation (IDEA, 2004).” When a student with disabilities reaches 16 years old, IDEA clearly requires schools to include appropriate measurable

postsecondary goals and transition services needed to assist the child in reaching those goals in the child's individualized education program (IDEA, 2004). Even though IDEA does not explicitly define transition, one can see that *transition* is largely considered as a support process that starts no later than 16 years of age based on the definition of the transition services of the legislation.

Indicator 13. The IDEA, Part B State Performance Plan (SPS), requires states to develop a six-year plan to measure and monitor their progress in order to improve the education of students with disabilities based on federally identified indicators of compliance and performance (Pennsylvania Department of Education, 2011). Indicator 13 is one of the 20 SPS indicators that focus on the quality of transition, and “the development of IEPs that meet transition requirements, including coordinated, measurable, annual IEP goals that will reasonably enable students to meet post-secondary outcomes (Pennsylvania Department of Education, 2011).”

Section 504 of the Rehabilitation Act of 1973. Along with the IDEA, section 504 of the Rehabilitation Act of 1973 also applies to the transition process. Section 504 is, “a federal law designed to protect the rights of individuals with disabilities in programs and activities that receive federal financial assistance from the U.S. Department of Education (USDOE, 2015).” Subpart E of Section 504 ensures equal access to necessary accommodations in postsecondary educational programs or activities that receive federal funds for individuals with disabilities (USDOE, 2011).

Vocational rehabilitation services. In addition, under Title I of the Rehabilitation Act of 1973, as amended, all states receive federal funding in order to provide individuals with disabilities with vocational rehabilitation (VR) services (RSA, 2003). VR plays an

important role in the success of students with disabilities. VR helps students attain their postsecondary goals through comprehensive assessment, consultation, and counseling services. During the process, VR counselors determine students' vocational interests, strengths, and weaknesses, set appropriate vocational goals, and connect or provide the services needed to accomplish those goals (Kentucky Office of Vocational Rehabilitation, 2016; Pennsylvania Department of Education, 2011). VR services should be available to students with disabilities who are served under either the Individuals with Disabilities Education Improvement Act (IDEA) or Section 504 of the Rehabilitation Act of 1973.

In sum, transition is not only a term indicating the biological changes from adolescence to young adulthood or placement changes from high school to post-secondary activities, it is also a legally-bounded concept specific to the provision of necessary services for students with disabilities aged 16 (14 in some states) to 22.

Adolescents and Young Adults with ASD and Transition Experiences

Autism spectrum disorder (ASD) is a lifelong, pervasive, developmental disorder characterized by social and communication deficits and restricted, repetitive, and stereotypical behaviors, interests, and activities (American Psychiatric Association, 2013). Generally, a clinical diagnosis of ASD can be made around two years of age (Baird et al., 2001; Newschaffer et al., 2007). Despite the possibility of early diagnosis and effectiveness of early interventions, autism symptoms continue to affect the majority of individuals with ASD throughout late adolescence and adulthood (Billstedt et al., 2007; Gillberg & Steffenburg, 1987; Volkmar, Reichow, & McPartland, 2014).

The aforementioned legislations have provided a foundation of accessible services for individuals with ASD as they age. However, many of them experience a “service

cliff' when they graduate from high school. Despite continual challenges in daily life, 25% of adults with ASD reported that they do receive all the services they need in order to obtain a quality of life (Roux et al., 2017). Even more so, young adults with ASD (18 to 24 years old) are less likely to receive the services they needed compared to older individuals. In order to understand the service cliff, I aim to focus on the transition experience of adolescents and young adults with ASD in this section.

Hendricks and Wehman (2009) carried out a thorough review that provides a comprehensive outlook on youth with ASD who transition from school to adulthood. The current literature review will summarize the findings by Hendricks and Wehman (2009) and build on their work.

Ability and achievement. Extant evidence shows that a considerable number of individuals with ASD have improved autism symptoms, cognitive, and adaptive skills throughout adolescence and young adulthood. For instance, between 20-55% of individuals with ASD demonstrate cognitive improvement (Levy & Perry, 2011). Despite cognitive improvement, the educational achievement of students with ASD is consistently lower than their typically developing peers. For instance, when assessed using standardized achievement tests, a study found that high-functioning students with ASD in the general education classroom are around four grade levels behind in reading and five grade levels behind in mathematics (Myles & Simpson, 1998). Another study also found that adolescents and young adults with ASD aged 16 to 18 scored, on average, three standard deviations below the mean in language arts, mathematics, science, and social studies. Even more so, the learning difficulties of students with ASD prevent them from completing regular coursework on time. In the

year 2010–2011, less than 50% of students with ASD graduated high school within four years (USDOE, 2008). In general, learning ability and educational achievement are lower in the population of students with ASD.

Transition planning. Transition planning is critical to a successful transition outcome because of the continual learning, behavioral, and social difficulties experienced by students with ASD. Effective planning involves collaboration with a multidisciplinary team that includes the student with ASD and the stakeholders (National Council on Disability, 2000). Even though the majority of students with ASD have a transition plan (81%) and receive instruction on transition planning (71%), the existing data indicated that the participation of students with ASD in the transition process and their transition outcomes are less than desirable because only few of them take a leadership role in the transition process (<3%; Cameto et al., 2004). In particular, students with autism and/or an intellectual disability are significantly less likely to make decisions about their transition plan compared to students with other disabilities (Shogren & Plotner, 2012). Two thirds of students with ASD do not actively participate in transition planning meetings, sometimes leaving their voices unheard.

Cameto and colleagues (2004) found that parents and special education teachers are the two main participants, attending more than 90% of the IEP meetings for students with ASD. The next most likely attendees were related services personnel (57.7 %), followed by school administrators (57.0%), school counselors (54.5%), general education academic teachers (38.9%), and general education vocational teachers (19.9%). Surprisingly, vocational rehabilitative counselors only attended 19.2 % of the IEP meetings. The study also showed that around 30% of the IEP meetings were attended by

“other professionals,” including personnel from outside agencies (e.g., Social Security Administration), representatives of postsecondary education institutions or employers, and advocates or consultants. We still have a limited understanding of the actual responsibilities and the roles of each party in the transition process.

Quality transition goals are another critical factor in successful transition planning. Currently, only a handful of information is available with regard to the transition goals of students with ASD. The National Longitudinal Transition Study-2 by Cameto and colleagues (2004) found that more than half of the students (58%) with autism had goals targeting independence, while one fifth of them (25%) had independent living goals. Around one fifth of the students (22%) had goals for competitive employment. Generally, students with autism are less likely to be expected to engage in competitive employment, and are more likely to have goals involving supported and sheltered employment placements when compared with students with other disabilities (Wagner, Newman, Cameto, Garza, & Levine, 2005). Cameto and colleagues (2014) also found that of all the transition plans, around one fifth (23%) included goals related to studying in college, and more than half (57%) contained goals targeting social skills development. Despite all the goal setting and planning, only 66% of students with autism had an IEP that specified a course of study to meet those transition goals, highlighting a lack of detailed documentation of the means to achieve transition goals (Cameto et al., 2004).

Postsecondary education. Participation in post-secondary education is a common step to acquiring advanced knowledge and skills in preparation for a higher paying job. Cameto and colleagues found that around 43.9% of students with autism

participated in postsecondary schools. Thirty-two percent of these students enrolled in a 2-year college, while 21.0 % of them enrolled in a vocational, business, or technical school. Among all the students with ASD, 17.4% enrolled in a 4-year college. Generally speaking, most of the students with ASD (76%) identified themselves as an individual with a disability and informed their postsecondary schools of their disability (63%). However, only 36% of the students received accommodations and support from their schools (Cameto et al., 2004). Some additional analyses revealed a more in-depth understanding of the post-secondary situation of young adults with autism. Roux and colleagues (2013) found that individuals with autism who were older, from higher-income households, and had higher conversational and functional skills were more likely to obtain a paid job. Also, communication skills, the severity of autism, health conditions, primary post-high school goals, parental expectations, high school type, academic performance, family SES, and parental involvement were found to be important factors that led to positive outcomes (e.g., being employed or in secondary education; Lipstak et al., 2011; Chiang et al., 2012). Additionally, Wei and colleagues (2013) reported an interesting finding that students with autism were more likely to partake in Science, Technology, Engineering, and Mathematics (STEM) learning. All of this information provides a more in-depth understanding of the life of young adults with autism.

Employment. Working a job is a milestone of the transition process. In general, the job outcomes of individuals with ASD (e.g. employment rate, job status, job stability) are typically negative (Levy & Perry, 2011; Volkmar et al., 2014). According to Cameto and colleagues (2004), around 63.2% of students with ASD had been employed since high school. Oftentimes, employment difficulties for individuals with ASD are not due to

a lack of ability to complete work tasks, but a failure to function in a socially appropriate manner (Hurlbutt & Chalmers, 2004; Müller et al., 2003).

Unfortunately, individuals with autism were less likely to be employed compared to most of the students who had other categories of disabilities (e.g., emotional disturbance or hearing impairment). An updated report found that only 14% of adults with ASD hold a paid job in the community (Roux et al., 2017). The most popular types of job among those who were employed were office and administrative support (19.1%) and food preparation and serving related work (12.8%). Among those who were employed, individuals with autism worked significantly fewer hours (24.1 hours weekly) than individuals with other disabilities. Additionally, individuals with autism earned an average hourly rate of \$9.20. Compared to some other types of disabilities (e.g., learning disabilities), individuals with autism were more likely to earn less. Employment difficulties are not only limited to individuals with lower cognitive and adaptive functioning, but also extend to those with postsecondary educational experiences (Howlin, 2000).

On the positive side, almost 90% of individuals with autism reported that they like their job either fairly well or very much. Also, individuals with autism were more likely to hold a job for a longer time compared to some individuals in other disability categories (e.g., learning disability, other health impairment, etc.). Additionally, compared to some categories of disabilities (e.g., learning disabilities), the employers of individuals with autism were more likely to be aware of their disability (73.1%) and provide accommodations (37.2%) (Cameto et al., 2004).

Independent living. In addition to enrollment in secondary education and employment, independent living is an important adult outcome. However, only 17% of individuals with autism live independently, a number that is lower when compared to most of the other disability categories. Almost half of the adults with ASD (49%) live with their parents or relatives, while half of them (51%) have a limited or full legal guardian (Roux et al., 2017). Financial independence is another related area; Cameto and colleagues (2004) showed that 56.7% of individuals with autism had a savings account, 45.0% had a checking account, but only 26.9% of them had a credit card. The level of financial independence is relatively low compared to most of the individuals with other types of disability (see Hendricks & Wehman, 2009).

Community participation. Another indicator of a successful transition to adulthood is the ability to have stable and healthy relationships with others in the community. According to Cameto and colleagues (2004), many individuals who are able to live independently may decide to have a stable relationship or even parent children. However, only 3% of individuals with ASD ever gave birth to or fathered a child, while only 0.9 % of them were married. Other than romantic or familial relationships, it was reported that individuals with autism had lower quality friendships. For instance, they were among the least likely to meet at least weekly with friends. This limited interaction with friends even extends to computer-based interactions. It was reported that only 24.5% of individuals with ASD communicated with others at least daily by computer (Cameto et al., 2004).

On top of the difficulties in forming relationships, the researcher found that individuals with autism partook less in the community. Only 33.4 % of individuals with

autism had a driver's license or learner's permit. Also, only 55.4% of them were registered to vote. However, on the positive side, it appeared that a commensurate or even higher level of participation in lessons or classes outside of school, community service activity, and community groups was found among young adults with autism when compared with individuals with other disabilities (Cameto et al., 2004).

Seltzer, Shattuck, and Abbeduto (2004) conducted a review on the trajectory of development in adolescents and adults with autism. They found that 10-15% of individuals with ASD obtained more favorable adult outcomes (e.g., become "symptom-free"), meaning that some individuals with ASD improve to such an extent that they no longer meet the diagnostic criteria of ASD. However, in terms of daily living, only 3-25% of individuals with ASD are able to function independently in the community, meaning that a large portion of this group of individuals still depend on others as they age, mainly parents or family members (Krauss, Seltzer, & Jacobson, 2005). In sum, one can see that the transition outcomes of the majority of students with ASD are pessimistic when compared to students with other disability categories. The disparities in transition outcomes between students with ASD and others not only reveal the unique detrimental effects of ASD, but also a systemic failure to support students with ASD nationwide. To combat the negative phenomena, one has to look at the problem from a broader angle and take into consideration families of students with ASD.

Families of Adolescents and Young Adults with ASD and Transition Experiences

Autism Spectrum Disorder (ASD) is a developmental disorder. The negative impacts experienced by individuals with ASD extend to their families. The unique, complex challenges of rearing a child with ASD threaten the psychological health of

these parents (Seltzer, Krauss, Orsmond, & Vestal, 2001). In particular, the need for an intensive level of care for individuals with ASD causes a high level of stress, negative emotions, and health-related problems among this group of parents (Benson & Kersh, 2011; Bristol, 1987; Hayes & Watson, 2013; Howlin & Asgharian, 1999; McGrew & Keyes, 2014; Stuart & McGrew, 2009). A myriad of studies have showed that parents of children with ASD report higher stress levels than both parents of typically developing children and parents of children with other types of disabilities (Benson & Kersh, 2011; Dabrowska & Pisula, 2010; Hayes, & Watson, 2013; Higgins, Bailey, & Pearce, 2005). As the child ages, caregiver stress varies and may be particularly high during key transition points, such as transitioning from high school to post-secondary activities. Oftentimes, the burden on families does not decrease as individuals with ASD age; a large portion of individuals with ASD continuously rely on their caregivers' intensive support, even through late adolescence and into adulthood (Smith et al., 2010; Khanna et al., 2011). In many cases, individuals with ASD do not have close friends or romantic partners with whom to share their lives (Cameto et al., 2004). Caregivers and families are often the only advocates and sources of support who are consistently present in the lives of individuals with ASD (Ankeny, Wilkins, & Spain, 2009; Hanley-Maxwell, Pogoloff & Whitney-Thomas, 1998).

The transition process is not only particularly hard on students with ASD, it is also a stressful period for their parents (see Lounds, Seltzer, Greenberg, & Shattuck, 2007; Baxter, Cummins, & Polak, 1995) as they play a critical role in the transition process. Oftentimes, aging parents continue to be the major caregivers of their children and make important decisions for them. For instance, many parents need to obtain

services for their children, apply for guardianship, participate in an array of transition meetings, and help set post-school goals for their children (see Levinson & Palmer, 2005). As one can imagine, aging parents may decline in their ability to take care of their children, yet their responsibilities do not decrease as their children age. Not uncommonly, many parents also experience financial hardship (Parish, Thomas, Williams, & Crossman, 2015) because the costs of caring for a child with ASD over the long-term are high. The tremendous demands and limited resources available for parents of transitioning individuals with ASD threaten the mental health of this group of parents.

Despite the alarming mental health issues among parents of children with ASD, we only have a limited understanding of what interventions and factors can improve parents' psychological health (Neece & Blacher, 2009). Lounds and colleagues (2007) revealed a preliminary picture of the stress of aging parents of individuals with ASD. The authors found that during the transition process, parents reported better wellbeing when their child displayed fewer behavioral problems, was prescribed more psychotropic medications, and exited high school (Lounds et al, 2007). It is reasonable to expect that a child's symptom abatement leads to better parent mental health. However, it is less clear why leaving high school is a significant predictor of improvements in parental wellbeing. Lounds and colleagues (2007) postulated that mothers may have anticipated this transition with a great amount of worry. Yet, parents' stress level declining when their children graduated because, for the most part, their children transitioned successfully (Lounds et al, 2007). Nevertheless, the high level of parental stress experienced before students with ASD had graduated from high school may also be a potent indicator of the

inefficacy of the current educational system in supporting families and parents of students with ASD.

Additional evidence elaborated upon the results found by Lounds and colleagues (2007). It was reported that even though the majority of parents of students with ASD participated in transition planning (Shogren & Plotner, 2012), less than 30% of parents of students with ASD felt that the transition planning is very helpful (Cameto et al., 2004). Despite the high level of reported parental participation during the transition process, more than 40% of parents reported that their child's IEP goals were determined mostly by the school (Cameto et al., 2004), indicating that parents might not be the core decision makers in the process. In general, about one-third of parents of children with disabilities received information with regard to post-school services and programs when their children were 15 years old, compared to about three-fourths of parents who received such information when their children were 17 and 18 years old (Cameto et al., 2004). Furthermore, about one-fourth of parents of disabled students aged 17 to 18 and about to leave high school had not yet received information for transition planning (Cameto et al., 2004). These results revealed that parents often do not receive necessary support to make informed decisions with regards to their child's transition.

To summarize, we only have limited understanding about the outlook, predictors, and interventions of desirable outcomes for parents of children with ASD during the transition period. Emerging evidence has showed that this group of parents' experience high levels of stress, yet only have limited support from the school and community during the transition process.

Family-Centered Transition Outcomes and Predictors

Family and transition outcomes. Knowing what is a successful transition outcome is critical in goal setting, intervention planning, and progress monitoring. When setting transition goals, one often compares the status of individuals with disabilities to their typically developing adult peers. Usually, the more similar the lives of individuals with disabilities to those of typically developing peers, the better the transition outcomes are. Traditionally, postsecondary education enrollment, independent employment, residential independence, financial independence, and social and community participation, are some commonly used measures to gauge transition outcomes (Institute of Education Sciences, 2009).

However, these traditional measures of a successful transition outcome may not be appropriate for students with more severe disabilities (see Smith et al., 2010; Ankeny, Wilkins, & Spain, 2009; Hanley-Maxwell et al., 1998), while the meaning of good transition outcomes is changing in response to the historical context (Henninger & Taylor, 2013). As mentioned before, parents often continue to be the major caregivers and decision makers of the lives of children with disabilities; therefore, a successful transition should also be based on how well the family is doing and how parents perceive the transition process (Dunst & Bruder, 2002; Neece, Kraemer, & Blacher, 2009). The three medical professional societies together highlighted the significance of family's role in health care for adults with special needs and described "the critical first steps that the medical profession needs to take to realize the vision of a family-centered, continuous, comprehensive, coordinated...health care system" (American Academy of Pediatrics, American Academy of Family Physicians, American College of Physicians- American

Society of Internal Medicine, 2002). In order to facilitate good family-centered transition practices, we first need to know the definition of good family transition outcomes.

Definitions of family transition outcomes. Using family as a unit of transition outcome measure is not a new idea, yet only limited theoretical and/or empirical investigations are available (Blacher, 2001). More efforts, not only limited to the field of research but at the policy level, have been made to explore the concept of family outcomes. In 2003, the Early Childhood Outcomes (ECO) Center was funded by the Office of Special Education Programs (OSEP) to select child and family outcomes and develop measures for states and federal programs to evaluate the effectiveness of the Part C early intervention and Part B preschool programs of IDEA (Bailey et al., 2006; ECO, 2005).

The ECO defined family outcome as, “a benefit experienced by families as a result of services received” (Bailey, 2006). Through an extensive qualitative investigation with stakeholders, the ECO identified five family outcomes - they are: (a) families understand their child’s strengths, abilities, and special needs; (b) families know their rights and advocate effectively for their child; (c) families help their child develop and learn; (d) families have support systems; and (e) families are able to gain access to desired services and activities in their community. Later, the results were translated into a measure, namely the Family Outcomes Survey – Revised Version (FOS-R), used by state and federal programs (ECO, 2010).

Then, Arkey and colleagues (2007) further investigated the concept among aging parents of adult children with disabilities. They found that both parents with young children and adult children with disabilities reported that positive family outcomes should

include the following: Parents (a) have a life/identity of their own (not just parents/caretakers); (b) have control over their life; (c) spend quality time with the person with disability (not just taking care of them); (d) are physically and emotionally healthy; (e) have adequate resources, (f) feel skilled and informed; (g) are able to maintain family life; and (h) have positive and constructive relationships with professionals and work in partnership with them. Even though many parents of adults with disabilities have the same hope as parents with typically developed children, parents of adult with disabilities reported more desire to limit the time spent on and the range of caring tasks and paid more attention to the value for money in services (Arkey, et al., 2007).

Other than the aforementioned definitions, a number of researchers suggested that family quality of life alone is also an appropriate construct to represent the family outcomes of children with disabilities (see Epley, Summers, & Turnbull, 2011). Similarly, family wellbeing and family quality of life are two important constructs when measuring family transition outcomes (Neece et al., 2009). At times, wellbeing and quality of life are used interchangeably (see Plagnol & Scott, 2011). In the current literature review and study, family quality of life and wellbeing are treated as the same construct.

A considerable number of researchers and scholars tried to explore the nature and meaning of family quality of life and wellbeing. Poston and colleagues (2003) conducted a qualitative study with family members of children and adolescents with or without disabilities, as well as some related service providers and administrators. The research group found that the conceptual foundation of family quality of life consists of ten specific domains (Poston et al., 2003). The domains include advocacy, emotional

wellbeing, health, environmental wellbeing, productivity, social wellbeing, daily family life, family interaction, financial wellbeing, and parenting. See table 2.1 for the domains and subdomains of the conceptual framework and associated indicators. It is clear that family quality of life is a multidimensional concept that captures an array of knowledge, skills, and efficacy that contribute to the development and stability of the family.

Table 2.1

Individually Oriented Domains, Subdomains, and Indicators Reported by Poston and Colleagues (2003) Direct Extract

Domain/Subdomain	Definition	Indicator
Advocacy	Activities that family members undertake to learn and act on behalf of themselves and each other.	
Advocacy role		Family members advocate when and where they want.
Advocacy activities		Family members advocate to improve services and outcomes for themselves and/or other family members.
Facilitators of advocacy		Family members have support from others to advocate successfully.
Emotional Wellbeing	The feeling aspects of life.	
Identity		Family members feel a sense of pride in their own and each other's' accomplishments.
Respect		Family members are treated with respect by people outside the family.
Reducing stress		Family members are able to take time for themselves.
Choice		Family members have opportunities to make choices.
Health	Physical and mental wellbeing.	
Physical health		Family members have the best possible physical health.
Mental health		Family members have the best possible mental health.
Health care		Family members can get medical care on a regular basis.
Environmental Wellbeing	The conditions of the physical contexts within which family members live.	
Home environment		My family's home has enough space.
School environment		My children are safe at school.
Work environment		Family members are safe at work.
Neighborhood and community environment		My family lives in a community that has services to meet my
Productivity	Skills and opportunities to participate and succeed in education, work, and leisure.	
Education		My child with a disability is receiving an appropriate education (diagnosis, IEP, inclusion, behavior support).

Table 2.1 (continued)

Work		Family members balance work and family life.
Leisure		Family members can participate in the hobbies they enjoy.
Personal development		Family members support each other's growth and development.
Social Wellbeing	Skills and opportunities to have relationships with people outside the family.	
Social acceptance		Family members are accepted by people they meet.
Social relationships		Family members have friends.
Social support		Family members get practical help from people outside the family.
Daily Family Life	Recurring activities that sustain families logistically--the daily routines of life.	
Family care		My family provides care to family members.
Daily activities		My family members do chores within the home (cleaning, cooking, yard work).
Getting help		My family plans for help from others (finding, asking, supervising).
Family Interaction	Relationships that family members have with each other and the emotional climate within which the relationships exist.	
Positive interactional environment		My family members feel loved and accepted by each other.
Communication		My family members talk openly with each other.
Supporting each other'		My family members help each other.
Flexibility		My family can fairly quickly make plans to do things without a lot of complicated planning.
Financial Wellbeing	Families having income that at least meets or preferably exceeds their expenses.	
Paying for basic necessities		My family can pay for basic necessities (housing, food, clothing).
Paying for health care		My family can pay for health care.
Paying for other needs		My family can pay for childcare.
Sources of income		My family has salary and benefits from employment.

Table 2.1 (continued)

Financial security		My family is financially secure.
Parenting	Providing guidance, structure, and teaching to children and youth.	
Providing parental guidance		My family helps our child(ren) learn right from wrong.
Discipline		My family sets boundaries and rules for our child(ren).
Teaching		My family helps our child(ren) with school work.

Poston and colleagues' (2003) model provided a comprehensive foundation of the components of family quality of life. Yet, there are a few problems associated with the application of Poston and colleagues' (2003) model. First, the qualitative and exploratory nature of the study does not provide a clear picture of the relative weight of each quality of life domain. It is possible that, in fact, only a portion of the domains predict family quality of life (Summers et al., 2005). Second, measuring ten domains of family quality of life may not be feasible in research and clinical settings. The same research team was well aware of the limitation of qualitative studies and then conducted two more follow-up quantitative studies in order to confirm the structure of family quality of life and develop a family quality of life measure (Summers et al., 2005). The latter quantitative work confirmed a five-factor solution model, indicating that only five out of ten domains of family quality of life compose the construct of quality of life. The five domains are family interaction, parenting, emotional wellbeing, physical/material wellbeing, and disability related support (Summers et al., 2005). The Beach Center Family Quality of Life Scale was then developed to capture these five domains of quality of life. Based on all the extensive research work done by the Beach Center on Disability from the University of Kansas (n.d.), they defined family quality of life as, "the extent to which families' needs are met, family members enjoy their life together, and family members have a chance to do the things that are important to them."

Indeed, more definitions of family quality of life are available on top of the work done by the Beach Center. Two other popular models of family quality of life are developed by Aznar and Castanon (2005) and the International Family Quality of Life Project (Isaacs et al., 2007). Aznar and Castanon (2005) conceptualized family quality of

life as emotional wellbeing, personal, strength and development, interpersonal and community relations, and physical/marital wellbeing; whereas the International Family Quality of Life Project theorized health, family relationships, supports from disability-related services, careers and preparing for careers, community interaction, financial wellbeing, supports from others, influence of values, and leisure and recreation as important components of family quality of life (Isaacs et al., 2007). In general, the definitions of family quality of life are similar across study.

Other than family quality of life, Williamson and Perkins (2014) summarized that parents' economic, mental, and physical health outcomes are also important family-level outcomes. Currently, parents' overall wellbeing, absence of mental disorders, stress, and quality of life were commonly used as parental outcomes in studies of parents of children with ASD (e.g., Jones & Kingston, 2005; Manning, Wainwright, & Bennett, 2011; McGrew & Keyes, 2014).

Predictors of family transition outcomes. The ABCX is a prominent model that provides an understanding of the adaptation and adjustment process during stressful events within the family structure (Lustig & Akey 1999). This model has also been extensively applied to the context of families of children with disabilities (Saloviita; Italinna, & Leinonen, 2003). The ABCX model consists of three predictors, including family stressors (A), family resources (B), family perception and coping strategies (C), and one outcome variable, family adaptation outcomes (X).

Blacher (2001) modified Hill's (1949) ABCX model in order to guide research targeting individuals with intellectual disability during the transition from late adolescence into young adulthood. Blacher's (2001) model illustrated the complexity

between family outcomes and predictors. These components of families' wellbeing are directly influenced by four main factors:

- (1) Stressor/Individual characteristics (A): Child's age, gender, physical health, cognitive functioning, adaptive behavior, and maladaptive behavior or psychiatric status;
- (2) Resources/ Environment and culture (B): Resources available to the family system and the social cultural contexts in which they operate;
- (3) Coping/Involvement or detachment (C): Family planning and decision-making about transitional services, as well as family involvement with the child and the service agencies, are primary factors in transition success ;
- (4) Transition success (X): Success in the areas of residence, education, employment, or social environment.

The current section will borrow the ABCX model (McCubbin & McCubbin, 1996, p. 5) and Blacher's (2001) framework to discuss the existing knowledge about predictors of family quality of life, especially in the context of transition.

Stressors

Child cognitive ability, adaptive level, and symptom severity. It is clear that individuals with higher cognitive and adaptive ability are more likely to obtain better outcomes (e.g, work status, residential situation, and number and quality of friendships; see Farley et al., 2009; Kanne et al., 2011). However, parents of higher functioning adult children do not necessarily report less stress during the transition process. It appears that the relationship between a child's symptoms and their parents' mental health is complex. Lounds and colleagues (2007) found that a comorbid diagnosis of intellectual disability is

correlated with lower maternal anxiety depressive symptoms. The authors postulated that this pattern of maternal anxiety and stress may be related to the fact that lower-functioning young adults are more likely to receive support services in school until 22 years old. Therefore, when comparing parents of young adults aged 16 to 22 during the transition process, the effects of symptom severity and ability may be moderated by the amount of services available to the family.

The effects of symptom severity on parents' mental health is another relatively well-researched area. Among parents of children with ASD, mixed results have been found about whether ASD core symptom severity relates to parental wellbeing (see Benson, 2006; Tobing & Glenwick, 2002). For instance, Benson (2006) found that autism severity is related to maternal depression among aging parents of children with ASD, but some others did not (see Lounds et al., 2007). Yet, the child's behavioral and health problems are positively related to maternal anxiety and depression (Lounds et al, 2007).

Challenging behaviors. Challenging behaviors - such as severe tantrums - are often concomitant with developmental disabilities due to a variety neurological, familial, social-economical, and motivational factors (Hastings, 2002). MacCarthy and colleagues (2010) found that adults with ASD were four times more likely to display challenging behaviors as compared to non-ASD adults. The same group of researchers also found that challenging behavior was predicted by the severity of ID and the existence of ASD. These challenging behavior take a toll on parent's outcomes as a previous meta-analysis (Hayes & Watson, 2013) and a myriad of findings have revealed that challenging behaviors were the most significant predictors of parents' burden (e.g., Baghdadli, Pry, & Michelon, 2014; Blacher et al., 1997; Hodapp, Dykens & Masino, 1997). Despite the

known linkage between challenging behaviors and parents' outcomes, the mediating or moderating mechanism between the two variables are less researched (Hastings, 2002). Hastings (2002) postulated that challenging behaviors exacerbate parenting stress, which then leads to more negative parenting strategies, which in turn cause more child's challenging behaviors in the child. During adolescence and young adulthood, without appropriate interventions, these challenging behaviors may become out of control and develop into mental health crises (e.g., eloping, aggressive behaviors towards others; Kalb, Hagopian, Gross, & Vasa, 2017).

Normative stressors. Many parents of adults with disabilities experience satisfaction, hope, and fulfillment (Smith, 2010; Lutz, Patterson, Klein, 2012). However, even though parental wellbeing was reported to improve across time (Lounds, Seltzer, Greenberg, & Shattuck, 2007), many parents continue to experience high-level negative emotions or feelings during transition, such as sadness and anxiety (Seltzer et al, 2001). Aging parents not only need to face the challenges related to their child's disabilities, but also the normative stressors related to aging. Schulz and Heckhausen (1996) theorized that successful aging is a process of selection ("increasing restriction of life domains as a consequence or in anticipation of changes in personal and environmental resources"), compensation ("facilitating mastery of loss in reserves in old age"), and optimization ("enriching and augmenting reserves or resources") based on their goals in life and in face of the increasing vulnerabilities. Having a child with a disability and insufficient support might mean that aging parents need extra efforts to select, compensate, and optimize. Continual caregiving responsibilities might also exacerbate the negative effect of a normative aging process, such as retirement, deteriorating health, and taking care of

one's own parents (Grundy & Henretta, 2006; Quittner, Glueckauf, & Jackson, 1990; Thoits, 2010). Oftentimes, parents might need to prepare for the life of their children with disabilities after they themselves die (Seltzer, Krauss, Orsmond, & Vestal, 2001).

Resources

Social support. Social support plays an important role for families of children with ASD. Generally, social support has been found to be correlated with positive parent outcomes, such as lower stress (Bristol & Schopler, 1983), anxiety, and fewer depressive symptoms (Gill & Harris, 1991; Gray & Holden, 1992). Social support was found to be correlated with fewer spousal problems among parents of children with ASD (Dunn, Burbine, Bowers, & Tantleff-Dunn, 2001; Sturt & McGrew, 2009). More importantly, the powerful effect of social support contributes to a better quality of family life (Sturt & McGrew, 2009). Similar positive effects of social support were also found in aging parents with adult children with intellectual disabilities (Greenburg, Seltzer, Krauss, & Kim, 1997; Heller, Miller, & Factor, 1997). Even though there is a lack of studies focusing on the effect of social support on aging parents of ASD and their families, it is reasonable to expect that social support is a critical factor underwriting a high quality of family life.

Social economic status. A variety of social locations can alter one's daily opportunities and experiences. In the case of students with ASD, social economic status (SES) is particularly influential. Research has found that individuals with autism who were from higher-income households were more likely to obtain a positive transition outcome, such as getting a paid job or enrolling in post-secondary education (Roux et al, 2013; Lipstak et al., 2011; Chiang, Cheung, Hickson, Xiang, & Tsai, 2012). Families'

SES is also related to access to general and specialized services that help students succeed (Longtin & Principe, 2014; Magana, Parish, Rose, Timberlake, & Swaine, 2012). Compared to their middle-class counterparts, low-SES parents' access to information and services is more limited, and relies on publicly-funded agencies for support (e.g., school, waiver services; see Dorsett, 2015). Families' SES is a critical, yet under-researched, factor that underpins the quality of transition process and outcomes. Even though there is a lack of accounting of how SES and other social locations intersect during the transition process, it is reasonable to expect that low-SES students with ASD and their parents experience more stress and constrained access to services, which result in negative transition outcomes.

Service support. Young adults and adolescents aging out of the school system are susceptible to negative outcomes, such as deteriorating health, limited learning opportunities, and unemployment (Collins, 2011). No one will doubt the importance of service support during the transition process. It is clear that receiving services is positively related to positive student post-secondary outcomes, such as high school graduation and secondary outcomes (Collins, 2001). Continual services not only benefits young adults with disabilities during the transition process, but also their caregivers; however, many aging caregivers do not have enough support (Minnes & Woodford, 2005). Subsequently, unmet service needs lead to deteriorating caregiver wellbeing (Selzer & Krauss, 1989)

Religion. In general, parents tend to use more religious coping mechanisms when their children with disabilities grow older (Gray, 2006). Importantly, religion gives meaning to and reasons for raising a child with ASD (Tarakeshwar & Pargament, 2001).

However, the use of such a practice might vary depending on race, with black parents of adults with ASD using religion more often than their white counterparts (Miltiades & Pruchno 2002). In general, the use of a religious coping mechanism is associated with positive parent's outcomes. For instance, it is associated with decreased chances of having depression (Rogers-Dulan, 1998) and increased acceptance (Skinner, Bailey, Correa, & Rodriguez, 1999). Interestingly, Miltiades and Pruchno (2002) found that religious coping mechanisms were associated with higher levels of caregiving satisfaction, but not with burden, which might imply that some aspects of parents' wellbeing might be less responsive to this type of coping.

Parenting efficacy. Parenting efficacy is broadly defined as “the expectation caregivers hold about their ability to parent successfully” (Jones & Prinz, 2005), and is an important factor that influences parenting outcomes (e.g., lower levels of stress and depression) and practices (e.g., fewer harsh disciplines) (Coleman and Karraker, 1998; Jones & Prinz, 2005). As early as the receipt of the ASD diagnosis, higher parenting efficacy was correlated with better adjustment and coping skills (Pakenham, Sofronoff, & Samios, 2004). Parents' self-efficacy was often found to be and treated as a mediating mechanism between stressors and parents' outcomes (Teti, O'Connell, & Reiner, 1996; Weiss, Robinson, Fung, Tint, Chalmers, & Lunskey, 2013). For instance, parenting efficacy is an important mediating factor between parenting stress and increased parental depression among parents of children with ASD (Rezendes & Scarpa, 2011). It is also possible that self-efficacy is related to some environmental factors. For instance, Paquette-Smith, & Lunskey (2014) found that parent self-efficacy was not only associated with a child's clinical status, but also with child age, parent immigrant status, barriers to

obtain services, and caregiver burden. More research studies have been carried out on the levels and impacts of the self-efficacy of parents of young children with ASD, but less is known for those of adult children with ASD.

Family perception and coping

Family appraisal and optimism. How parents perceive the challenges experienced during the transition process is critical. Even though raising a child with ASD is challenging, many parents of adult children with ASD are also able to see positivity (Hastings et al., 2005). Such a positive perception may serve as a resulting adaptive function used to cope with stress (Hastings & Taunt, 2002). In difficult situations, optimism helps human beings see hope in the future, solve problems persistently, and obtain necessary resources (Geers, Wellman, & Lassiter, 2009). A number of studies of parents of children with ASD also found that optimism was associated with positive parents' outcomes, such as lower parenting stress, lower levels of depression, lower levels of negative affect, greater positive affect, greater life satisfaction, and higher levels of psychological wellbeing (Ekas, Lickenbrock, & Whitman, 2010; Greenberg, et al., 2004). Wehman and colleagues (2015) even found that positive parental expectations for post-school employment significantly predicted actual post-school employment among youth with disabilities. These results show the importance of maintaining a positive view toward the difficulties experienced by the families during the transition process and their ability to stay positive about the future.

Family coping strategies. Coping is defined as both cognitive and behavioral efforts used to, “master, tolerate, or reduce external and internal demands and conflicts (Folkman & Lazarus, 1980, p.233).” Dunn and colleagues (2011) found that the use of

escape-avoidance (e.g., avoid to confront the problems; Billings & Moos, 1981) and emotion-focused coping strategies (e.g., focus on the emotional impacts of stressors and to maintain emotional equilibrium; Billings & Moos, 1981) was related to increased depression and isolation, and decreased spousal relationships among the parents of children with autism. Similarly, Kim and colleagues (2003) found that emotion-focused coping was found to lead to lower levels of wellbeing while problem-focused coping resulted in a reduction in stress. However, many other studies did not find such effects or even find a positive relationship between emotion-focused coping and parents' outcomes (Benson, 2010; Manning et al., 2011). In a more recent study, Yu (2017) also found that using passive-avoidance coping strategies predicted negative parent outcomes, such as increased caregiver burden, among parents of adolescents and young adults with ASD. However, Yu (2017) did not find a significant relationship between emotion-focused coping and parent outcomes.

On the other hand, the use of problem-focused coping was also found to be correlated with better mental health, more social support, and positive spousal relationships (Dunn et al., 2001). However, some studies did not find any positive effects (Baum, Fleming, & Singer, 1983) or even found a negative relationship between problem-focused coping and parents' outcomes (Pottie & Ingram, 2008). The mixed results found in coping can be explained by the contextual characteristics of coping, meaning that coping is not innately good or bad, but is based on the context in which it expresses (Folkman & Moskowitz, 2004). That is, the effectiveness of coping depends on the types of issues (Pearlin & Schooler, 1987). For instance, if a problem cannot be solved, using problem-focused strategies may lead to negative psychological effects.

Parents' appraisal system also changes over time. Gray (2006) found a declining parent-reported importance of treatment services by aging parents and an acceptance of unfulfilled expectations. Consistent with the existing literature, the same author also found that more parents of children with ASD use emotion-focused strategies when they and their children get older, indicating that aging is positively correlated with emotion-focused coping strategies (Gray, 2002).

Mediating effects

As presented previously, a large number of variables is associated with parent outcomes. To truly untangle the relationships, one has to consider the mediating effects between the predictors and parent outcomes. In fact, many researchers often underestimate the prevalence of indirect effects, especially when predictors do not have a direct effect on the outcome variables (Hayes & Rockwood, 2006).

The ABCX model postulates that resources and family perception/ coping strategies mediate the effects of stressors on adaptive outcomes. The emerging literature also provides support for such a claim. For instance, parents' cognitive appraisal of caregiving responsibilities mediates the relationship between the child's level of disability and parents' outcomes, such as stress, depressive symptoms, and lack of quality of life (Dardas & Ahmad; Plant & Sanders, 2007; MacDonald, Hastings, & Fitzsimons, 2010). Feeling uplifted was also an important mediator between resources and parents' depressive symptoms (Christensen, 2014), implying that one has to perceive positivity on top of the receipt of resources in order to obtain desirable outcomes. Contrarily, stigmatic perception was a detrimental mediator on parents' depressive symptomology (Cantwell, Muldoon, Gallgher, 2015). Perception of the amount of support also acted as a mediator;

Herman and Marcenko (1997) found that the adequacy of respite care mediated the relationship between the actual amount and quality of respite and parental distress. Other than how parents view their children's difficulties, parents' coping strategies were also an important mediator between family stressors and their own health. In a more recent study on parents of adolescents and young adults with ASD, Yu (2017) found that passive-avoidance was a mediator between stressors and parent stress.

On top of family perception and coping, resources are also a significant mediator found in the literature. For instance, Feldman and colleagues (2007) found that general support had a mediating effect on the relationship between children's behavior problems and caregiver depressive symptoms. The same research team also found that time was an important resource that mediated the effect of children's emotional and behavioral problems on caregivers' depressive symptoms. Similarly, McConnell, Savage, and Breitzkreuz (2014), also found that the effect of financial hardship on family life congruence was fully mediated by social support. Self-esteem and stress management were also associated with parents' mental and physical health (Cantwell et al., 2015; García-López, Sarriá, & Pozo, 2015; Hastings & Brown, 2002). At the family-level, Weiss and colleagues (2013) revealed that self-efficacy and social support mediated the pile-up of stressors on family hardiness, while family hardiness was also a partial mediator between stressors and family distress. This study provided a preliminary outlook of the complexity of mediators of interest and suggested the potential use of sequential mediation. Other than social resources or internal resources, social economic status was also found to be a significant mediator between role occupancy (e.g., whether parents have multiple roles in life) and wellbeing (Eisenhower & Blacher, 2006). Beyond

simple regressions, Nachshen and Minnes, 2005) further confirmed the mediating role of resources between stressors and family empowerment at a structural level.

However, divergent results with regards to the mediating roles of resources and family perception/coping strategies complicated the full picture of mediators. For instance, Fieldman and colleagues (2007) could not find any mediating effect of escape-avoidance coping strategies on the relationship between children's challenging behaviors and parent depressive symptoms. Similarly, Duchovic, Gerkenmeyer, and Wu (2009) found that perceived tangible support and intangible support did not mediate the relationship between children's internalizing and externalizing behavior problems and parental distress. Also, despite a relatively large amount of studies reporting the indirect effects of resources and family perception/coping, less is known about the sequential mediating effects between the two variables. For instance, Ekas, Lickenbrock, & Whitman, 2010) identified that optimism mediated the relationship between support (i.e., friend support, partner support, and family support) and parents' outcomes (i.e., parents' depression, negative affect, and parenting stress). This result implied that resources might influence parents' perception.

The relationships among the outcome variables also presented an issue in the literature. We often assume outcome variables, such as depressive symptoms, stress levels, and quality of life, are parallel variables (e.g., Ekas et al.; Hastings & Brown, 2002); however, some emerging findings suggested that these variables might be predictors of other desirable outcomes or even predictors of resources and family perception/coping strategies. For instance, parenting stress was found as a mediator between children's challenging behaviors and parenting self-efficacy (Rezendes &

Scarpa 2011). A similar result was also found by Sales, Greeno, Shear, and Anderson (2004), showing that parenting strain mediated between children's mental health and maternal mental health.

Limitation of the Existing Literature with Regard to Transition

Even though some studies about young adults with ASD are available, many questions are left unanswered (Tincani & Bondy, 2014). One critical topic is understanding the transition from high school to work and what schools, outside agencies, parents, and individuals with ASD can do in order to obtain an optimal outcome. Wehman and colleagues (2014) summarized that there is an urgent need to develop evidence-based interventions and programs in academic, vocational, and social settings, and understand their impact on work and community functioning. It is also important to understand the role of schools and the importance of accessing internships and paid employment, as well as continual behavioral and social communication therapies during the transition period. Likewise, researchers must understand effective transition activities in school, college, and the workplace for individuals with ASD across the spectrum. Additionally, more attention needs to be paid to new technologies and their potential effects on assisting older individuals with ASD in order to help them function independently at home and in the community, workplace, and school. The authors also highlighted the importance of documenting the positive experiences of individuals with ASD throughout the transition and aging processes.

Other than the summary by Wehman and colleagues (2014), there are three additional limitations that are pertinent to the present study. First, we do not have a comprehensive picture of the sequence of events, experiences, and actions associated

with the transition. Without a clear, comprehensive picture of the current situation, practitioners are less likely to pinpoint areas of needs of students with ASD and their families. Second, traditional measures of successful transition outcomes, such as competitive employment and independence, may not be appropriate for students with more severe disabilities. Merely focusing on the traditional measures of outcomes will miss the big picture of the wellbeing and quality of life of young adults with ASD. For individuals with more severe disabilities, the number of services and support received by the family is also a critical indicator of good transition outcomes. Third, since parents often continue to be the major caregivers of children with ASD, a successful transition should also be based on how well the family is doing and how parents perceive the transition process (Neece et al., 2009). Yet, we have a limited understanding of the role of parents and their impact on transition planning quality, as well as the impact of transition on caregivers' wellbeing.

Part Two – A Systematic Review

The ABCX model has been used extensively in order to understand the adaptation and adjustment process within the family structure during stressful events (Lustig, 1999). Under this model, family stress (i.e., the outcomes) is viewed as a product of the interactions among different demands (e.g., stressors or events), available resources (e.g., social support), coping styles (e.g., problem-focused or emotion-focused coping), and cognitive appraisal (e.g., the perception of the stressors) (McCubbin & Patterson, 1983). In order to understand the adaptation and adjustment process of families with ASD in the field of ASD, several attempts to use the ABCX model were made (e.g., McGrew &

Keyes, 2014; Orsmond & Seltzer, 2007; Pozo, Sarria & Brioso, 2014; Stuart & McGrew, 2009).

Limitations of the Literature with Regard to ABCX Model

Despite efforts to understand the adaptation and stress of families of individuals with ASD using the ABCX, the existing studies lack systematic literature reviews or meta-analyses to review how the ABCX model was used and the relative weight of the components of the models (i.e., stressors, pile-up demands, internal resources, external resources, appraisal, and coping). A recent study by McStay, Trembath, and Dissanayake (2015) organized some major findings related to the adjustment and adaptation of the families of individuals with ASD using the ABCX model. This study was helpful in order to understand the potential factors that could impact the adjustment and adaptation process of the families of individuals with ASD. However, it posed a few limitations. First, since the article had a focus on providing a general developmental view on family processes and was not a systematic review, it failed to capture multiple high quality empirical studies that used the ABCX model with the families of individuals with ASD (e.g., McGrew & Keyes, 2014; Stuart & McGrew, 2009; Renty & Royers, 2007; Pozo et al., 2014). Second, the general focus and descriptive nature of the literature review lead to an additional problem; McStay and colleagues (2015) included a considerable amount of studies that did not employ the ABCX Model. Without understanding all the potential effective variables using the ABCX model, the weight of each variable on the family outcomes (e.g., family adaptation) and how the ABCX model was used in the field were unclear. Third, McStay and colleagues (2015) only focused on the role of parents in the

family adaptation process; their study did not take into account the active impact of individuals with ASD during this process (i.e., the use of the ABCX model with individuals with ASD; see Renty & Royers, 2007). Fourth, McStay and colleagues (1995) failed to account for non-traditional outcomes with regard to family adaptation using the ABCX model (e.g., empowerment and advocacy; see Ewles, Clifford, Minnes, 2014; Nachshen & Minnes, 2005). Other studies attempted to use the ABCX model in order to understand the variables that impact the adaptation process of the families of individuals with ASD and guided program development, but also also suffer similar limitations (e.g., Bluth, Roberson, Billen, Sams, 2015; Probst, Jung, Micheel, & Glen, 2010; Ramisch 2012).

In this systematic review, I will examine the available published evidence regarding the use of the ABCX model for individuals with ASDs and their families. This review aims to briefly understand the predictors and outcomes (X) used for individuals with ASD and their families that are organized according to the constructs of the ABCX model. The results will provide information specifically related to the ABCX model for the research question and model development of the current study.

Procedures

Search Details

The current review used three databases: PsycINFO, Medline, and ERIC. In addition, an ancestry search (i.e., reviewing the references of an article) was also conducted. The subject headings used were “ABCX Model”, “Double ABCX Model”, and “autism,” and these search headings yielded 44 articles in the databases. An

ancestry and manual search identified an additional 52 articles. The literature search covered articles published up to December 2017.

Inclusion Criteria

The selection of articles included in the current literature review adhered to the following criteria: The article had to (1) clearly mention the use of the ABCX model as a conceptual framework; (2) examine at least two out of six components of the model (i.e., stressors, pile-up demands; internal resources; external resources; appraisal/ family perception; coping); (3) have individuals with a n medical diagnosis of ASD or their families as participants; (4) have at least 15 participants in total; (5) be an empirical study; (6) use quantitative outcome measures; and (7) be published in a peer-reviewed journal. Nineteen studies met these criteria. One study was excluded due to its qualitative nature of the study. Eight-five articles were excluded due to either the descriptive nature of the article, a lack of use of the ABCX model as a conceptual framework, or an absence of participants with ASD or of family members with ASD.

Results

Outcomes Variables

The results showed that twenty types of outcomes were collected in the 19 studies. The outcomes can be categorized by three levels (i.e., family, dyadic, and individual levels). At the family level, the variables included family burden/ family psychological distress, family quality of life, family functioning, family empowerment, and family social and environmental characteristics. Thirty-seven percent of the total number of studies used family-level variables as their outcomes (Sturt & McGrew, 2009,

Paynter, Riley, Beamish, Davies, & Milford, 2013, Pozo, Sarria & Brioso, 2014, McStay, Trembath, & Dissanayake, 2014, Reddon, McDonald, & Kysela, 1992, Nachshen & Minnes, 2005, Manning, Wainwright, & Bennett, 2011). The majority of the family-level outcome variables were only used by one study (e.g., family psychological distress). The only exception was family quality of life, which was used in two studies.

At the dyadic level, the variables included marital adjustment and marital satisfaction. Around 26% of studies used dyadic-level variables as their outcomes (McGrew & Keyes, 2014, Sturt & McGrew, 2009, Bristol, 1987, Renty & Royers, 2007, Paynter, et al., 2013). Four studies used marital adjustment as their outcome, whereas only one study used marital satisfaction as its outcome.

The variables at the individual level used were individual/caregiver burden, depression/psychological distress, quality of parenting, parental stress, parent psychological well-being, quality of parenting, parental stress, parent quality of life, instrumental involvement, affective involvement, parent social functioning, parent advocacy, parent subjective health status, caregiving satisfaction, and caregiver self-efficacy. The majority of these studies (84.2%) included individual-level variables as outcomes. The most commonly used individual-level outcome variables were depression/psychological distress and parental stress. These two variables were used by at least four to six studies. The next most reported variables were individual/caregiver burden, parent social functioning, and parent subjective health status. These three outcome variables were used by two to three studies. The rest of the individual-level variables were used only by one study.

Forty-two percent of studies used variables at different levels in order to capture the adaptation and adjustment process. For instance, Paynter and colleagues (2013) included family psychological distress (family level), marital satisfaction (dyadic level), and parental stress (individual level) as outcomes.

Outcome Measures

The previous section showed that twenty types of outcomes were collected in the 19 studies. However, researchers sometimes use different measures, even when assessing the same construct. See Table 2.2 – 2.4 for the descriptions of the measures used and their psychometric properties. Overall, all the measures, except one, have at least an acceptable internal consistency (Cronbach, 1951). However, only six measures (28.6%) had information regarding test-retest reliability coefficients.

Factors that Impact Outcomes

Articles that included regression analyses were analyzed in this section. See Table 2.6 for the descriptions of the predictors and their impact on the respective outcomes.

At the family-level, it was found that the child's problem behavior, pile-up demands, reframing, subjective social status, ASD severity, sense of coherence, formal and informal resources, and social support were some potential predictors.

At the dyadic level, the child's externalizing behaviors, family sense of coherence, perceived social support from spouse, perceived social support from family friends and acquaintances, pile-up demands, social support, negative appraisal, avoidant coping, and coping skills were some potential predictors.

At the individual level, it was found that the child's externalizing behaviors, ASD severity, child choice making, family challenge, family sense of coherence, social

support, parent community involvement, family coping style, received social support from family friends and acquaintances, SES, distance to the sibling's residence, sibling's level of independence, parent overall health, perception of aging, perceived stress, parent educational level, pile-up demands, coping style, negative appraisal, parental internal locus of control, and parent-teacher alliance were some potential predictors.

Study Characteristics

The majority of the studies (76.47%) focused on parents with young and school-age children (range from 44 – 300.24 months old). Only one study examined the outcomes from the perspective of individuals with ASD. Also, only one study examined the outcomes from the perspective of the siblings of individuals with ASD. Consistent with other studies (e.g., Benson, 2006; Cox, Reeve, Cox, & Cox, 2012), females (mostly mothers) were the major participants in the current studies reviewed. The study was also consistent with epidemiology studies that show there are more boys affected by ASD (CDC, 2014); these 19 studies included more respondents with male children with ASD. Among those studies reported the gender of the individuals with ASD, 86% of them were constituted by 70% or more males with ASD in their studies. Of all the reviewed studies, only five of them reported information with regard to the participant's race. It was reported that more than 90% of participants were white in two studies. See Table 2.6.

Table 2.2

Descriptions of Out Measures Used at Family Level

Construct measured	Measures	Numbers of item	Scales	Internal consistency (a)	Test- retest reliability	Used by
Family Burden/ Family Psychological Distress	The Impact on Family Scale (IOF: Stein & Reissman, 1980)	24	4-point Likert scale (1 = strongly agree; 4 = strongly disagree)	0.88	0.72	Sturt & McGrew, 2009
						Paynter, Riley, Beamish, Davies, & Milford, 2013
Family quality of life	The Beach Center Family Quality of Life Scale(FQOL, Park et al., 2003)	25	5-point Likert scale (1 = very dissatisfied to 5 = very satisfied)	.88 - .94 based on subscales	.54-.82 based on subscales	Pozo, Sarria & Brioso, 2014
						McStay, Trembath, & Dissanayake, 2014
Family Functioning	Family Assessment Measure HI. The Family Assessment Measure III (FAM III;Skinner, Steinhauer, & Santa-Barbara, 1984)	50	4-point Likert scale (1 = strong agree; 4 = sribgky disagree)	0.93	----	Reddon, Mcdonald, & Kysela, 2006

Table 2.2 (continued)

Family empowerment	The Family Empowerment Scale (FES; Koren et al., 1992)		5-point Likert scale (1 = not true at all; 5 = very true)	.87 - .88 based on subscales	.77 - .85 based on subscales	Nachshen & Minnes, 2005
Family social and environmental characteristics	The Family Environment Scale (FES) (Moos & Moos, 1986) Relationship dimension	27	True; False	0.81	----	Manning, Wainwright, & Bennett, 2011

Table 2.3
Descriptions of Measures Used at Dyadic Level

Construct measured	Measures	Numbers of item	Scales	Internal consistency (a)	Test- retest reliability	Used by
Marital adjustment	Dyadic Adjustment Scale (DAS: Spanier, 1976)	32	6-point Likert scale (0 = always disagree; 5 = always agree)	0.96	----	McGrew & Keyes, 2014
	Short Marital Adjustment Test (Locke & Wallace, 1959)	15	Used a variety of scale	.38 - .74 based on subscales	----	Sturt & McGrew, 2009 Renty & Royers, 2007 Bristol, 1987
Marital Satisfaction	The Marital Satisfaction Questionnaire (MSQ: Norton, 1983)	6	Used a variety of scale	.96	----	Paynter, Riley, Beamish, Davies, & Milford, 2013

Table 2.4

Descriptions of Measures Used at Individual Level

Construct measured	Measures	Numbers of item	Scales	Internal consistency (a)	Test- retest reliability	Used by
Individual Burden/Caregiver Burden	The Caregiver Strain Questionnaire (CGSQ; Brannan & Heflinger, 1997)	21	5-point Likert scale (1 = not at all a problem; 5= very much a problem)	0.93	0.76	Sturt & McGrew, 2009
	Caregiving burden (Heller et al. 1994)		5-point Likert scale (1 = not at all a problem; 5= very much a problem)	0.87		McGrew & Keyes, 2014 Burke, & Heller, 2016
Depression/ Psychological Distress	Center for Epidemiologic Studies-Depression Scale (CES-D; Radloff, 1977)	20	4-point Likert scale (1 = rarely or none of the time (less than 1 day); 4 = more or all of the time (5-7 days)	0.85	0.51	Bristol, 1987

Table 2.4 (continued)

						Minnes, Woodford, & Passey, 2007
	The Depression Anxiety Stress Scale- 21 (DASS-21: Lovibond & Lovibond, 1995)	21	4-point Likert scale (1 = did not apply to me at all; 3 = Applied to me very much)d	0.82-0.93 based on subscales	----	Paynter, Riley, Beamish, Davies, & Milford, 2013
						Pakenham, Sofronoff, & Samios, 2003
Parent psychological well being	The Brief Psychological Well-being Spanish Version (Diaz et al. 2006) * A translated version of Psychological Well-being Scale (Ryff 1989)	29	4-point Likert scale (1 = completely disagree to 4 completely agree)	0.84	----	Pakeham, Samios, & Sofronoff, 2005
Quality of parenting	Home Quality Rating Scale (HQRS), Factor I, Harmony of Home and Quality of Parenting (Meyers, Mink, & Nihira, 1977)	7	----	0.83	----	Bristol, 1987

Table 2.4 (continued)

Parent stress	The Parenting Stress Index: Short Form (PSI-SF: Abidin, 1995b)	36	5-point Likert scale (1 = strongly agree; 5= strongly disagree)	0.95	.68 –.84. Based on subscales	Paynter, Riley, Beamish, Davies, & Milford, 2013 McStay, Trembath, & Dissanayake, 2014 Pozo & Sarria, 2014 Manning, Wainwright, & Bennett, 2011 Krakovich, McGrew, Yu, & Ruble 2016
	Questionnaire on Resources and Stress - Short Form (QRS-SF; Holroyd, 1974)	31	True/False	.95 (Kurder-Richardson-20 reliability)	----	Jones & Kingston, 2005
Parent quality of life	"Overall, how do you feel about the quality of your life?"	1	7-point Likert scale (1 = terrible; 7 = delighted)	----	----	Minnes, Woodford, & Passey, 2007

Table 2.4 (continued)

Instrumental Involvement	"How often they saw their brother or sister in person and spoke with them on the phone" + siblings indicated the type of activities that they shared with their brother or sister in the last year.	3	Used a variety of scale	----	----	Orsmond & Seltzer, 2007
Affective Involvement	Positive Affect Index (PAI; Bengston & Black 1973)	10	6-point Likert scale (1 = not at all ; 6 = extremely)	0.94	----	Orsmond & Seltzer, 2007
Parent Social Functioning	The Social Adjustment Self-Report Questionnaire (SAS-SR) (Weissman, 1986)	54	5-point Likert scale	0.72	----	Pakenham, Sofronoff, & Samios, 2003
Parent Advocacy	The Parent Advocacy Scale (PAS; Nachshen, Anderson, & Jamieson, 2001)	26	4-point Likert scale	0.87	----	Pakenham, Samios, & Sofronoff, 2005 Ewles, Clifford, Minnes, 2014

Table 2.4 (continued)

Parent subjective health status	As a global rating of subjective health status	1	5-point Likert scale (1 = extremely poor; 5 = excellent)	----	----	Pakenham, Sofronoff, & Samios, 2003
						Pakeham, Samios, & Sofronoff, 2005
Caregiving satisfaction	Caregiving satisfaction (Lawton et al. 1982)	5	5-point Likert scale (1 = strongly disagree; 5 = strongly agree)	0.78		Burke, & Heller, 2016
Caregiver self-efficacy	Caregiver self-efficacy (Heller et al. 1999)		5-point Likert scale (1 = strongly disagree; 5 = strongly agree)	0.71		Burke, & Heller, 2016

Table 2.5
Descriptions of Regression Analyses

Articles	Predictors	Outcome variables	Description (Direct Excerpts)	Mediation/Moderation Analysis
Bristol, 1987	----	----	No regression analysis	No
Burke, & Heller, 2016	(1) Child problem behavior (2) Presence of an intellectual disability (3) Child health (4) Family income (5) Parent age (6) Child community involvement (7) Child choice making*(-) (8) Future planning for the child*(+) (9) Unmet service needs	Caregiving satisfaction	Results showed that greater future planning and community involvement related to more caregiving satisfaction and increased caregiving self-efficacy, respectively. Less choicemaking of the adult with ASD related to greater caregiving satisfaction and self-efficacy. Maladaptive behaviors and poor health of the adult with ASD related to greater caregiving burden.	No
	(1) Child problem behavior (2) Presence of an intellectual disability (3) Child health (4) Family income (5) Parent age (6) Child community involvement*(+) (7) Child choice making*(-) (8) Future planning for the child (9) Unmet service needs	Caregiving self-efficacy		
	(1) Child problem behavior*(+) (2) Presence of an intellectual disability (3) Child health*(-) (4) Family income (5) Parent age (6) Child community involvement (7) Child choice making (8) Future planning for the child (9) Unmet service needs	Caregiving burden		

Table 2.5 (continued)

Ewles, Clifford, Minnes, 2014	(1) Maladaptive coping strategies* (-) (2) Emotional support	Parent advocacy	Results showed that use of maladaptive coping strategies was a significant predictor of current levels of advocacy, which suggests that advocacy may itself be an active coping strategy for parents.	No
Krakovich, McGrew, Yu, & Ruble 2016	(1) Language ability (2) Intellectual ability (3) Child problem behaviors*(+) (4) Child adaptive behaviors (5) ASD severity (6) Number of children in the home (7) Parent education*(-) (8) Family income (9) Parent race (10) Pile-up demands (11) Parent-teacher alliance*(+) (12) Receipt of COMPASS intervention (13) No. of services a child received	Parent stress	Stronger parent–teacher alliance correlated with decreased Parent domain stress and participation in COMPASS correlated with decreased Child domain stress after controlling for baseline stress.	No
Jones & Kingston, 2005	(1) Social support * (-) (2) Family coping style* (-) (3) Support coping style* (-) (4) Medical coping style (5) Parental efficacy * (-) (6) Parental internal locus of control* (+) (7) Parental belief in fate/chance (8) Control by parent	Parent stress	Results indicated that the strongest predictors of parental stress were family coping style and parental internal locus of control. Parents who believed their lives were not controlled by their child with a disability and who coped by focusing on family integration, co-operation, and were optimistic tended to show lower overall stress.	No

Table 2.6

Study Characteristics

Articles	Mean Child age (Months)	Mean Participant age (Years)	Child gender (Male)	Participant gender (Female)	Race (White)	<i>N</i>	Participants
Bristol, 1987	63.6	31	75.60%	100%	----	45	Parent
Burke, & Heller, 2016	300.24	54.64	72.3%	83.8%	73.8%	130	Parents
Ewles, Clifford, Minnes, 2014	134.52	43.89	----	100%	----	28	Parents
Krakovich, McGrew, Yu, & Ruble 2016	70.68	----	----	91&	78.9%	79	Parents
Jones & Kingston, 2005 (DD)	96	----	68.60%	----	----	48	Parent
Manning, Wainwright, & Bennett, 2011	105.6	10.9	82.56%	95.90%	59%	195	Parents
McGrew & Keyes, 2014	57.06	35.04	78.50%	98.70%	94.90%	78	Parent
McStay, Trembath, & Dissanayake, 2014	106.8	43	85.70%	50%	----	196	Parent
Minnes, Woodford, & Passey, 2007	428.4	65.7	62.50%	----	----	80	Parent
Nachshen & Minnes, 2005	103.32	40.32	70%	99%	----	100	Parents
Orsmond & Seltzer, 2007	418.56	38.17	72.70%	58.40%	----	77	Sibling
Pakeham, Samios, & Sofronoff, 2005	----	----	----	100%	----	47	Parents

Table 2.6 (continued)

	129	41.49	84.70%	47/59	----	59	Parents
Pakenham, Sofronoff, & Samios, 2003 (DD)							
	49.35	----	83.80%	58.14%	----	43	Parent
Paynter, Riley, Beamish, Davies, & Milford, 2013							
	148.8	45.65	92.20%	50%	----	118	Parents
Pozo & Sarria, 2014							
	148.8	45.65	79.70%	50%	----	118	Parent
Pozo, Sarria & Briosio, 2014							
	44	32.5	----	50%	----	16	Parent
Reddon, McDonald, & Kysela, 2006 (DD)							
	513.18	----	----	50%	----	42	Men with ASD and their wives
Renty & Royers, 2007							
	57.06	35.04	78.50%	98.70%	94.90%	78	Parent
Sturt & McGrew, 2009							

Discussion of the Systematic Review

The ABCX model is a flexible model that can be used partially or wholly depending on the needs of projects (McCubbin & Patterson, 1983). Consistent with this view, the current review found a range of outcomes at different levels measured by the 19 articles using the ABCX model with individuals with ASD and their families. Family adaptation and adjustment are multi-level and multidimensional concepts in relation to time (see Masten & Monn, 2015). The ABCX model provides a vehicle to better organize and capture these dynamic concepts. With that being said, researchers need to pay attention to three conceptual issues in particular when using the ABCX model. First, family is a hierarchical mechanism (Lazarus & Folkman, 1984; Pottie & Ingram, 2008) that has an overarching effect on the individuals in it. When using the ABCX model, one has to consider the “level” of the outcome variables. However, the results showed that only forty-seven percent of studies used variables at different levels in order to capture the adaptation and adjustment process. Among all the articles, none examines the influences of and impact on family members nested under the family. Even more so, none of the studies used multilevel modeling to understand the levels of the variables. An absence of multilevel analyses does not only simplify the family system, it also limits our empirical understanding of the multilevel nature of family systems.

Second, family adaptation and adjustment is multidimensional, meaning that it includes a variety of positive aspects in life. Even though the outcome variables differ at a micro-level, they were surrounding the traditional factors used to capture family adaptation and adjustment, such as quality of life, stress level, and family relationships. Newer, nontraditional concepts, such as advocacy and empowerment were underused as

parts of the family adaptation and adjustment processes. Poston and colleagues (2006) found out some important aspects of positive family outcomes; they are advocacy (advocacy role, advocacy activities, and facilitators of advocacy), emotional well-being (identity, respect, and reducing stress, choice), health (e.g., physical and mental health and health care), environmental well-being (home, school, work, and neighborhood and community environment), productivity (education), work (leisure and personal development), and social well-being (social acceptance, relationships, and support). One can see that the concept of family adaptation and adjustment outcomes are far broader than those captured by the current reviewed studies. Considering broader positive family adaptation and adjustment outcomes is important to facilitate a more accurate picture of meaningful family outcomes.

Third, from a life-long standpoint, family adaptation and adjustment itself is a fluid process. Parents of children with ASD may face different stressful situations and change their strategies for coping with them as they and their children age (Gray, 2002). In the meantime, expectations about positive family adaptive outcomes may change over time as well. For instance, Gray (2006) found a declining importance of treatment services by aging parents and an acceptance of unfulfilled expectations. The same author also found that more parents with ASD use religious faith and other emotion-focused strategies when they and their children get older, which is consistent with the existing literature that indicated aging is positively correlated with emotion focused coping strategies (Gray, 2002). Apparently, the element of “time” is critical to help us understand important predictive and outcome variables at a particular time point. Longitudinal studies play an important role in understanding the impacts of time on the

family adjustment and adaptation process. However, only one article (McGrew & Keyes, 2014) longitudinally examined individual burden and marital adjustment and their predictors using the ABCX model. A lack of attention to the multi-level, multidimensional concepts, and time sensitive natures of the issues faced by individuals with ASD and their families when using the ABCX model, underplays the complexity of the family adaptation and adjustment process.

As mentioned before, multiple attempts have been made to use the ABCX model to organize variables relevant to the outcomes, stressors, pile-up demands, internal resources, external resources, appraisal, and coping in order to understand the family adaptation and adjustment process (e.g., McStay et al., 2014; Bluth et al., 2015; Probst et al., 2010; Ramisch 2012). However, there is still a lack of a comprehensive picture of the relationships. Four additional factors with regard to study designs complicate the process towards a more in-depth, comprehensive understanding of the family adaptation and adjustment outcomes. First, existing literature often fails to use consistent terminology or differentiate between similar outcome constructs. For instance, Sturt and McGrew (2009) used the Impact on Family Scale (Stein & Reissman, 1980) to measure family burden as an outcome. Later, Paynter and colleagues used the same measure to assess family psychological distress. A lack of consistency in terminology and use of measures may lead to conceptual confusion. Also, the existing literature fails to differentiate between similar outcome constructs. For instance, marital adjustment was used in three studies as one of the proxies of the family adjustment and adaptation outcome (McGrew & Keyes, 2014; Sturt & McGrew, 2009), whereas marital satisfaction was used in one study (Paynter et al., 2013). Even though the two constructs are conceptually similar and their

measures are correlated, marital adjustment is a more inclusive, comprehensive concept than marital satisfaction (see Heyman, Richard, Steven, Sayers, & Bellack, 1994; Winch, 1963). Paynter and colleagues (2013) failed to build on the previous findings that showed a significant relationship between the ABCX model and marital adjustment, nor does this study point out the reason of the selection of a more narrowed construct. This phenomenon can also be found among the individual-level outcome variables. It is unclear how caregiver burden, parent psychological distress, parent psychosocial wellbeing, and parental stress totally differ from each other and how they relate to a potential latent variable (e.g., family adaptation and adjustment). The inclusion of all potential outcome variables and predictors into one single analysis and the use of multivariate statistical analysis to analyze structural relationships (e.g., structural equation modeling) can be used in order to help answer some important questions, such as the weights of the outcome measures in relation to the latent variable (e.g., family adaptation and adjustment).

Second, another issue associated with the outcome measures is that the use of the ABCX model is largely limited to parents of school-age children. Currently, only one study examined the outcomes from the perspective of individuals with ASD. Also, only one study examined the outcomes from the perspective of the siblings of individuals with ASD. The original design of the ABCX model is to measure family-level adaptation and adjustment processes (McCubbin & Patterson, 1983). Ideally, all family members who live together should be interviewed in order to capture the opinions and experiences within the family based on Figley (1995)'s view. Understandably, many studies had to select one member to be measured due to limited resources. However, it seems like the

existing narrowed scope on family adaptation and adjustment exceeds beyond the limitations of resources. Fifty-three percent of the studies only used parent functioning reported by parent respondents as the adaptation and adjustment outcomes, whereas individuals with ASD were frequently categorized as stressors when using the ABCX model. The findings showed that some important family members other than parents, such as siblings and individuals with ASD, are not treated as active mechanisms that bring positive changes to the families. This phenomenon is consistent with the general low expectation of the families of individuals with disabilities (Jackson, 1994; Russell, 2003). It is important to have a more in-depth understanding of the role of siblings and individuals with ASD on family outcomes, as their roles will become more important as their parents age (Orsmond & Seltzer, 2007; Seltzer, Shattuck, Abbeduto, & Greenberg, 2004).

Third, along with the second point of view, the limited use of the ABCX model with parents of older or adult children with ASD leaves some of the important questions unanswered. The stress of caring for children with ASD is high and varies across time as the child moves through various developmental milestones. Research on autism suggests families usually experience an increase in stress as the child with ASD moves into adolescence, followed by a possible decreasing trend of stress levels when the child moves into adulthood (Orsmond, Greenberg, and Krauss, 2006; Seltzer et al., 2003). Families with ASD may also experience negative emotions and a decrease in functioning during key transition points as their child ages (e.g., transition from high school) (see Baxter, Cummins, & Polak, 1995; Thornin & Irvin, 1992). Many studies tried to understand the protective factors and stressors of families of children with ASD during

this period of time. The ABCX model is a useful conceptual framework with which to organize and compare a variety of variables that promote positive family outcomes. However, there is relatively little research comprehensively examining the aging of individuals with ASD and their families (Tantam, 2014).

Fourth, the current review showed that only five studies reported information with regard to the participant's race. Yet, cultural factors may have a huge impact on the perceptions and coping of parents with disabilities (Dyches, Wilder, Sudweeks, Obiakor, & Algozzine, 2004). Also, it is known that significant racial/ethnic disparities exist in the identification of ASD (e.g., African American children; Mandell et al., 2009). A lack of racial and ethnic information regarding to participants may limit the understanding of the application of the ABCX model on individuals from nonmainstream cultures. Meanwhile, the ABCX model is a useful framework to compare the adaptation and adjustment process between families with different cultural backgrounds.

Overall, the general literature review and the systematic review pinpointed some strengths and weaknesses of the current literature. Since there is little known about the transition process from a parent's perspective, the current study needs to explore such areas and hopes to enrich the literature with regard to transition support for families of youth and young adults with ASD.

Chapter 3 Method

A mixed methods approach, **exploratory sequential research design**, was used. It included a qualitative phase followed by a quantitative phase. The purpose of this method was to use qualitative data to guide the development of quantitative studies (Creswell & Clark, 2011, p.80). The use of exploratory sequential design further confirmed the potential significance of the variables that were used in the latter quantitative phase and estimated the relationships among the variables. The quantitative phase was modified according to the findings from the prior qualitative phase. This method is particularly useful when limited empirical evidence is available, which is the case for the transition experiences of families with children with ASD.

Phase One: Qualitative Study

Participants

Participants. I recruited 13 parents of adolescents or young adults, aged from 16 to 26, with a clinical diagnosis of ASD, who currently have or previously had an IEP. The number of participants was believed to be sufficient to capture a complete picture (Guest et al., 2006). In order to take into account the differential effect of demographic variables on transition outcomes, the sample was systematically recruited based on geographic locations (e.g., suburban, and rural), SES, race, and gender, with at least 20% of the participants representing minority groups. Twenty-three percent of the parents were classified as low SES based on the Pew's income calculator based (Pew Research Center, 2017). The average age of the parents was 56 years old. More than half of them (58.3%) had a college or higher degree. Approximately half of their children were

reported to have a low cognitive ability (IQ score <70). Six children had finished high school. See Table 3.1 for demographic information.

Table 3.1
Demographic Information of the Qualitative Phase

Parent variables	<i>M (SD)</i>	Range
Age	56(8.43)	39-66
No. of children per family	2.17(.83)	1-4
No. of children with ASD per family	1.25(.45)	1-2
Therapies currently receiving (no. of different types)	.33(.65)	0-2
	N	%
Race (Non-Caucasian)	2	12.5
Gender (Male)	3	23.1%
Marital status (Married)	10	76.9%
Employment status (primary caregiver; employed full time)	10	76.9%
Education (college or above)	7	53.8%
Gender (Male)	3	23.1%
Annual household income (<\$60,0001 annual income)*	3	25%
Child variables	<i>M (SD)</i>	Range
Age	21.2(3.82)	15-27
No. of diagnoses other than ASD	1.21(1.12)	0-3

Table 3.1 (continued)

	<u>N</u>	<u>%</u>
Gender (male)	10	76.9%
Race (white)	10	76.97%
Reported cognitive ability (has ID)	6	46.2%
No. of diagnoses other than ASD	1.21(1.12)	0-3

*= has 1 missing data point

Measures

Survey packet. The Survey Packet consisted of the following two parts: (a) an open-ended interview protocol (OIP) and (b) a background questionnaire (BQ).

OIP. Participants answered untimed, semi-structured, open-ended questions. This began with four questions regarding the family’s transition experiences and followed up with individually tailored sub-questions related to the responses of each participant. Interviews were approximately 45-60 minutes in length (See Appendix A). These questions were developed to acquire information to research question one (i.e., What are the stressors, external and internal support, coping strategies, and parent transition outcomes from a parent’s perspective?) and were set up following the guidance of Jacob and Frierson (2012).

BQ. To understand and describe the sample of the parent participants, a 26-item BQ was administered. The BQ was used to capture the demographic information of parents (e.g., age, gender, income, education, services received, family situation) and children (e.g., age, education, services received, diagnosis).

Procedures

The principal investigator of the study conducted the interviews with the parents. All the individual interviews were conducted at places convenient to the participants, mostly at their homes. Confidentiality was discussed and informed consent was obtained before the interviews. All interviews were audio-recorded. Following the interviews, the parent participants were asked to complete the BQ.

Analyses

The analysis of the qualitative data was guided by the thematic analysis approach (Daly, Kellehear, & Glikman, 1997). Thematic analysis aims to capture the essential components of a phenomenon (e.g., the positive and negative transition experiences of parents) by searching for emerging themes (Braun & Clarke, 2006). In particular, a hybrid version of the thematic approach (Fereday & Muir-Cochrane, 2006) was used. The hybrid approach is a combination of the inductive approach (i.e., data-driven; Boyatzis, 1998) and deductive approach (i.e., develop a codebook before an extensive analysis of the data; Crabtree & Miller, 1999). That is, before extensive data analysis occurred, a codebook was developed based on the Double ABCX model for deductive analysis (Crabtree & Miller, 1999), and data-driven codes were developed and applied for inductive analysis (Boyatzis, 1998). The qualitative data analysis followed the guidelines by Fereday and Muir-Cochrane (2006).

Creating codes and saturation. At first, four deductive codes were developed. Based on Schaefer, Coyne, and Lazarus (1981) and Thoits (2010), three main sources of social support were identified – emotional, instrumental, and informational. In addition to

external resources, internal resources have also found to be important for parents who rebound in face of adversity (Bayat, 2007), therefore one additional code – personal resources – was developed in order to capture parents’ internal strengths.

After applying these four codes to all transcripts, an inductive coding method was employed to generate sub-codes for the four predetermined codes and to further categorize other emerging ideas. During the inductive coding phase, descriptive coding (i.e., a brief descriptive code assigned to a passage that contains a prominent idea) and emotion coding (i.e., a code assigned to label the emotions described or recalled by parents) were heavily used. At this stage, 48 main codes were identified from and applied to the four transcripts for the first round.

After testing the codes, the codes were further applied to five more transcripts for the second round. As new themes appeared and new codes developed, the new codebook was reapplied to the coded transcripts. At this stage, 51 main codes were identified.

Then, the new codebook was applied to the four remaining transcripts. The iterative process stopped until the data were saturated (i.e., with no new themes emerging for three consecutive transcripts).

Finally, the relationships among the codes, such as causes/explanations, relationships among people, and theoretical construct were examined repeatedly. Finally, the codes were further clustered deductively into the ABCX model (see Figure 3.1).

Data saturation. In order to ensure the reliability and validity of the results, plans must be put into place to ensure data saturation. Data saturation is obtained when “there is enough information to replicate the study, when the ability to obtain additional new information has been attained, and when further coding is no longer feasible” (Fusch &

Ness, 2015). Based on the suggestions by Fush and Mess (2015) and Guest and colleagues (2006), three steps were taken.

First, the interview questions were structured in such a way as to facilitate the same understanding among participants. In the current study, participants were given the same set of semi-structured, open-ended questions. Even though the follow-up questions were tailored based on participants' responses, the standard questions were asked in a consistent way. Second, data triangulation was implemented. By collecting data from multiple sources (e.g., collecting data from parents of children with different ages/ gender, and of different race/SES), it is believed that data triangulation was achieved. Third, 20% of the transcripts were coded by an independent researcher. Themes were compared with those coded by the independent researcher. The process was listed as follows: First, 20% of the transcripts were randomly selected for the secondary coder to review, and the secondary coder came up with her own themes. Second, the two coders cross-checked their themes to see whether there were any new or divergent themes. Third, since there were no divergent themes, the second coder independently applied the codebook developed by the primary coder to 20% of the transcripts. Reliability was calculated based on both the appearance and absence of the themes (i.e., whether a particular code appeared in a transcript). The exact-agreement reliability by transcript between two coders was 88.5%. Fourth, the two coders discussed any disagreements and reached a 100% agreement. When no new themes emerged (Guest, Bunce, & Johnson, 2006; Fusch & Ness, 2015), data collection was ceased. As expected, the data saturation was achieved with about 12 participants (Guest et al., 2006; Morse, 2000).

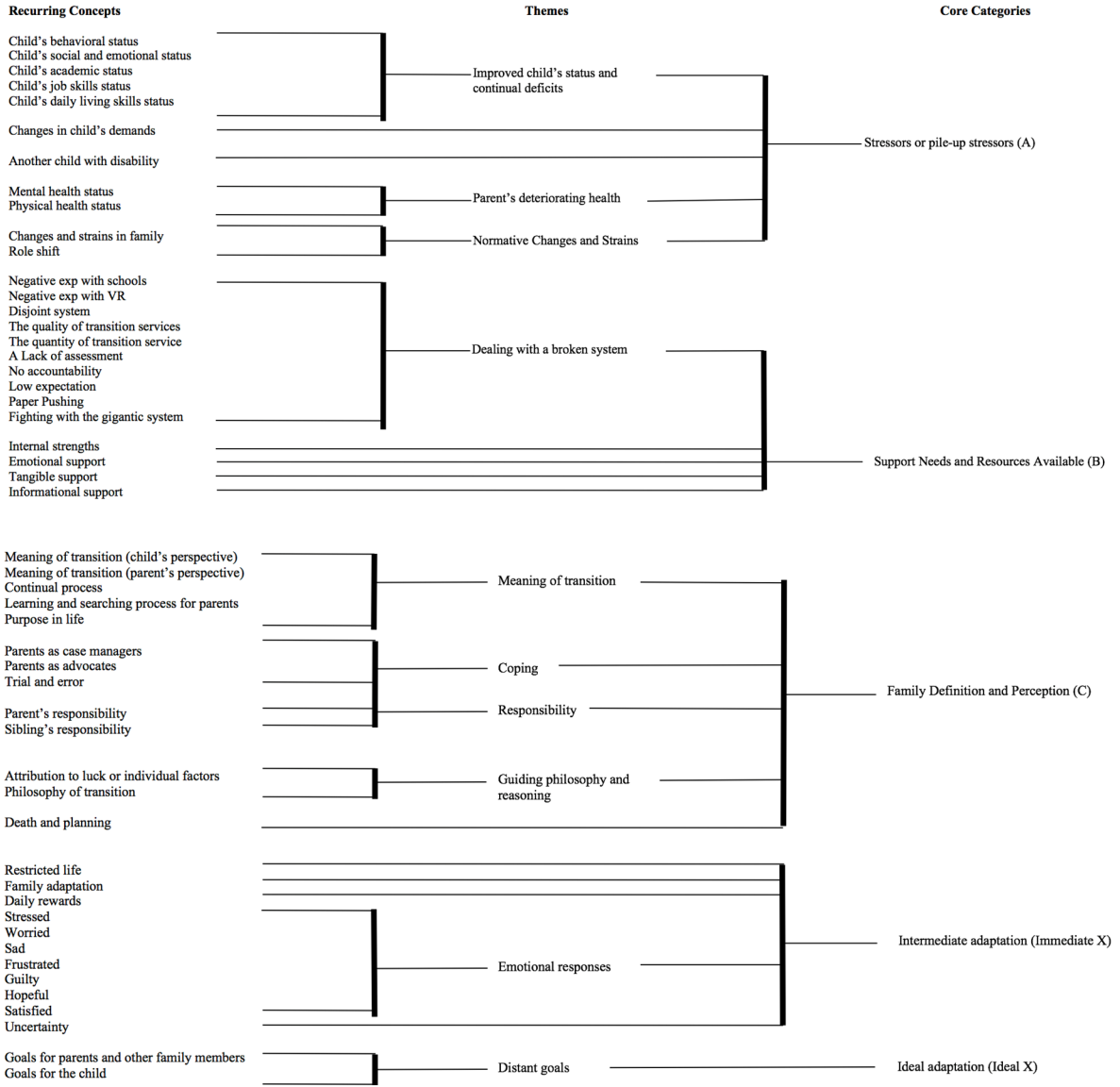


Figure 3.1. The stressors, resources, and coping during transition.

Modifications

As mentioned in the previous section, the current study employed an Exploratory Sequential Design (ESD) with an initial phase of qualitative data collection and analysis followed by a phase of quantitative data collection and analysis. The qualitative data collection and analyses were completed in May 2017. The purpose of the quantitative phase was to respond to the second research question (what are the predictors of parent transition outcomes?). In order to strengthen the relevance and comprehensiveness of the structural equation model (SEM), theoretically-driven and empirically-driven variables were included in the model. In particular, the qualitative results were used to inform important, empirical-driven variables to be included in the quantitative phase. The procedure was straightforward; the qualitative results were compared against the original SEM model. Prominent themes reported by parents were directly extracted in order to inform the current variables at two levels – inclusion (i.e., whether a new variable was needed to capture a new construct; e.g., parent-teacher alliance was added as a new variable) and comprehensiveness (i.e., whether new items were needed in order to capture a construct comprehensively; e.g., income and education were not enough to capture SES; therefore, debt, insurance, and zip code were added). See Table 3.2 for the modifications.

Table 3.2
Modification

Proposed changes	Changes made
<i>At item level</i>	
1. Income → increment by 5000	Changed the item
2. Debt	Added one more question to the background form
3. Insurance	Added one more question to the background form
4. Are you the primary or secondary caregiver	Added one more question to the background form
5. Zip code	Added one more question to the background form
6. Exercise	Added one more question to the background form
<i>At construct level</i>	
1. Parent-school relationship	Added Parent-Teacher Alliance (Ruble et al., 2005)
2. Optimism	Added The Life Orientation Test- Revised (LOT; Scheier, Carver, & Bridges, 1994)
3. Mental health crisis management	Added Mental Health Crisis Assessment Scale (MCAS; Kalb, 2017)
4. Religious/faith	Added Santa Clara Strength of Religious Faith Questionnaire (Plante & Boccaccini, 1997)
5. Filial obligation	Adapted and added the filial attitude measure by Mangen, Landry, and Bengtson 1987

Phase Two: Quantitative Study

Participants

The parent participants (N=252) was recruited through Amazon Mechanical Turk and each participant was paid \$7 for their participation. The survey contained five attention check questions which were randomly distributed throughout the survey (e.g., Please check “yes”). Participants who did not pass the attention check questions were screened out, resulting in a sample of 226. It is worth noting that six (2.7%) of the participants were not the parents but assumed the parenting roles of at least one transition-age youth with ASD. These relationships included uncles or older cousins. All of the participants were located in the United States. The parenthood status and locations were verified by Amazon Mechanical Turk and their IP addresses. All the participants reported that their children had an IEP during high school and received a clinical diagnosis of ASD from a psychologist, psychiatrist, or medical doctor. The current study also used the Social Communication Questionnaire as a measure of autism severity. Around 11.5% of the participants reported a SCQ score lower than 11 (i.e., a score of 11 represents a detection sensitivity of .92 to detect autism; Oosterling et al., 2010). The current study decided to retain the parents of individuals with ASD with minimal autism symptoms. Although ASD symptoms continue to affect the majority of individuals with ASD throughout adulthood (Volkmar, Reichow, & McPartland, 2014), approximately 10-15% of individuals with ASD obtained more favorable adult outcomes (e.g., become “symptom-free”; Seltzer, Shattuck and Abbeduto, 2004). The tendency of declined ASD symptomology in older age (Howlin & Moss, 2012) implies that some higher functioning adults with ASD may no longer meet the diagnostic criteria. In the current study, the

percentage of adolescents and young adults with a SCQ score lower than 11 is similar to the percentage reported in the Seltzer (2004)'s study. Since all the parents reported that their children are receiving special education services or received such services before they graduated from high school, I believe that the sample is a good representation of the whole spectrum of ASD that can help us understand transition-age youth during the transition process. Especially, the final model fit the two sets of data well. Thus, for the current study, the full data set (N=226) and reported corresponding results. Overall, the majority of the parents were white (77%) and female (68.2%). Half of them had a college degree. See Table 3.3 for more information.

Table 3.3
Demographic Information for Quantitative Phase

<u>Parent variables</u>		
	<u>N</u>	<u>%</u>
Race		
White	174	77.0
African American	24	10.6
American Indian/ Alaska Native	3	1.3
Asian	5	2.2
Latino or Hispanic	10	4.4
Bi-or Multi-racial	10	4.4
Family annual income		
Less than or = \$20,000	13	5.8%
\$20,001-\$25,000	15	6.6%
\$25,001-\$30,000	25	11.1%
\$30,001-\$35,000	10	4.4%
\$35,001-\$40,000	14	6.2%
\$40,001-\$45,000	11	4.9%
\$45,001-\$50,000	14	6.2%
\$50,001-\$55,000	7	3.1
\$55,001-\$60,000	19	8.4%
\$60,001-\$65,000	12	5.3%
\$65,001-\$70,000	9	3.0%
\$70,001-\$75,000	14	6.2%
\$75,001-\$80,000	14	6.2%
More than \$80,000	49	21.7%
Highest education		
High school graduate/GED	25	11.1%
Some college	65	28.8%
Technical or trade school	21	9.3%
College graduate	85	37.6%
Advanced graduate or professional degree	30	13.3%
Gender		
Female	154	68.1%
Male	72	31.9%
	<u>Mean (SD)</u>	<u>Range</u>
Age	40.68 (7.23)	23-65
Number of children	2.40(1.24)	1-7
Number of children with ASD	1.06(.31)	0-3
<u>Child variables</u>		
	<u>Mean (SD)</u>	<u>Range</u>
Age (years)	17.34 (1.65)	16-24
	<u>N</u>	<u>%</u>
Gender		
Female	69	30.5%
Male	157	69.5%
Graduated from high school		
Yes	70	31%
No	156	69%

Measures

A

Child's autism severity. The Social Communication Questionnaire (SCQ; Rutter et al., 2003) is a dichotomously rated (Yes/No), 40-item questionnaire that measures the severity of autism, with higher scores indicating greater autism symptom severity. A cut-off score of 11 indicated elevated likelihood to have an ASD diagnosis (Norris & Lecavalier, 2010). It was found good sensitivity and specificity in identifying autism (sensitivity = .85, specificity = .75; Norris & Lecavalier, 2010) and good internal consistency reliability ($\alpha = .80$ in McStay et al., 2014).

Child's adaptive skills. The Waisman Activities of Daily Living (W-ADL) Scale is a 17-item measure that uses a three-point Likert scale (0=does not do at all, 1=does with help; 2=independent) to evaluate the adaptive skills of individuals with disabilities. W-ADL demonstrated good construct validity and internal consistency ($\alpha = .88-.94$; Maenner et al., 2013).

Child's mental and behavioral health crisis/ challenging behaviors. The Mental Health Crisis Assessment Scale (MCAS; Kalb, Hagopian, Gross, & Vasa, 2017) is a 28-item measure that uses a hybrid scale to measure the presence of emotional and behavioral symptoms exhibited by a child. After reporting the symptoms, the parent then selects the most dangerous behavior and rates the acuity of such behavior and their efficacy in managing this behavior. MCAS demonstrated good internal consistency ($\alpha = .87$), construct validity, criterion validity, and convergent validity (Kalb et al., 2017). It's worth noting that MCAS was also used as a proxy of challenging behaviors because its first section measures the severity of 14 types of challenging behaviors (i.e., injures or

hurts self, physically aggressive towards others; $\alpha = .89$). The overall scale correlated highly with the sum of the first section ($r = .84$).

Family accumulative stressor. The Social Adjustment Rating Scales (SRRS; Holmes & Rahe, 1967) is a 43-item measure that uses a six-point Likert scale (1= not experienced; 5 = experienced with extreme stress) to measure general stressful events. The SSRS demonstrated good internal consistency ($\alpha = .87$; Sturt & McGrew, 2009).

Parent's filial obligation. The Filial Obligation Scale (FOS) was adapted by the author based on the Filial Obligation Attitude Questionnaire ($\alpha = .87$ in the current study; Mangen, Landry, & Bengtson, 1987). FOS is a six-point measure that uses a hybrid scale.

Household income. Annual household income was measured by an item rated on a 14 anchored scale with a 1-point increase associated with a \$5,000 increase (1 = Less than or equal to \$20,000; 14 = More than \$80,000). Household income was treated as an indicator under A instead of B because it represented parent's financial strains, and a later CFA analysis showed that it was loaded significantly on A instead on B in the current model.

B

Parent's general social support. The Multidimensional Scale of Perceived Social Support (MSPSS; Zimet, 1998) is a 12-item measure that uses a seven-point Likert scale (1 = very strongly disagree; 7 = very strongly agree) to measure general social support. MPSS demonstrated good internal consistency ($\alpha = .92$; Zimet, 1998).

Parent's transition-related support. The Transition Quality Questionnaire is a 33-item measure that uses a four-point Likert scale to assess the quality and quantity of the transition support provided by the school. The TPQQ was developed by the authors based

on the best-practices for transitioning youth (Landmark, Ju, Zhang, 2010) Indicator 13, and focus group data collected from more than 40 stakeholders (e.g., policy makers, parents, teachers; Snell-Rood et al., 2017). This measure demonstrated good internal consistency ($\alpha = .94$).

Parent-teacher relationships. The Parent–Teacher Alliance Questionnaire (PTAQ) is a 20-item measure that uses a five-point Likert scale (1 = strongly disagree; 5 = strongly agree) to measure the parents’ perceptions of the parent–teacher relationship. It demonstrated a good internal consistency ($\alpha = .95$ in Krakovich, Yu, McGrew, & Ruble, 2016).

Religious support/ faith. The Santa Clara Strength of Religious Faith Questionnaire (SCSRFQ; Plante & Boccaccini, 1997) is a 10-item measure that uses a four-point Likert scale to assess the level of faith. It demonstrated good internal consistency ($\alpha = .99$; $\alpha = .94$ to $.97$; Plante, 2010).

Parenting efficacy. The adapted Mastery Subscale of the Revised Caregiver Appraisal Scale (MS-RCA; Lawton et al., 2000) was modified by Weiss, Tint, Paquette-Smith, and Lunsky (2016). It contains eight five-point-Likert-scale items (1 = disagree a lot/never; 5 = agree a lot/nearly always) and has good internal consistency ($\alpha = 0.80$ in Weiss et al., 2016).

C

Coping strategies. The Brief COPE (Carver, 1997) is a 28-item measure that uses a four-point Likert scale (1 = I haven’t been doing this at all; 4 = I’ve been doing this a lot) to assess parents’ coping strategies, namely problem-focused, emotional approach, or

passive-avoidance coping. This measure demonstrated good internal consistency ($\alpha = .60$ to $.81$; Stuart & McGrew, 2009).

Optimism. The Life Orientation Test- Revised (LOT; Scheier, Carver, & Bridges, 1994) contains ten five-point Likert items to measure optimism (1 = strongly disagree; 5 = strongly agree). It demonstrated adequate test-retest reliability (ICC = $.72$) and internal reliability ($\alpha = .69-.72$; Hirsch, J. K., Britton, P. C., & Conner, 2010).

X

Parents' burden. The Caregiver Strain Questionnaire (CGSQ; Brannan & Heflinger, & Bickman, 1997) is a 21-item measure that uses a five-point Likert scale (1 = not at all a problem; 5 = very much a problem) to measure parents' stress and burden. CGSQ demonstrated good internal consistency ($\alpha = .94$; Stuart & McGrew, 2009)

Parents' transition experiences. The Transition Daily Rewards and Worries Questionnaire (TDRWQ; Glidden & Jobe, 2007; Menard, Schoolcraft, Glidden & Lazarus, 2002) contains twenty-one five-point Likert items that measure parents' perception of rewards and concerns towards the transition process (1 = strongly agree; 5 = strongly disagree). It demonstrated good internal consistency ($\alpha = .74-.85$), test-retest reliability ($r = .56-.68$), convergent validity, and divergent validity (Conti-Ramsden, Botting, & Durkin, 2008).

Family quality of life. The Beach Center Family Quality of Life Scale (FQoL; Hoffman, Marquis, Poston, Summers, & Turnbull, 2006) contains 25 five-point-Likert-scale items (1 = very dissatisfied; 5 = very satisfied). It demonstrated good internal reliability ($\alpha = .88-.94$; Hoffman et al., 2006), test-retest reliability ($r = .59-.63$), convergent validity, and construct validity (Hoffman et al., 2006)

Parents' subjective health. Parents' health was measured by "please rate your overall health" using a four-point scale (1 = poor; 4 = excellent).

Data Analysis

First, I conducted tests for multicollinearity, outliers, and missing data using the VIF and Tolerance indices, Cook's Distance, and Little's Missing Completely at Random Test (MCRT), respectively. This dataset demonstrated no multicollinearity or significant outliers. However, the MCRT showed that three measures, including PTAQ, BRIEF-COPE, and CGSQ, were not missing at random, even though the missing data were no more than 0.2% per each item. I deleted all the cases ($N=26$) that contained at least one missing response for these three measures and created a "cleaned" dataset. Due to the absence of major differences between the two datasets and the scattered missing data pattern, I decided to impute the missing data in the original dataset using the Expectation-Maximization (EM) approach in SPSS 24. Second, assuming a p-level of .05, a two-tailed test, a power of at least .80, and a large effect size of .80, a sample of 91 would be needed for the current study using structural equation modeling (SEM; Soper, 2017). Third, I conducted correlational analyses and four linear regression analyses using SPSS 24 in order to answer research question one. Fourth, prior to testing the mediational hypotheses, I conducted four CFA models verifying the latent A, B, C, and X variable using AMOS 24. Fifth, to test the mediational hypothesis for research question two, I used SEM to develop two partially latent structural regression models. I evaluated the model fit using the following standard measures of practical fit: RMSEA, CFI, TLI, and NFI. Modification indices and recommendations were used for improving the fit of the model. Nonsignificant effects were removed from the model. Sixth, the two models were

compared based on the AIC index, BIC index, parsimony, and theoretical relevance. Lastly, a final model was selected and finalized based on Noack (2004)'s guidelines: A model was finalized if the three following criteria were met: "(a) showed an acceptable fit with the empirical data that (b) could not be significantly improved by additional paths but (c) yielded a significantly poorer fit when skipping any of the paths specified. (p.717)"

Chapter 4 Manuscript One

“We are Mama and Papa Bears”:

A Qualitative Study of Parents’ Adaptation Process during Transition

Transition from high school to post-secondary activities may result in changes that might lead to growth or deterioration (Schlossberg, 2011). Unfortunately, the transition outcomes of students with Autism Spectrum Disorder (ASD) are less than desirable in terms of employment, independent living, and community participation (Newman et al., 2011).

The negative transition experience extends to their families. The unique, complex challenges of rearing a child with ASD threaten the psychological health of the parents (Seltzer, Krauss, Orsmond, & Vestal, 2001). The need for intensive care for individuals with ASD causes a high level of stress among this group of parents (Hayes & Watson, 2013; Howlin & Asgharian, 1999); such stress is higher than parents of typically developing children as well as parents of children with other types of disabilities (Benson & Kersh, 2011). As the child reaches adolescence, the realization of the continuity of the child's disabilities and worries about the child's future may increase family stress (Bristol & Schopler, 1983). Oftentimes, the burden on families does not decrease because many individuals with ASD continuously rely on their caregivers’ support through late adolescence and into adulthood (Smith et al., 2010; Khanna et al., 2011).

Despite the importance of parents and the huge impact on families, parents’ voices are not often represented in clinical research of the transition period (Davies & Beamish, 2009). To deepen the understanding of this neglected population, Kucharczyk et al. (2015) and Snell-Rood et al (2017) conducted two qualitative studies with

stakeholders, including parents, to understand the transition process and needs. The results showed that schools' support was insufficient to meet the educational needs of students with ASD because of a lack of resources and the preference for academic achievement over other areas of need.

Transition can be tough and uncertain. To cope with the challenges, compared to parents of young children with ASD, parents of adolescents and young adults with ASD relied less on service providers and family support, and demonstrated less social withdrawal and individualism (Gray, 2006). They also gained coping skills; for instance, religious practices and emotion-focused strategies were used more frequently. Generally, mothers of adolescents and young adults with ASD who used problem-focused coping (e.g., obtaining services) reported less psychological distress (Abbeduto et al., 2004; Benson, 2010). In terms of emotion-focused coping, positive reframing was found to be associated with less parenting stress (Manning, Wainwright, & Bennett, 2011), whereas avoidance was associated with more parental stress (Hastings et al., 2005).

The parenting experience is not totally negative. Even as these parents spend more time on childcare, less in leisure activities, and experience more marital distress, they experience positive interactions with their children and want to contribute back to their community (Smith, 2010). The adjustment process is complex because it may be full of disappointment, sacrifice, guilt, and doubt but also include personal growth and a new meaning in life (Lutz , Patterson, Klein, 2012).

Gap in the literature

Despite some efforts to foster an understanding of the parents of adolescents and young adults with ASD during transition, parents' experiences and family-level outcomes

are largely neglected when gauging ASD transition outcomes (Henninger & Taylor, 2014). The U.S. Department of Health and Human Services (2017) particularly highlighted that “services and programs should consider the role of the family during the process of transitioning to adulthood. Understanding how to support and include families, without undermining the autonomy of the individual with ASD, is an important but complicated need.” With family as the constant in a child’s life, a successful transition should address family wellbeing and parental perceptions of transition (Neece, Kraemer, & Blacher, 2009). Such a family-centered approach treats collaboration with families as critical to successful treatment outcomes. It also recognizes all families have strengths, and they should be included in shared decision making (Beatson, 2008). A lack of studies focusing on families’ perspectives, experiences, and well-being prevents practitioners from gaining in-depth insight in the transition process and outcomes of students with ASD and their families (Gerhardt & Lanier, 2011).

In particular, the current literature has three major limitations. First, there is a lack of theory guiding the understanding of the experiences of this group of parents. Second, parents are often treated as the voices of their children but not themselves (e.g., Kucharczyk et al., 2014). However, in order to empower parents and families with ASD, parents need to be given a venue to speak to their own needs and desires (Yoder-Wise & Kowalski, 2003). Third, little is known about the adaptation process of families of older children with ASD in the context of normative changes related to aging (Seltzer, Krauss, Orsmond, & Vestal, 2001). Understanding the particular issues during this period will inform future intervention research that can support transition so that families and youth achieve their desired outcomes.

Guiding framework

The ABCX Model (McCubbin & McCubbin, 1993) was used to conceptualize and analyze family adaptation and adjustment experiences during the transition process (Lustig, 1999). The model consists of three main predictive components (stressors, resources, and family coping and perception) and one outcome component (family adaptation). *Stressors (A)* are defined as life events or transitions that have an impact on the family system (e.g., the severity of autism; McCubbin & Patterson, 1983) and the cumulative effects of daily stressors over time (Lavee, McCubbin, & Patterson, 1985). *Resources (B)* are defined as the family's abilities to counteract the negative effects implicated by the stressors (e.g., family's social network), the existing resources, and newly developed resources following the crisis experienced by the family (McCubbin & Patterson, 1983). *Family coping and perception (C)* are defined as the family's views on the crisis (e.g., perceived impacts; McCubbin & Patterson, 1983) and the family's general orientation to their situations (e.g., overall appraisal, coping strategies; Florian & Dangoor, 1994). *Family adaptation (X)* is the outcomes of the adaptation and adjustment process and is a product of the "A", "B", and "C" components (Lavee et al., 1985). In the current study, the ABCX model was used to guide the selection of interview questions and theoretically interpret the results.

Current Study

Qualitative studies contribute to the field of special education by detailing the experiences and needs of individuals with disabilities and their families and exploring associated solutions (Brantlinger, Jimenez, Klingner, Pugach, & Richardson, 2005). The

current study responded to the U.S. Department of Health and Human Services (2017)'s call for attention to family's roles and needs during the transition process and aimed to answer a question – What are the stressors, external and internal support, coping strategies, and parent transition outcomes during transition from a parent's perspective? This study was approved by the University Office of Research Integrity, while informed consent was obtained from the participants.

Methods

Participants

Recruitment and sample selection. Twenty-eight associations for parents of children with ASD in a Midwest state were contacted. Thirteen parents of adolescents or young adults, aged from 15 to 27, with a clinical diagnosis of ASD, who currently have or previously had an IEP were recruited. The sample was systematically recruited based on geographic locations (e.g., suburban, and rural), SES, race, and gender, with at least 20% of the participants representing minority groups. The average age of the parents was 56 years old. More than half of them (53.8%) had a college or higher degree. Approximately half of their children were reported to have a low cognitive ability (IQ score <75). See Table 3.1.

Measures

Background. To understand and describe the sample of the parent participants, a 26-item questionnaire was administered. The questionnaire includes demographic information of parents (e.g., age, gender) and children (e.g., age, education).

Open-ended question. Participants answered semi-structured, open-ended questions. Interviews were approximately 40-60 minutes in length. See Appendix A for the interview questions. The first author conducted the semi-structured interviews with the parents at locations convenient to them. All interviews were audio-recorded.

Data Collection and Analyses

The 13 participants were interviewed, and the interviews were recorded. A research assistant transcribed the audio recordings of all interviews, which were then entered into a qualitative data analysis software. A hybrid thematic approach (Fereday & Muir-Cochrane, 2006) was used by employing a combination of a deductive and inductive approach in which we aimed to capture the essential components of a phenomenon (i.e., the positive and negative transition experiences of parents) by searching for emerging themes (Braun & Clarke, 2006) as well as those already described in the research. That is, before extensive data analysis occurred, a codebook was developed based on major constructs of the ABCX model for deductive analysis (Crabtree & Miller, 1999).

Creating codes and saturation. At first, four deductive codes were developed. Based on Schaefer, Coyne, and Lazarus (1981) and Thoits (2010), three main sources of social support were identified – emotional, instrumental, and informational. Other than external resources, internal resources are also found to be important for parents who rebound in face of adversity (Bayat, 2007), therefore one additional code – personal resources – was developed to capture parents’ internal strengths.

After applying these four codes to all transcripts, an inductive coding method was employed to generate sub-codes for the four predetermined codes and to further

categorize other emerging ideas. During the inductive coding phase, descriptive coding (i.e., a brief descriptive code assigned to a passage that contains a prominent idea) and emotion coding (i.e., a code assigned to level the emotions described or recalled by parents) were heavily used. At this stage, 48 codes were identified from and applied to the four transcripts for the first round.

After testing the codes, the codes were further applied to five more transcripts for the second round. As new themes appeared and new codes developed, the new codebook was reapplied to the coded transcripts. At this stage, 51 codes were identified.

Then, the new codebook was applied to the four remaining transcripts. The iterative process stopped until the data were saturated (i.e., with no new themes emerging for three consecutive transcripts).

Finally, the relationships among the codes, such as causes/explanations, relationships among people, and theoretical construct, were examined repeatedly. Finally, the codes were further clustered deductively into the ABCX model.

Data triangulation. In order to ensure the reliability and validity of the results, the analyses followed the recommendations of Fusch and Ness (2015) and Guest and colleagues (2006). For instance, data triangulation was implemented by collecting data from multiple sources (e.g., collecting data from parents of children with different ages/ gender, and of different race/SES). The data collection was ceased when no new themes emerged. Twenty percent of the transcripts were coded by an independent coder (i.e., a doctoral student). The procedure is listed as follows: First, 20% of the transcripts were randomly selected for the secondary coder to review, and the secondary coder came up with her own themes. Second, the two coders cross-checked their themes to see whether

there were any new or divergent themes. Third, since there were no divergent themes, the second coder independently applied the codebook developed by the primary coder to 20% of the transcripts. The reliability was calculated based on the appearance and absence of the themes (i.e., whether a particular code appeared in a transcript). The reliability between two coders was 88.5%. Fourth, the two coders discussed any disagreements and reached a 100% agreement.

Results

A-Parents' Stressors and demands

"A" includes the stressors and hardships the families experience during the transition process (demands associated with stressors) (McCubbin & Patterson, 1983). Five themes were identified.

Parent's deteriorating health. During the transition period, parents become middle-age or elderly caregivers. More than half of parents reported that their physical health was deteriorating. Several of them had significant health issues (e.g., cancer). One mother expressed, *"I have actually been diagnosed four times with cancer and I have multiple sclerosis, and I have a rare joint disease. I actually had surgery last Thursday and I came back to work Friday. I'm worn out."*

Other than physical health, three parents mentioned mental health conditions (e.g., depression). Rearing a child with ASD may exacerbate the symptoms, while having a past or current mental condition may make parents prone to negative experiences. A father who has a diagnosis of Attention Deficit Disorder said, *"Oh gosh. My mental health, it's gone, I don't have any. I'm serious."*

Continual deficits. All of the parents in the current study reported that they continued to see the impact of ASD on the daily living skills, learning, social/emotional skills, behaviors, and work skills of their children, in spite of improvement. The demands could be tremendous. One single father with two adolescents with ASD shared, *“I have an 8-hour job. Sometimes [my children] have sleeping difficulties, I am up at 2.00, 3.00 in the morning... When I'm sleeping sometimes they are doing things like raiding the refrigerator or doing things that could be dangerous, but I have to get my sleep because I'm about to pass out.”*

Changes in child's demands. All parents noticed some sort of change in the child's demands driven by development. The demands mainly lie in five areas: daily activity/ educational/job demands, social or community participation opportunities, physical or mental health, living situation, and daily living skills.

One significant event that marks adulthood is employment or post-secondary education. A number of parents reported seeing excitement in soon-to-be adult children with ASD to work or further their education. One parents observed that her child *“was really looking forward to [the job] and he was reading up on things and he wants to know.”* The parents of low-functioning children also mentioned the need for their children to continue to be challenged in some structured activities after school.

More than half of the parents observed changes in the social or community participation needs of their children. Adolescence and young adulthood are the prime times for developing romantic relationships. The parents reported seeing the demands of developing intimate relationships in their children and the resulting tension and discomfort. For instance, a parent regretted allowing her daughter with ASD to be alone

with her boyfriend, which resulted in a sexual assault. Adult children also show the desire to have friends. However, the friends do not always have the best interests of the individuals with ASD at heart, with several parents reporting that they felt the need to monitor their children's social life. In the new technological era, meeting a new friend is different from the parents' generation. With several parents reporting how their children made friends online, parents stated that they need to adjust to the new ways their children with ASD were making friends. As one said, *"I had to adjust my understanding of how people are making friends now."*

As the children grow, parents also see changes in the demands associated with their children's physical development and mental health status. Several parents particularly mentioned that their children did not understand sex, despite *"repeated"* and *"explicit"* attempts at education. Also, many children become stronger as they age, which pose challenges for caregivers to control them physically. One father noted, *"As I'm getting older I'm fearful he can be dangerous to me. Even though he is my son, he has strength that's beyond belief so I can get hurt."* Children's' new or continued physical and mental comorbidity, such as obesity and generalized anxiety disorder, also pose additional stressors to parents.

As children grow and parents age, concerns are raised about the children's living situation and daily living skills. Almost all parents reported that there was a demand to plan for their children's future living situation. In order to successfully transition out of the family, daily living skills should be prioritized.

Having more than one child with disabilities. Autism has high heritability. Five parents in the current study have more than one child with a disability. Three of them

have at least two children with ASD going through the transition process together. The doubled quantity of demands can multiply the stress on parents. A single father noted, *“I’m not a typical person with one autistic child, I have two...I can’t be in two places or three places at the same time.”*

Normative changes and strains. As time passes, a family experiences normative transitions and stressful events, which produces tension and role strains. Normative transitions can be broadly defined as expected family events, such as a child’s leaving home; while stressful family events can be defined as less expected stressors, such as a family member’s illness (Aldous, 1990). Almost all parents reported they went through some normative family strains throughout the transition process. As parents age, their own parents age too. Several parents reported that they took on great responsibility taking care of their parents and children simultaneously. One mother whose mother was diagnosed with Alzheimer’s said *“I’m like so overwhelmed with my mom but [child] is getting the shaft.”* A few parents also reported that their parents or spouses actively involved in their lives died. Additionally, more than half of the parents reported that they experienced job changes, retirement, or having a child without disability moving out of the household.

B – Support Needs and Resources Available

"B" includes resources that help families meet the demands of the stressors and hardships (McCubbin & Patterson, 1983). In this section, parents’ experience of receiving insufficient support and resources available will be reported. Six themes were identified.

Dealing with a broken system.

Negative experience with schools. School is an important source of support during the transition. Students with ASD and their parents are entitled to educational services; however, nearly all parents reported significantly negative experiences with their schools. Approximately half of the parents observed a lack of quality teaching during high school; a mother noted, *“The school was an embarrassment as far as I was concerned because some of the stuff that they would send home was so watered down...they weren’t trying so hard to adapt the materials the way they needed to.”* In addition to academic skills, half of the parents also reported that their schools did not provide adequate social skills support. The teaching at school is also not flexible or individualized to meet the children’s needs. A father reported that his son had to choose between a class he liked and transition services because of time conflicts and said *“[Child] literally had to sign a form which says I’m declining this job hunting service.”* The schools often provided minimal, inflexible educational support.

Aside from quality instruction, parent-school collaboration is also critical to the success of students. However, more than half of the parents expressed that they were not fully included in the decision-making process. A father with a non-verbal child recalled that *“the IEPs were made ahead of time”* and that he was not consulted with for his daughter’s needs and educational plans. Additionally, almost all parents reported tensions developed between them and their schools. One parent even *“started recording all of our meetings because of what they were doing.”*

Parents’ reasoning behind the insufficient support. A few parents with low functioning children with ASD reported that the insufficient support was related to a lack of appropriate assessment. A parent said, *“By the time she became a freshman, they gave*

her a picture vocational assessment...the assessment they gave her was from 1982. One of the jobs was bathroom attendant, you know the person who hands you a towel? Oh wait no place even has that...that job doesn't exist... what are you people doing?"

Another observation of the majority of the parents was that the system had no accountability, was all about paper pushing, and had low expectations of their children.

Overall, parents reported the quantity and quality of transition services are lacking. Students with ASD often need a long period of time to adjust to a new environment or to learn new skills. However, the lack of transition services limits the length and breadth of support a student with ASD can receive. A mother said that her district only had twenty slots for vocational schools, *"The school said it [vocational school] was very competitive and he had to have certain scores. They basically told me that was out, like he was not smart enough to go to vocational school believe it or not."* Even if a student with ASD receives transition support, they are not perceived as sufficient or sustainable. As one parent said, *"But the job coach just taught [child] one task and that was it."* Other than school-or job-related support, a few parents mentioned that they did not have access to autism-specialized medical professionals and that they could not recruit community-based workers for their waiver program.

Negative experience with VR. The Office of Vocational Rehabilitation (VR) and job agencies play an important role. However, more than half of the parents expressed that the VR's services do not always meet expectations. A mother reported that, *"One guy [job coach] came here and sat here two hours and talked to me about why he didn't like his job. And I kept trying to bring the conversation back to [child] ... at one point he turns to me and he goes, "You know it's really hard to get a job for a person with a disability."*

At times, parents are also unsure about the status or progress of the VR services. Negative experiences seemed to circulate in the ASD community. A mother said, “*I probably have 100 people in town who have had kids who have gone through voc rehab; I don’t have one positive experience.*”

Fighting the gigantic system. Despite all the reported unfair treatment or insufficient support, it appears that the system is too big to change or fight. A mother felt like she was “*spending all this time trying to get the school to do their jobs correctly, but they are not going to do it.*” Even though there is due process for parents to dispute unfair treatment, most parents could not “*just sue them*” because they “*don’t have \$20000 to sue them.*”

Insufficient support from schools and VR is prominent. However, all parents were also able to identify the support that helped them buffer the stressors during the transition process. The roles of family members and other parents of children with ASD will be discussed separately because their support spills over multiple domains.

Tangible support. Tangible support is instrumental aids or services (Blalock, 2002). Parents identified five sources of tangible support from family members, quality professionals, community participation opportunities, job/salary, waiver services, and insurance. Half of the parents were able to recruit quality professionals for help and were able to identify some helpful school professionals/paraprofessionals they encountered. A few parents also reported that having recreational programs for older individuals with disabilities (e.g., swimming class) was important to them. In order to pay off all the services, almost all of the parents reported that their job or salary was crucial because they often needed to pay out-of-pocket. All parents, except one, held a job by the time of

the interview. The other financial support was from waiver services and insurance. Overall, parents' social-economic status plays an important role in access to tangible support, such as setting up a trust and paying out-of-pocket to recruit professionals.

Emotional support. Emotional support includes “expressions of empathy, love, trust, and caring” received from other people that help alleviate negative emotions (Blalock, 2002). The parents reported six sources of emotional support: religion, family members, spouses, other parents of children with disabilities, and professional counseling. More than half of the parents reported that their spiritual life or people associated with their religious practice help them cope, while a number of parents reported that their spouses are a major source of emotional support. A father expressed, “*Probably the best support I have was from my wife and she'd probably say the same with me.*” Almost half of the parents reported receiving counseling before, but only a small number of them found it useful.

Informational support. Information with regard to transition is overwhelming for almost half of the parents. As one parent said, “*There's just so many materials that are on there and you can just be inundated.*” Four main sources of information, including websites, conferences/talks/training, other professionals, and other parents of children with ASD were reported. The majority of parents mentioned that they seek information online regularly. Several of them also mentioned that they went to seminars, talks, training, or conferences to get more advanced information and highlighted the importance of being in the same social network with “*a bunch of people [resourceful professionals.]*”

Internal support. In face of the hardships involved with taking care of a child with disabilities, parents' internal resources also play a critical role. In the current study,

the parents identified eight useful personal characteristics or practices: Me time, imagination, sense of justice, perseverance, optimism/ a sense of humor, care/love, research, analytic, execution skills, and health/exercise. Several parents reported that preserving time for oneself is the key to function effectively as a parent with a full load of responsibility because “ *if you are a total giver you will break down.*” Several parents also mentioned that imagination or creativity is needed in order to create learning opportunities for their children, while almost all of the parents thought that perseverance is an invaluable character. They do not give up easily until their goals are met. Oftentimes, optimism or a sense of humor is needed when encountering chronic or acute stress. A mother highlighted that “*there are situations where you either laugh or cry, and I would rather laugh than cry ... there is something positive in every situation.*” Parents’ genuine care and love for their children are the driving force behind all their actions. The powerful love can be illustrated in a father’s statement, “*I care in my heart about my daughter...I will do everything I can for her to be successful.*” However, almost half of the parents also recognized the importance of their research, analytic, and execution skills and health.

Other parents as support. Taking care of a child with ASD can be a lonely journey because “*a lot of people they want to distance themselves, they don’t know what to say, they don’t know how to react to you*”. The majority of the parents mentioned that other parents of children with ASD provided tremendous emotional and informational support during transition. A mother explained “*And the only reason we’ve come together is we all have kids that are similar...We laugh and complain about things but it’s kind of a camaraderie that comes because of shared experience.*”

Family member as support. Several parents reported that their own family members provided tangible and emotional support. However, the unreplaceable support from families, especially from one's parents, is fading. A mother recalled, "*my mom died in 2009 and she was a huge help to me...And now I don't have anybody else like that in town.*"

C- Coping strategies and perception

"C" includes families' coping strategies, perceptions, and meanings of the stressors and hardships (McCubbin & Patterson, 1983); in other words, how parents perceive the transition process, solve problems, and make meaning. Five themes were identified.

Death and planning. The majority of aging parents have planned for their children surrounding their own death. A mother said, "*You start thinking of kind of your own personal mortality... You become very calculating about it...*" Parents need to plan further than their own longevity for their children's lives, many of them have already set up a trust or had a detailed plan for their children with ASD after they themselves are gone.

Meaning of transition. In general, all parents agreed that transition is a change and is a phase which prepares their child for "*the next step*" – adulthood. Such a process is an "*ongoing*" and "*forever*" process. Transition also has another layer of meaning for half of the parents. They stated that "*when the children transitioned, it became our responsibilities*", highlighting that transition is a shift of responsibility from a shared one between the school and the parents to the parents alone.

However, adults or soon-to-be adults with ASD may have a different or a simpler understanding of transition. All parents of lower-functioning children perceived that their children have a limited understanding of transition. For instance, a father thought that to his daughter, *“it’s going to mean she’s going to be home a lot more.”* Several parents of higher functioning children thought that they are on the same page in terms of the perception of transition.

Responsibility. The majority of the parents believed that it is their responsibility to prepare their children to transition to adulthood. They thought that they *“had to own it and to do it.”* It was almost like *“unless [parents] do this, it’s not going to happen.”* Even though a number of mothers in the studies reported that they are united as a team with their husbands, half of them think that they take on more responsibilities than their spouses in their child’s lives. They often referred themselves as “mama bears” protecting their vulnerable children.

Other than themselves, the majority of parents also have expectations for their children without or with milder disabilities with regard to their responsibility to their siblings with ASD. None of the parents expect their siblings without disability to take care of their siblings with ASD to the extent of the parents; however, they do think that the siblings have a responsibility to look out for them. A mother told her child without disability that *“It’s your job to take care of your brother.”* But it doesn’t mean *“You do everything for him.”* It means *“You keep an eye on him,”* which siblings do anyway.”

Guiding philosophy. Almost all the parents reported that they have some life philosophies to guide their decisions, to reason about their experiences, or to support them to move on. For instance, a mother’s philosophy was that *“there’s a saying that I*

love it's 100 years from now doesn't matter how much money you make or what kind of car you drove or what kind of house you live but it's the fact that you made a difference in a child's life."

Coping. Parents reported using avoidance, emotion-focused, and problem-focused coping. For instance, one mother still avoids talking about her worries for her son with ASD. Another parent said that she felt overwhelmed a couple weeks ago, but decided to hang out with her friends and have a nice dinner. However, among all the coping strategies, problem-focused coping was mentioned most frequently. All the parents gave at least one example of how they solved a problem in their child's or their own lives. One mother said, *"Because we finally got to the point where I just realized I wasn't going to get anything from any of those people. So that's when I got interested and I got my supported employment training and I said basically, "Hell with you and I'll take this over."* Throughout the course of problem solving, parents have to stay *"open-minded"* because it is a *"trial-and-error"* process to find the *"kryptonite."*

Parents oversee and manage almost every aspect of their children's lives, and this is especially true for parents of lower functioning children. They seek out support and monitor progress. Almost all of the parents considered themselves as their child's *"unpaid"* case manager and advocate.

X- Adaptation outcomes

"X" includes family adaptation and outcomes as a result of the interaction among the A, B, and C factors (McCubbin & Patterson, 1983). Four themes were identified.

Restricted life. Due to the deficits and availability of resources, almost all the parents of adolescents or adults with ASD were living a relatively restricted life. For

instance, many parents could not move to another place, retire, or even freely engage in their own preferred activities freely. One father even felt “*like a prisoner.*”

Family adjustment. Across time, families find their own ways to adapt and adjust to the stressors. Half of the parents reported that they learned how to “*let go*”, allowing their children to grow as adults and reassessing their roles in their children’s lives. One mother reported that she used to wake her daughter up early for medication, but her son with ASD offered help. After a family discussion, the couple decided to let him assume the responsibility and said “*he gives her primary medication and we have never had a problem.*”

Spousal adjustment. Raising a child with disabilities can be stressful and caused a strain on the majority of the parents’ relationships with their spouse. One mother complained, “*[My husband] works evenings and I’m busy with the family and kids during the day and then I work on the weekends and so we are not even in the same place a lot of the time.*” Despite all the tension, parents usually find a way to balance the needs of the children and their spouses. The key was that “*there has to be love, understanding, and patience*” in the relationship. However, a few parents also mentioned that the unsolvable tension led to divorce.

Sibling adjustment. While the siblings were young, parents felt that many of them developed resentments or misunderstanding towards their siblings with ASD. As these siblings grew, the majority of the parents reported the siblings developed more understanding and a sense of responsibility. Some siblings even told their parents that they will take care of the sibling with ASD. A parent said that it made her “*feel really good*” when she heard her daughter saying so.

Daily rewards. Raising a child with disability is not all about negative experiences. More than half of the parents reported that they experienced small yet exciting successes, such as having a dinner outside without a tantrum. These small, seemingly easy successes were things that parents “*would never have dreamed of.*” Many parents were also able to see the positive influences that being a parent of children with ASD has on themselves. A mother concluded that “*anything good that’s made me able to do what I have done, I learned from being his mother.*”

Uncertainty. Many parents expressed that there were still many uncertainties during the transition process and that they did not know the exact next step. They “*see little kind of successes, but on the flipside of it, there was so many unknowns altogether in the transition.*”

Emotional responses. A combination of positive and negative emotions resulted from experiences during the transition process. Parents experienced seven types of emotions or feelings during transition: Stress, worry/ anxiety, frustration, sadness, guilt, peace/satisfaction, and hope. More than half of the parents reported that they are extremely stressed. One mother said, “*I’m telling you it’s a high stress life, a very high stress life...sometimes I do have moments where I am going home and I wish I could just keep on driving, to nowhere just run away sometimes.*” Almost all parents worried about their children’s future. A lack of support and understanding during transition was also *frustrating and sad*. In face of the excessive demands, a number of parents felt *guilty* towards their children because they felt like they could have done better. However, several parents were also *satisfied or hopeful*. A mother whose son finally got a job

noted, *“And it seems like things have kind of calmed somewhat since we now have the experience. So, it’s just living alive kind of thing. And so that’s been just lovely.”*

Ideal X – Ideal adaptation outcomes for parents

Having an adult child with ASD has an impact on the parents’ aging process. However, parents have their own dreams and ideas for a positive aging process. If things go well as planned, several parents said that they wanted to spend more time with their significant others (e.g., spouses, other adult children). Knowing their families are safe and sound was important to all parents. Many parents looked forward to being able to travel and do things that they like. One mother shared that she *“would like to travel; to visit Disney world!”* A father also said he just wanted to *“go to a beach and read a book.”* Feeling comfortable and happy was the ultimate goal for the parents. Many of them were looking forward to a time to unwind.

The majority of the parents also developed a sense of purpose in their lives – they wanted to contribute back to the community. For instance, two parents wanted to become ASD specialists. Four parents also wanted to extend service support through their non-profit organizations, volunteer work, or professional networks. A parent noted, *“So that’s why I developed this nonprofit, because I have a different idea of what transition should be.”*

Discussion

The current findings contribute to the literature by detailing the family adaptation process during transition from a parent’s perspective using the ABCX model (see Figure 4.1). Similar to previous studies, children’s deficits are continual stressors in older parents’ lives (Orsmond, Krauss, & Seltzer, 2004). Changes in the child’s demands (e.g.,

different symptoms representations and needs) add to the parent's stress. Such stressors are within the context of age-related normative changes (e.g., taking care of both descendent and ascendant relatives, Grundy & Henretta, 2006) and deteriorating health caused by chronic stress and aging among parents (Quittner, Glueckauf, & Jackson, 1990; Thoits, 2010). Transition stress can be double for some families. Grønborg, Schendel, and Parner (2013) found that the sibling recurrence risk for ASDs was 6.9 times, meaning that many parents are rearing more than one child with ASD; thus, the burden of transition is multiplied for some families (Orsmond, Lin, & Seltzer, 2007). The results suggest that interventions targeting transition support need to be cognizant of the fact that many aging parents are also experiencing normative stressful events, which may limit their ability to cope with child-related stressors.

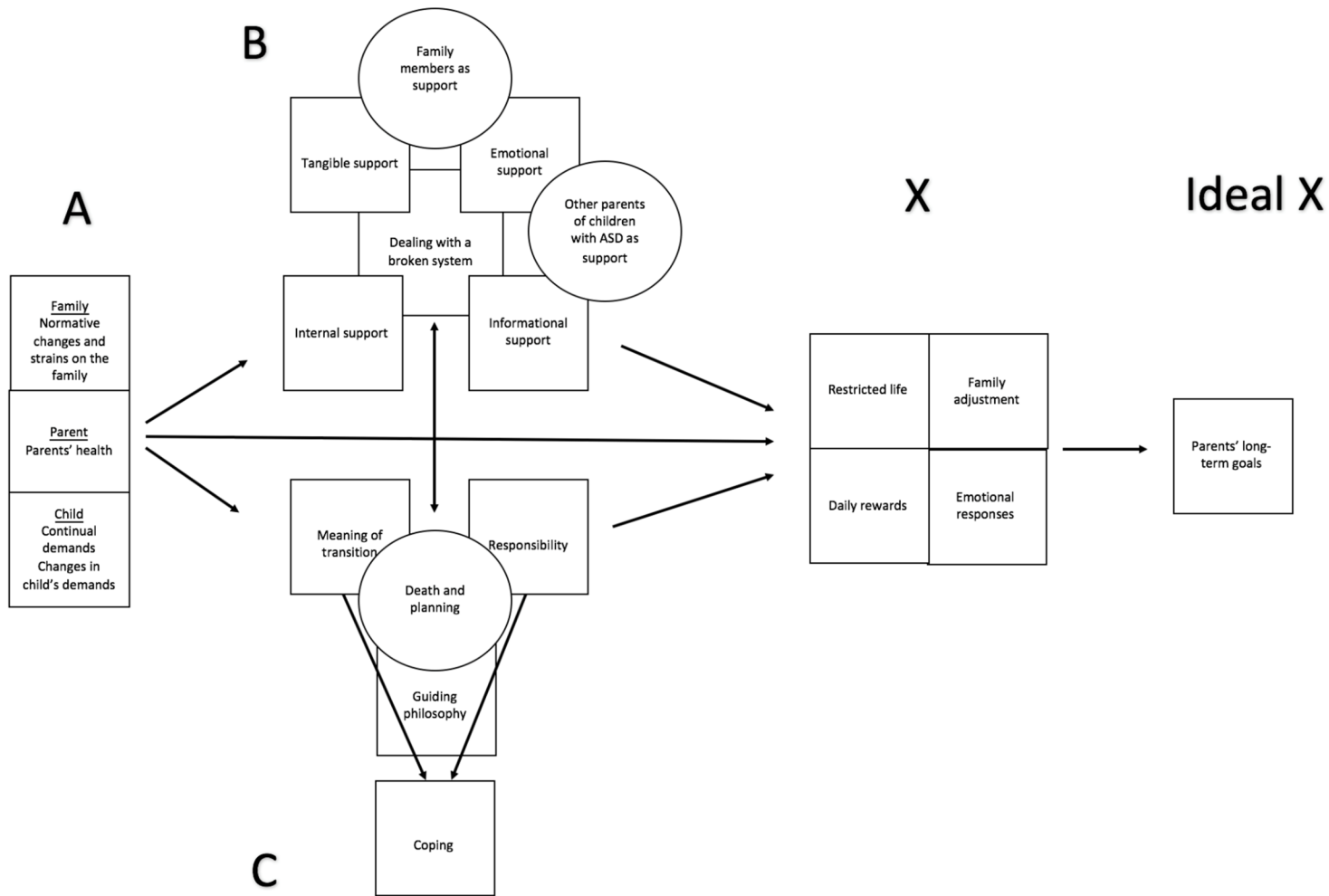


Figure 4.1. The stressors, resources, and coping during transition.

Consistent with previous studies, the parents were navigating through the lack of an effective, coordinated system with an overwhelmingly large amount of information during the transition (Kucharczyk et al., 2015, Snell-Rood, 2017). However, parents were able to identify four types of support—tangible, emotional, informational, and internal—that help them through the transition. The results showed that parents relied heavily on their family members, on other parents of children with ASD, and on themselves for support. Unfortunately, family members, especially the parents of the parents of a child with ASD, leave the support system as they age. The death of a significant source of support can be a double jeopardy for the parents – the loss of a loved one and the loss of a substantial source of support. Also, the nearly absent nomination of professionals as important sources of support poses questions for training and service delivery at the system- and individual-levels and challenges the expert model during transition (Dunst & Paget, 1991; Brookman-Frazee & Koegel, 2004). Instead, parents treat other parents who are going through or have gone through the transition process as experts. It highlights the value of parent-to-parent interventions (Ruffolo, Kuhn, & Evans, 2006; Singer et al, 1999) and parent support groups (Boyd, 2002).

Similar to previous studies, the results found that the parents of older children with ASD used emotion-focused coping (Gray, 2006). However, this group of parents also heavily employed problem-focused coping during transition, actively solving problems. The majority of the parents even perceived themselves as case managers and advocates. The results also provided unique information about the reasoning behind the parents' coping strategies and actions. Parents coped with the stressors according to their philosophy, perceived meaning of transition, and perceived responsibility. Echoing a

previous study with parents of individuals with ASD (Sanders & Morgan, 1997), mortality is salient for older-age parents. To them, planning during transition is urgent and paramount for their child's well-being after their death. As a result, they often show frustration and anger during advocacy or cause tension with professionals (Seligman, 2000). The current results provide a deeper look into the reasoning behind their actions and emotions and will hopefully facilitate more understanding (Stoner et al., 2005) and inform effective strategies to increase parent-teacher or parent-clinician alliance (Seligman, 2000).

As a result of both tremendous demands and limited support, many parents reported that they are living a restricted life (Traustadottir, 1991). Having a child with disability and insufficient support adds stressors to a normative aging process, such as retirement and engaging in social activity. Even though maternal well-being was reported to improve across time (Lounds, Seltzer, Greenberg, & Shattuck, 2007), the results showed that many parents continue to experience high-level negative emotions or feelings during transition, such as sadness and anxiety. The prevalent negative emotions and reported unhelpfulness of counseling confirms the need to study a less-researched area of effective counseling strategies and support particular to this group of parents (Langley, Totsika, & Hastings, 2007; Ziolko, 1991).

Across time, families do achieve positive adjustment. Consistent with some previous studies, non-disabled siblings might develop resentment against their siblings with disabilities (Gray, 1998). However, the results showed that the non-disabled siblings have, across time, gained more understanding and taken on more responsibility. Similarly, parents of adult children with ASD are also able to see positivity (Hastings et al., 2005)

and want to help others. Such positive perception may serve as a resulted adaptive function to cope with stress (Hastings & Taunt, 2002). Lynch and Morley (1995, p. 212) noted, “It is not uncommon for parents to move into leadership roles in groups or support relationships with other parents of newly diagnosed children with disabilities.” Aging parents went through difficult moments during transition, gained resiliency, and wanted to contribute back to society. Such help-giving behaviors may contribute to family empowerment (Dempsey & Dunst, 2004) and is aligned with Erickson’s (1968) theory about the importance of generativity for this age-group. This result highlights the need to explore the positive experiences of rearing children with ASD and their roles as outcomes or mediators (Hastings et al., 2005)

Limitations

First, despite some diversity with regard to geographical locations, ethnicity, and SES, the majority of the participants were white and English-speaking. Second, information was only collected through interviews but no other sources (e.g., document; Lincoln & Guba, 1985). Third, the current data are cross-sectional. Longitudinal studies would be more potent to describe the changes in the A, B, C, and X factors across time. Fourth, only parents, but not other family members, participated in this study.

Chapter 5 Manuscript Two

Predictors and Outcomes of Families with Transition-Age Youth or Young Adults with ASD: A Parent's Perspective

Each year, approximately 50,000 teens with Autism Spectrum Disorder (ASD) turn 18 in the United States (Shattuck et al., 2012), highlighting the urgency of preparing them to exit school and transition into adulthood. Unfortunately, the outcomes of students with ASD are worse when compared to their peers with other types of disabilities. For instance, individuals with autism are less likely to be employed, earn less, and seldom live independently and partake less in the community (Cameto et al., 2004). The negative transition outcomes and experiences transcend to their families because the majority of individuals with ASD continuously rely on their parents' intensive support through late adolescence and into adulthood and beyond (Smith et al., 2010; Wager et al., 2007).

Family's and Parent's Responsibility and Impacts

Families are expected to be the primary source of care for their children with disabilities (Grob, 1994; Reisser & Schorkske, 1994). Even though the civil rights of people with disabilities and their entitlement to quality education and services have been affirmed, and even though an increasing amount of support has been provided by public sectors throughout the past five decades (Parish & Lutwick, 2005), families still take on great responsibility for the care of their children with disabilities.

Within the context of transition, parents of transition-age youth with ASD are often the main decision makers during the transition process, such as advocating for post-secondary services and setting up financial plans for their children (Ankeny, Wilkins, & Spain, 2009; Hanley-Maxwell, Pogoloff & Whitney-Thomas, 1998). Close to eighty

percent of adult children with ASD continue to live with their parents after high school (Shattuck, Wagner, Narendorf, Sterzing, & Hensley, 2011). Many parents describe their care as “ongoing and forever” (Wong et al., 2017). These examples represent the profound and often life-long responsibility of families to take care for their maturing children with ASD.

Despite the high demand for caring, parents often find a reduction in services after high school and a lack of support in general (Kucharczyk et al., 2015; Selzer et al., 2011; Snell-Rood, 2017). For instance, some parents report that the support system is broken and that their children do not receive sufficient and timely educational and vocational support. It appears that the institutional support systems (e.g., schools, vocational rehabilitation agencies) intended to assist these stressed families do not function to the maximum extent, leaving aging parents overwhelmingly burdened.

A number of studies show that parents of children with ASD report higher stress levels than parents of typically developing children and parents of young children with other types of disabilities (e.g., Benson & Kersh, 2011). This pattern continues as the children age. When parents hit older age, parents of children with developmental disabilities and intellectual disabilities show more depressive symptoms, poorer health, and lower functional abilities, compared to those without an adult child with a disability (Selzer, Floyd, Song, Greenberg, & Hong, 2011). Having a child with autism may also impact other life domains, such as marital satisfaction (Rodrigue, Morgan, & Geffken, 1990), marital status (Selzer et al., 2011), and financial hardship (Parish, Thomas, Williams, & Crossman, 2015).

Even though a number of results show that aging parents of children with ASD experience gratification, for many of them, their children's transition from adolescence to adulthood is filled with anxiety, worries, frustration, and dissatisfaction (Blacher, Kraemer, & Howell, 2010; Fong, Wilgosh & Sobsey, 1993). Intersecting with normative stressors related to aging in life, such as deteriorating health and retirement, support from aging parents for their children with ASD is fading out (Ha, Hong, Seltzer, & Greenberg, 2008; Seltzer, Krauss, Orsmond, & Vestal, 2000). The dwindling familial support and the insufficient public services pose an emerging crisis in long-term care for individuals with ASD (Parish & Lutwick, 2005).

Family-Centered Transition

The notion of family being an integral part of the life of an individual with disability is commonly accepted. Even though existing evidence shows that family involvement in the transition process is associated with positive postsecondary outcomes (Hanger, Cloutier, Arakelian, & Bucker, 2016), it is often neglected in daily practices (Dempsey & Keen, 2008; Dunst, 2002; Kucharczyk et al., 2015). For instance, despite the high level of reported parental participation during the transition process, more than 40% of parents indicate that their child's IEP goals are determined mostly by the school (Cameto et al., 2004), indicating that parents may not be the core decision makers in the process. Further, some parents with students aged 17 to 18 and leaving high school had not yet received information for transition planning (Cameto et al., 2004).

In order to empower families of children with ASD, a family-centered approach is necessary. Dunst and Trivette (1996) defined family-centered practices as having two components - relational and participatory. The relational component includes “practices

typically associated with (a) good clinical skills (e.g., active listening, empathy) and (b) professional beliefs about and attitudes toward families, especially those pertaining to parenting capabilities and competencies” (Dunst, 2002). The participatory component is comprised of “practices (a) that are individualized, flexible, and responsive to family concerns and priorities and (b) that provide families with opportunities to be actively involved in decisions and choices, family–professional collaboration, and family actions to achieve desired goals and outcomes (p.139).” (Dunst, 2002). Instead of merely focusing on the child, a successful transition should also be based on how well the family is doing and how the parents perceive the transition process (Neece, Kraemer, & Blacher, 2009). That is, the transition process and goals should take family well-being into consideration. However, in the current educational and service delivery systems, parents’ experiences and family-level outcomes are often left out during planning and when gauging transition outcomes (Henninger & Taylor, 2014).

Aiming to enhance support for families with transition-age individuals with ASD, researchers and practitioners need to have a good understanding of the risk and protective factors at the parent and family levels. A lack of studies focusing on parents’ perspectives and experiences prevents us from having in-depth insight into the transition process or from developing family-centered support for these families (Gerhardt & Lanier, 2011).

ABCX Model and Protective Factors at Family Level

The ABCX Model (McCubbin & McCubbin, 1993) was used to conceptualize and analyze family adaptation and adjustment experiences during the transition process (Lustig, 1999). Under this model, family-level outcomes are treated as adaptation

outcomes. The ABCX model consists three predictors of adaptation – stressor (A), resources (B), and family coping and perception (C).

Stressors (A) are defined as life events or transitions that have an impact on the family system (e.g., the severity of autism; McCubbin & Patterson, 1983) and the cumulative effects of daily stressors over time (Lavee, McCubbin, & Patterson, 1985). During adulthood, emerging evidence showed that the symptoms of ASD are associated with family expectations, knowledge, and worries when compared to Down syndrome, learning disabilities, and cerebral palsy (Blacher, Kraemer, & Howell, 2010). Maladaptive behaviors (Lounds, J., Seltzer, Greenberg, & Shattuck, 2007) and the child's poor health status (Aschbrenner, K. A., Greenberg, J. S., Allen, S. M., & Seltzer, 2010) also have negative effects on aging parents' well-being.

Other than child-related stressors, aging parents of maturing children with ASD also encounter additional normative stressors, such as deteriorating health, divorce or widowed, or assuming the caregiving role for another family member (Kim, Greenberg, Seltzer, & Krauss, 2003). These normative stressors may also be detrimental to parents' well-being.

Resources (B) are defined as the family's abilities to counteract the negative effects of the stressors (e.g., family's social network), the existing resources, and newly developed resources following the crisis experienced by the family (McCubbin & Patterson, 1983). In general, even though it is commonly accepted that aging parents may have a higher salary than younger parents (Dykens et al., 2000), those with adult children with disabilities are more economically vulnerable than the general population (Fujiura et al., 1998, 2014). Other than financial resources, parents' relationships with their children

(Greenberg, Seltzer, Krauss, Chou, & Hong, 2004), support from the adult children (Heller, Miller, & Factor, 1997), and social support (such as partaking in a support group) are also important protective factors of maternal well-being and quality of life (Aschbrenner et al., 2010; Chou, Pu, Lee, Lin, & Kroger, 2009).

Formal support also plays a critical role. For instance, medical services and use of psychotropic medication were associated with improved maternal well-being (Lounds et al., 2007). Minnes, Woodford, & Passey (2007) found that receipt of formal services, such as case management and respite care, mediated between the stressors and the well-being of parents of adult children with intellectual disability. Such formal, publicly-funded support services reduce the family's out-of-pocket, disability-related expenses (Caldwell, 2006). One of the critical formal supports is school-based support. The National Longitudinal Transition Study-2 revealed that, among their participants with ASD, 97% attended public schools (Newman, Wagner, Juang, et al., 2011). Existing evidence showed that schools are important for desirable outcomes. For instance, parent-school relationships and collaboration are important to both parent's and child's outcomes (Test et al., 2009). Occupational courses, access to internships, and instruction for self-advocacy, are also evidence-based secondary transition predictors (Test et al., 2009). However, many schools' transition practices are not up to standard, such as not providing enough social and work-related interventions or chances to demonstrate self-determination during transition (Wehman et al., 2014). The disconnection of services between in-school and post-school services revealed that schools often fail to provide students with enough support to facilitate a seamless transition (Hendricks & Wehman,

2009), and highlighted the urgent need to understand the role of schools as sources of support during the transition period (Wehman et al., 2014).

Family coping and perception (C) are defined as the family's views on the crisis (e.g., perceived impacts; McCubbin & Patterson, 1983) and the family's general orientation to their situations (e.g., overall appraisal, coping strategies; Florian & Dangoor, 1994). Greenberg and colleagues (2004) found that optimism – seeing positivity and expecting positive events in life was a mediator between positive parent-child relationships and parents' well-being. Two other qualitative studies also replicated the importance of optimism on parent outcomes (Heiman, 2002; Wong, 2017). Similarly, Minnes and colleagues (2007) found that the parental perception of aging mediated the relationship between parental health and parental depression. Coping strategies also predict the well-being of mothers of adults with intellectual disability, with emotion-focused coping leading to lower levels of well-being while problem-focused coping resulted in a reduction in stress (Kim et al., 2003). However, some other studies did not find such effects (Pottie & Ingram, 2008). Most studies found that, passive-avoidance coping stably and negatively predicted parent outcomes (McGrew & Keyes, 2014).

Finally, **family adaptation (X)** represents the outcomes of the adaptation and adjustment process and is a product of the “A”, “B”, and “C” components (Lavee et al., 1985). Parents' outcomes have long been treated as an integral part of family outcomes. Williamson and Perkins (2014) summarized that parents' economic, mental, and physical health outcomes are important family-level outcomes. Currently, parents' overall well-being, absence of mental disorders, stress, and quality of life were commonly used as parental outcomes in previous studies (e.g., Jones & Kingston, 2005; Manning,

Wainwright, & Bennett, 2011; McGrew & Keyes, 2014). Overall, however, the family outcomes of those with adolescents and young adults with ASD are under-researched (Seltzer et al., 2000).

Current Study

In order to contribute to the development of family-centered transition support and respond to the U.S. Department of Health and Human Services (2017)'s call for attention to family's roles and needs during the transition process, the current study has two research questions: (1) What are the predictors of good parent transition outcomes? (2) Do resources (B) and family coping and perception (C) mediate the relationships between stressors (A) and parent outcomes (X) as predicted by the ABCX model? The current study will shed light on important factors that predict good parent transition outcome.

Structural Equation Model

A structural equation model was developed to answer the second research question, and its development was based on a prior qualitative study (Wong, 2017) and a detailed literature review as summarized in the previous section with a consideration of the availability of psychometrically sound measures and participant's burden. In the current model, six indicators were selected to represent A, including child's autism severity, child's adaptive skills, child's mental health crisis, family accumulative stressors, parent's filial obligation, and household income. Household income was treated as an indicator under A instead of B because it represented parent's financial strains, and a later CFA analysis showed that it was loaded significantly on A instead on B in the current model. Five indicators, including parent's general social support, parent's

transition-related support, parent-teacher relationships, religious support/faith, and parenting efficacy, were used to represent B. Four indicators, including problem-focused coping, emotion-focused coping, avoidance coping, and optimism, were used to represent C. Lastly, X included four indicators, they were parents' burden, parents' transition experience, family quality of life, and parents' subjective health. Two default models were built to represent the reciprocity of the B and C as proposed by the ABCX model (McCubbin & McCubbin, 1993). Mixed results have been found about the direction of the effects between B and C (i.e., does B cause X or the reverse? Carver, Scheier, & Segerstrom, 2010). The current model cannot support recursively related paths between B and C. Thus, the first SEM model included only the paths from C to B, while the second one included only the paths from B to C.

Methods

Participants

The parent participants (N=252) was recruited through Amazon Mechanical Turk and were asked to partake in an online survey. The inclusion criteria included having an adolescent or young adult aged from 16 to 24 with a clinical diagnosis of autism spectrum disorder, has or had an individualized Education Program (IEP), and is within 2 years of graduating from high school or your child graduated from high school within the past 2 years. The participant has to be the primary caregiver of the child with autism spectrum disorder. The majority of the parents were white (77%) and female (68.2%). Half of them had a college degree. See Table 3.3 for more information.

The survey contained five attention check questions which were randomly distributed throughout the survey (e.g., Please check "yes"). Participants who did not pass

the attention check questions were screened out, resulting in a sample of 226. It is worth noting that six (2.7%) of the participants were not the parents but assumed the parenting roles of at least one transition-age youth with ASD. These relationships included uncles or older cousins. All of the participants were located in the United States. The parenthood statuses and locations were verified by Amazon Mechanical Turk and their IP addresses. All the participants reported that their children had an IEP during high school and received a clinical diagnosis of ASD from a psychologist, psychiatrist, or other type of medical doctor. The current study also used the Social Communication Questionnaire as a measure of autism severity. Around 11.5% of the participants reported a SCQ score 11. I decided to retain the parents of individuals with ASD with minimal autism symptoms. Although ASD symptoms continue to affect the majority of individuals with ASD throughout adulthood (Volkmar, Reichow, & McPartland, 2014), approximately 10-15% of individuals with ASD obtained more favorable adult outcomes (e.g., become “symptom-free”; Seltzer, Shattuck and Abbeduto, 2004). The tendency of declined ASD symptomology in older age (Howlin & Moss, 2012) implies that some higher functioning adults with ASD may no longer meet the diagnostic criteria. In the current study, the percentage of adolescents and young adults with a SCQ score lower than 11 is similar to the percentage reported in the Seltzer (2004)’s study. Since all the parents reported that their children are receiving special education services or received such services before they graduated from high school, we believe that our sample is a good representation of the whole spectrum of ASD that can help us understand transition-age youth during the transition process. Especially, the final model fit the two sets of data well. Thus, the current study only utilized the full data set (N=226) and reported corresponding results.

Measures

Stressors (A)

Child's autism severity. The Social Communication Questionnaire (SCQ; Rutter et al., 2003) is a dichotomously rated (Yes/No), 40-item questionnaire that measures the severity of autism, with higher scores indicating greater autism symptom severity. A score of 11 indicated elevated likelihood to have an ASD diagnosis (Norris & Lecavalier, 2010). The SCQ has good sensitivity and specificity in identifying autism (sensitivity = .85, specificity = .75; Norris & Lecavalier, 2010) and good internal consistency reliability ($\alpha = .80$ in McStay et al., 2014).

Child's adaptive skills. The Waisman Activities of Daily Living (W-ADL) Scale is a 17-item measure that uses a three-point Likert scale (0=does not do at all, 1=does with help; 2=independent) to evaluate the adaptive skills of individuals with disabilities. W-ADL demonstrated good construct validity and internal consistency ($\alpha = .88-.94$; Maenner et al., 2013).

Child's mental and behavioral health crisis/ challenging behaviors. The Mental Health Crisis Assessment Scale (MCAS; Kalb, Hagopian, Gross, & Vasa, 2017) is a 28-item measure that uses a hybrid scale to measure the presence of emotional and behavioral symptoms exhibited by a child. After reporting the symptoms, the parent then selects the most dangerous behavior and rates the acuity of such behavior and their efficacy in managing this behavior. MCAS demonstrated good internal consistency ($\alpha = .87$), construct validity, criterion validity, and convergent validity (Kalb et al., 2017). It's worth noting that MCAS was also used as a proxy of challenging behaviors because its first section measures the severity of 14 types of challenging behaviors (i.e., injures or

hurts self, physically aggressive towards others; $\alpha = .89$). The overall scale correlated highly with the sum of the first section ($r = .84$).

Family accumulative stressor. The Social Adjustment Rating Scales (SRRS; Holmes & Rahe, 1967) is a 43-item measure that uses a six-point Likert scale (1= not experienced; 5 = experienced with extreme stress) to measure general stressful events. The SSRS demonstrated good internal consistency ($\alpha = .87$; Sturt & McGrew, 2009).

Parent's filial obligation. The Filial Obligation Scale (FOS) was adapted by the author based on the Filial Obligation Attitude Questionnaire ($\alpha = .87$ in the current study; Mangen, Landry, & Bengtson, 1987). FOS is a six-point measure that uses a hybrid scale.

Household income. Annual household income was measured by an item rated on a 14 anchored scale with a 1-point increase associated with an \$5,000 increase (1 = Less than or equal to \$20,000; 14 = More than \$80,000). Household income was treated as an indicator under A instead of B because it represented parent's financial strains, and a later CFA analysis showed that it was loaded significantly on A instead on B in the current model.

Resources (B)

Parent's general social support. The Multidimensional Scale of Perceived Social Support (MSPSS; Zimet, 1998) is a 12-item measure that uses a seven-point Likert scale (1 = very strongly disagree; 7 = very strongly agree) to measure general social support. MPSS demonstrated good internal consistency ($\alpha = .92$; Zimet, 1998).

Parent's transition-related support. The Transition Quality Questionnaire is a 33-item measure that uses a four-point Likert scale to assess the quality and quantity of the transition support provided by the school. The TPQQ was developed by the authors based

on the best-practices for transitioning youth (Landmark, Ju, Zhang, 2010) Indicator 13, and focus group data collected from more than 40 stakeholders (e.g., policy makers, parents, teachers; Snell-Rood et al., 2017). This measure demonstrated good internal consistency ($\alpha = .94$).

Parent-teacher relationships. The Parent–Teacher Alliance Questionnaire (PTAQ) is a 20-item measure that uses a five-point Likert scale (1 = strongly disagree; 5 = strongly agree) to measure the parents’ perceptions of the parent–teacher relationship. It demonstrated a good internal consistency ($\alpha = .95$ in Krakovich, Yu, McGrew, & Ruble, 2016).

Religious support/ faith. The Santa Clara Strength of Religious Faith Questionnaire (SCSRFQ; Plante & Boccaccini, 1997) is a 10-item measure that uses a four-point Likert scale to assess the level of faith. It demonstrated good internal consistency ($\alpha = .99$; $\alpha = .94$ to $.97$; Plante, 2010).

Parenting efficacy. The adapted Mastery Subscale of the Revised Caregiver Appraisal Scale (MS-RCA; Lawton et al., 2000) was modified by Weiss, Tint, Paquette-Smith, and Lunsky (2016). It contains eight five-point-Likert-scale items (1 = disagree a lot/never; 5 = agree a lot/nearly always) and has good internal consistency ($\alpha = 0.80$ in Weiss et al., 2016).

Perception and Coping (C)

Coping strategies. The Brief COPE (Carver, 1997) is a 28-item measure that uses a four-point Likert scale (1 = I haven’t been doing this at all; 4 = I’ve been doing this a lot) to assess parents’ coping strategies, namely problem-focused, emotional approach, or

passive-avoidance coping. This measure demonstrated good internal consistency ($\alpha = .60$ to $.81$; Stuart & McGrew, 2009).

Optimism. The Life Orientation Test- Revised (LOT; Scheier, Carver, & Bridges, 1994) contains ten five-point Likert items to measure optimism (1 = strongly disagree; 5 = strongly agree). It demonstrated adequate test-retest reliability (ICC = $.72$) and internal reliability ($\alpha = .69-.72$; Hirsch, J. K., Britton, P. C., & Conner, 2010).

Parent Transition Outcomes (X)

Parents' burden. The Caregiver Strain Questionnaire (CGSQ; Brannan & Heflinger, & Bickman, 1997) is a 21-item measure that uses a five-point Likert scale (1 = not at all a problem; 5 = very much a problem) to measure parental stress and burden. CGSQ demonstrated good internal consistency ($\alpha = .94$; Stuart & McGrew, 2009).

Parents' transition experience. The Transition Daily Rewards and Worries Questionnaire (TDRWQ; Glidden & Jobe, 2007; Menard, Schoolcraft, Glidden & Lazarus, 2002) contains twenty-one five-point Likert items that measure parents' perception of rewards and concerns towards the transition process (1 = strongly agree; 5 = strongly disagree). It demonstrated good internal consistency ($\alpha = .74-.85$), test-retest reliability ($r = .56-.68$), convergent validity, and divergent validity (Conti-Ramsden, Botting, & Durkin, 2008).

Family quality of life. The Beach Center Family Quality of Life Scale (FQoL; Hoffman, Marquis, Poston, Summers, & Turnbull, 2006) contains 25 five-point-Likert-scale items (1 = very dissatisfied; 5 = very satisfied). It demonstrated good internal reliability ($\alpha = .88-.94$; Hoffman et al., 2006), test-retest reliability ($r = .59-.63$), convergent validity, and construct validity (Hoffman et al., 2006)

Parent subjective health. Parents' health was measured by "please rate your overall health" using a four-point scale (1 = poor; 4 = excellent). See Table 5.1 for the information about the measures.

Table 5.1
Means, Standard Deviations, and Internal Consistency of Measures in the Current Study

Measure	No. items	M	SD	α
SCQ	40	17.82	6.50	.82
W-ADL	17	20.69	6.26	.87
MCAS	28	21.11	6.04	.89
SRRS	22	64.42	22.66	.94
FOS	6	12.03	6.14	.87
MSPSS	20	64.64	17.46	.96
TPQQ	33	103.29	14.72	.94
PTAQ	21	83.27	14.14	.95
SCSRFQ	10	25.04	10.89	.99
MS-RCA	8	29.86	5.54	.84
Problem-focused Coping	6	16.16	3.88	.76
Emotion-focused Coping	10	24.67	5.82	.78
Passive Avoidance Coping	12	19.77	6.38	.83
LOT	10	34.97	8.42	.88
CGSQ	21	42.73	18.51	.96
TDRWQ	28	94.22	19.41	.94
FQoL	25	95.68	17.01	.96

Data Analysis

First, I conducted tests for multicollinearity, outliers, and missing data using the VIF and Tolerance indices, Cook's distance, and Little's Missing Completely at Random Test (MCRT), respectively. No multicollinearity or significant outliers were found. However, the MCRT showed that three measures, including PTAQ, BRIEF-COPE, and CGSQ, were not missing at random, even though the missing data were no more than 0.2% per each item. I deleted all the cases ($N=26$) that contained at least one missing response for these three measures and created a "cleaned" dataset. Due to the absence of

major differences between the two datasets, the scattered missing data pattern, and the intention to maintain a large data set, I decided to impute the missing data in the original dataset using the Expectation-Maximization (EM) approach in SPSS 24. Second, assuming a p-level of .05, a two-tailed test, a power of at least .80, and a large effect size of .80, a sample of 91 would be needed for the current study using structural equation modeling (SEM; Soper, 2017). Third, I conducted correlational analyses and four linear regression analyses using SPSS 24 in order to answer research question one. Fourth, prior to testing the mediational hypotheses, I conducted four CFA models verifying the latent A, B, C, and X variable using AMOS 24 (Figures 5.1– 5.4). Fifth, to test the mediational hypothesis for research question two, I used SEM to develop two partially latent structural regression models. I evaluated the model fit using the following standard measures of practical fit: RMSEA, CFI, TLI, and NFI. Modification indices and recommendations were used for improving the fit of the model. Nonsignificant effects were removed from the model. Sixth, the two models were compared based on the AIC index, BIC index, parsimony, and theoretical relevance. Lastly, a final model was selected and finalized based on Noack (2004)'s guidelines: A model was finalized if the three following criteria were met: "(a) showed an acceptable fit with the empirical data that (b) could not be significantly improved by additional paths but (c) yielded a significantly poorer fit when skipping any of the paths specified."

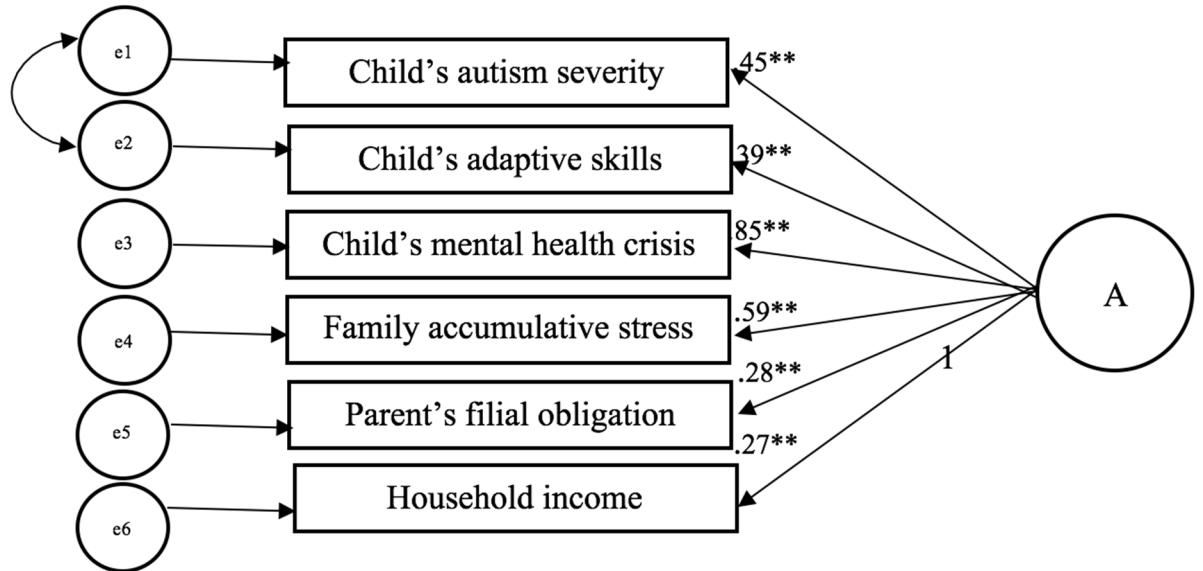


Figure 5.1. CFA for latent variable A.

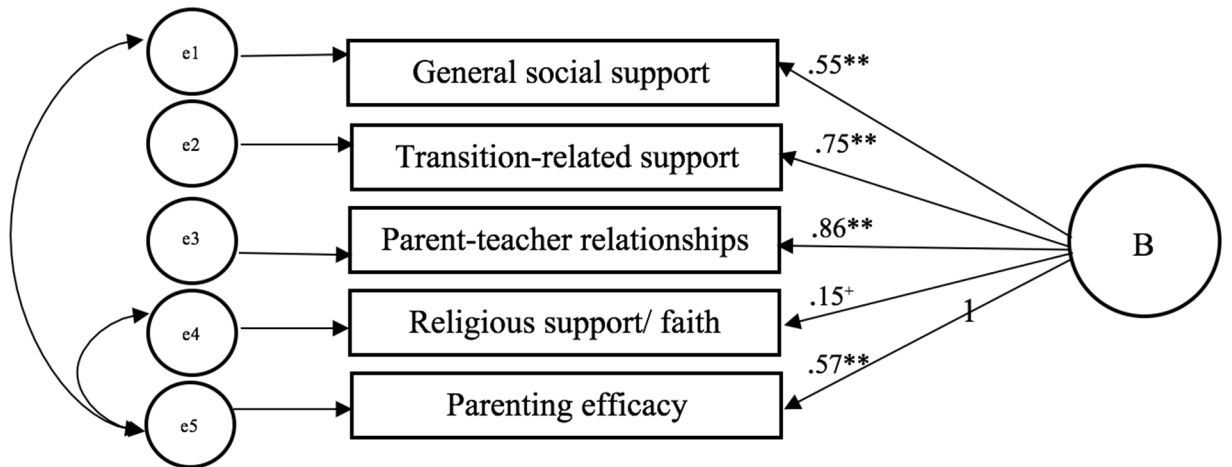


Figure 5.2. CFA for latent variable B.

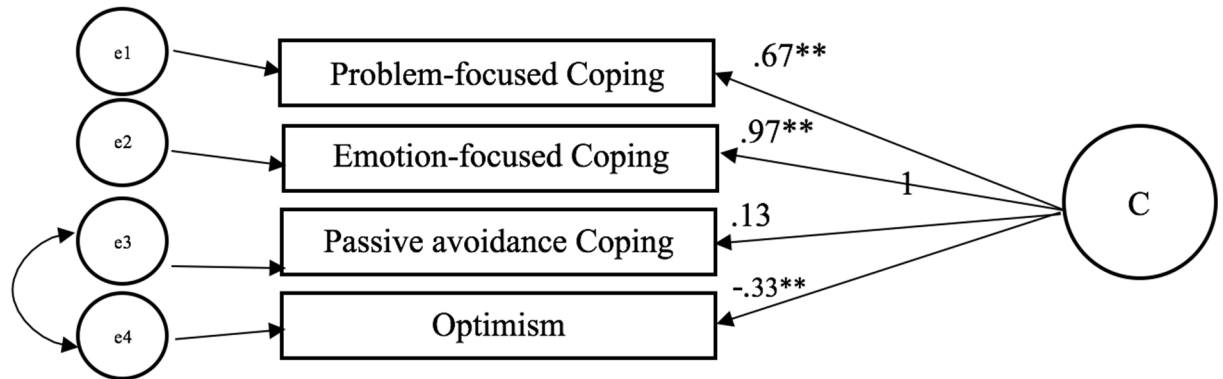


Figure 5.3. CFA for latent variable C.

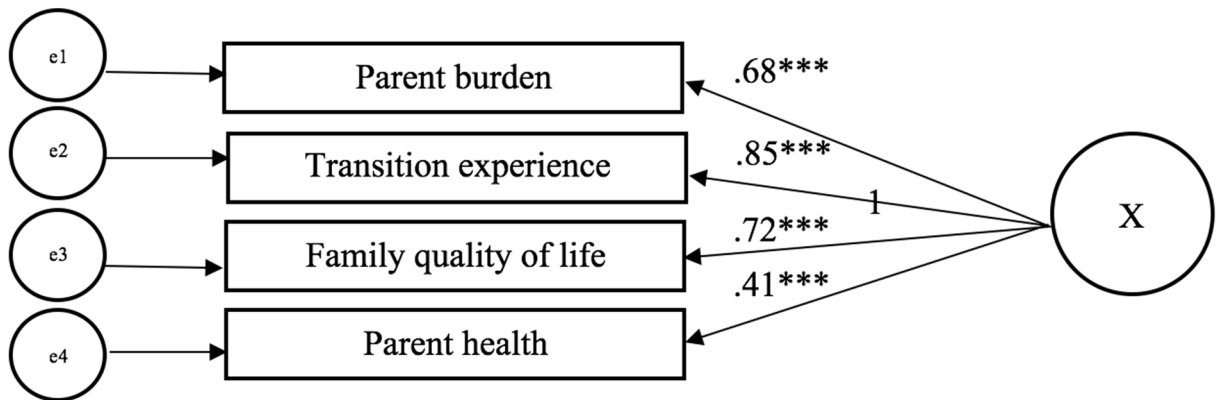


Figure 5.4. CFA for latent variable X.

Results

Regression

As the first step of the multiple analyses, I wanted to understand the significant predictors of parents' burden, parents' transition experiences, family quality of life, and parent subjective health. See Table 5.2 and 5.3 for the correlations and regressions.

Parents' burden. Mental health crisis ($b = .50$, $t(210) = 2.61$, $p = .01$), problem-focused coping ($b = .91$, $t(210) = 3.00$, $p = .003$), avoidance-focused coping ($b = .97$, $t(210) = 5.14$, $p < .001$), and optimism ($b = -.44$, $t(210) = -3.14$, $p = .002$) were significant

predictors of parents' burden. The overall model was significant, $F(15, 210) = 17.72, p < .001$, and accounted for 56% of the variance.

Transition experience. Autism severity ($b = -.61, t(210) = -3.82, p < .001$), filial obligation ($b = .32, t(210) = 2.03, p = .04$), transition planning quality ($b = .28, t(210) = 3.44, p = .001$), parenting efficacy ($b = .91, t(210) = 3.00, p = .003$), problem-focused coping ($b = -.63, t(210) = -2.04, p = .04$), avoidance-focused coping ($b = -.56, t(210) = -2.92, p = .004$), and optimism ($b = .53, t(210) = 3.70, p < .001$) significantly predicted transition experience. The overall model was significant, $F(15, 210) = 20.35, p < .001$, and accounted for 59% of the variance.

Family quality of life. Filial obligation ($b = .35, t(210) = 2.95, p = .004$), social support ($b = .42, t(210) = 7.67, p < .001$), transition planning quality ($b = .16, t(210) = 2.56, p < .001$), parent-teacher alliance ($b = .18, t(210) = 2.57, p = .01$), and avoidance-focused coping ($b = -.39, t(210) = -2.63, p = .01$) were significant predictors of family quality of life. The overall model was significant, $F(15, 210) = 30.01, p < .001$, and accounted for 68% of the variance.

Parent subjective health. Parenting efficacy ($b = .02, t(210) = 2.04, p = .04$) and optimism ($b = .03, t(210) = 4.61, p < .001$) were significant predictors of parent subjective health, while transition planning quality was a marginal predictor ($b = .02, t(210) = 1.95, p = .05$). The overall model was significant, $F(15, 210) = 5.01, p < .001$, and accounted for 62% of the variance.

Table 5.2

Correlations among variables.

Measures	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	
1. Autism severity (SCQ)	---																		
	-																		
2. Adaptive skills (W-ADL)	.46**	---																	
		-																	
3. Mental health crisis	.40**	.34**	---																
4. Accumulated life events (SRRS)		-																	
	.20**	.18**	.50**	---															
		-																	
5. Filial obligation	.08	.20**	.21**	.22**	---														
			-	-															
6. Annual income	-.16*	.07	.20**	.22**	-.10	---													
	-		-	-															
7. Social support (MPSS)	.28**	.31**	.34**	.31**	-.02	.25**	---												
8. Transition planning quality (TPQQ)	-.12	.15*	-.02	-.11	.16*	.05	.43**	---											
9. Parent-teacher alliance (PTA)				-															
	-.09	.13	-.12	.31**	.01	.04	.46**	.65**	---										
		-																	
10. Religious faith (SCSRDF)	.09	.21**	.20**	.17**	.29**	.03	.06	.17*	.10	---									

Table 5.2 (continued)

	-	-	-															
11. Parenting efficacy	.34**	.31**	.47**	.41**	-.14*	.12	.48**	.40**	.51**	-.04	---							
12. Problem-focused coping	.07	.10	.14*	.05	.07	.02	.20**	.20**	.18**	.15*	.12	---						
13. Emotion-focused coping	.04	.02	.14*	.10	.15*	.06	.34**	.33**	.22**	.50**	.13	.65**	---					
		-					-		-		-							
14. Avoidance-focused coping	.27**	.28**	.45**	.50**	.25**	-.04	.40**	-.14*	.30**	.15*	.55**	.10	.12	---				
	-		-															
15. Optimism (LOT)	.28**	.32**	.33**	.31**	-.02	.23**	.60**	.32**	.33**	.11	.49**	.21**	.33**	.44**	---			
		-					-	-	-		-							
16. Parent stress (CSQ)	.40**	.36**	.51**	.40**	.18*	-.14*	.42**	.25**	.31**	.10	.55**	.10	-.02	.62**	.52**	---		
17. Transition experiences (TRAW)	-		-															
	.43**	.32**	.27**	.21**	.05	.16*	.43**	.49**	.44**	.12	.61**	.04	.18**	.44**	.54**	.59**	---	
18. Family quality of life (BEACH)	-		-															
	.30**	.27**	.31**	.28**	.10	.21**	.74**	.54**	.56**	.12	.55**	.18**	.27**	.44**	.58**	.50**	.61**	---
														-		-		
19. Parent health	-.16*	.14*	-.15*	-.14*	-.08	.18**	.30**	.24**	.14*	.11	.31**	.01	.17	.19**	.45**	.24**	.35**	.31**

Table 5.3

Summary of Regression Prediction

<i>DV</i>	<i>Parent burden</i>			<i>Parent transition experience</i>			<i>Family quality of life</i>			<i>Parent health</i>		
	<i>Standardized coefficient</i>	<i>Unstandardized coefficients</i>		<i>Standardized coefficient</i>	<i>Unstandardized coefficients</i>		<i>Standardized coefficient</i>	<i>Unstandardized coefficients</i>		<i>Standardized coefficient</i>	<i>Unstandardized coefficients</i>	
<i>IV</i>	β	β	<i>SE</i>	β	β	<i>SE</i>	β	β	<i>SE</i>	β	β	<i>SE</i>
Autism severity (SCQ)	.10	.29	.16	-.21**	-.61	.16	-.05	-.14	.12	-.003	.000	.01
Adaptive skills (W-ADL)	-.07	-.20	.17	.07	.22	.17	-.002	-.01	.13	-.009	-.001	.01
Mental health crisis	.16**	.50	.19	.06	.20	.20	-.03	-.09	.15	.07	.01	.01
Accumulated life events (SRRS)	-.01	-.01	.05	.10	.09	.05	.06	.05	.04	-.01	.000	.002
Filial obligation	.02	.05	.15	.10*	.32	.16	.13**	.35	.12	-.10	-.01	.01
Annual income	-.02	-.07	.20	.08	.33	.21	.06	.22	.16	.07	.02	.01
Social support (MPSS)	.05	.05	.07	-.09	-.10	.07	.43**	.42	.10	.01	.000	.003
Transition planning quality (TPQQ)	-.07	-.08	.08	.22**	.28	.08	.14*	.16	.06	.16+	.01	.004
Parent-teacher alliance (PTA)	-.03	-.04	.09	.06	.09	.09	.15*	.18	.07	-.16	-.01	.004
Religious faith (SCSRDF)	.06	.11	.10	.06	.10	.10	.05	.08	.08	.06	.004	.01
Parenting efficacy	-.11	-.37	.23	.32**	1.11	.23	.10	.29	.18	.18*	.02	.02
Problem-focused coping	-.19**	.91	.31	-.13*	-.63	.31	.05	.21	.24	-.16	-.03	.01
Emotion-focused coping	-.15	-.49	.25	.06	.20	.25	-.06	-.16	.19	.06	.01	.01
Avoidance-focused coping	.34**	.97	.19	-.18*	-.56	.19	-.15**	-.39	.15	.06	.01	.01

Table 5.3 (continued)

Optimism (LOT)	-.20**	-.44	.14	.23**	.53	.14	.10	.20	.11	.48**	.03	.01
R ²	.56			.59			.68			5.01		
F	17.72			20.35			30.09			.26		

CFAs

The four separate CFAs constructed on each of the latent variables (A, B, C, X) found that all the models had good model fit. See Table 5.4 for the fit indices. However, for Factor C, avoidance coping was not significantly loaded ($\beta = -.15, p = .08$) on Factor C despite the good overall model fit. Also, optimism and avoidance coping were negatively loaded on Factor C. In fact, the literature does not have a coherent view on the relationship among the four indicators selected, even though they were usually treated as components of C (e.g., Aldwin & Revenson, 1987; Benson, 2010). Despite the fact that the four indicators did not load coherently on C, the four indicators were entered separately in the model. That is, the four indicators were treated as their own constructs. Overall, the indicators selected were representative of A, B, and X latent variables. See Figures 5 – 8.

Table 5.4
CMIN, RMSEA, CFI, and TLI of the four CFA models

Models	CMIN	RMSEA	CFI	TLI	NFI
A	$\chi^2 (8, N = 226) = 12.28, p = .14$.05	.98	.96	.94
B	$\chi^2 (3, N = 226) = .451, p = .21$.05	1.00	.98	.98
C	$\chi^2 (1, N = 226) = .16, p = .69$.00	1.00	1.02	1.00
X	$\chi^2 (2, N = 226) = 1.13, p = .57$.00	1.00	1.11	.99

SEM

Model 1 (with only paths from B to C)

The original model did not demonstrate sufficient model fit, $\chi^2 (139, N = 226) = 529.39, p < .001$; RMSEA = .11 CFI = .78; TLI=.73; NFI=.73. See Figure 5.5. Based on the modification indices, 35 unique pairs of error terms were allowed to be correlated. In this model, five paths were non-significant. These paths were trimmed.

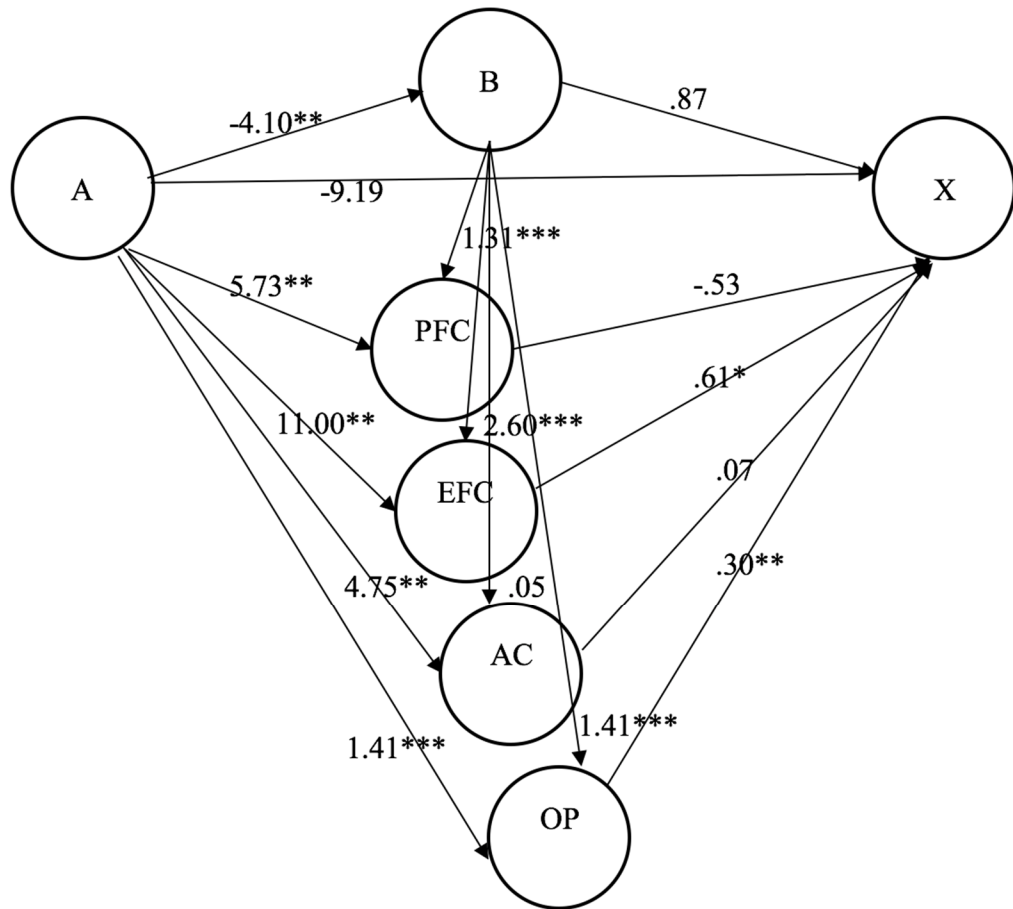


Figure 5.5. Model 1; +=.05; =<.5; **=<.03; ***=<.00; A= Stressors; B=Resources; PFC=Problem-focused coping; EFC=Emotion-focused coping; AC=Avoidance coping; OP=Optimism; X=Parents' transition outcomes.

Model 1.1

The trimmed Model 1.1 found adequate fit with the data, χ^2 (92, $N = 226$) = 169.05, $p < .001$; RMSEA=.06; CFI=.96; TLI=.94; NFI=.91; AIC=347.55; BIC = 642.73. Despite a significant overall chi-square statistic, the rest of the fit indices suggest good model fit. See Figure 5.6.

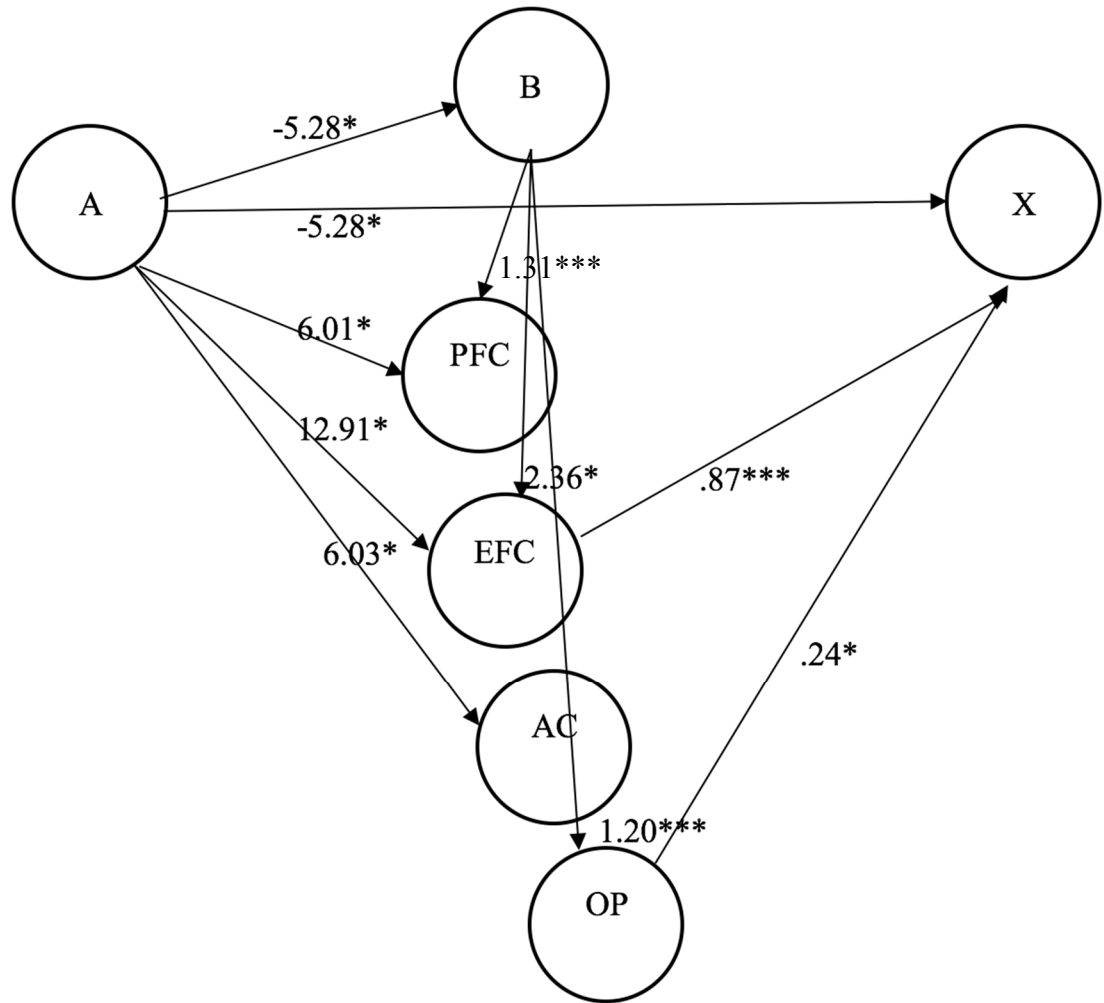


Figure 5.6. Model 1.1; +=.05; =<.5; **=<.03; ***=<.001; A= Stressors; B=Resources; PFC=Problem-focused coping; EFC=Emotion-focused coping; AC=Avoidance coping; OP=Optimism; X=Parents' transition outcomes.

Model 2 (with only paths from C to B)

The original model did not demonstrate sufficient model fit, $\chi^2 (139, N = 226) = 659.60, p < .001$; RMSEA = .13 CFI = .69; TLI=.62; NFI=.65. Thus, based on the modification indices, 58 unique pairs of error terms were allowed to be correlated. Seven paths were non-significant and were pruned. As a result, problem-focused coping was not significantly related to any variables and was deleted from the model. See Figure 5.7.

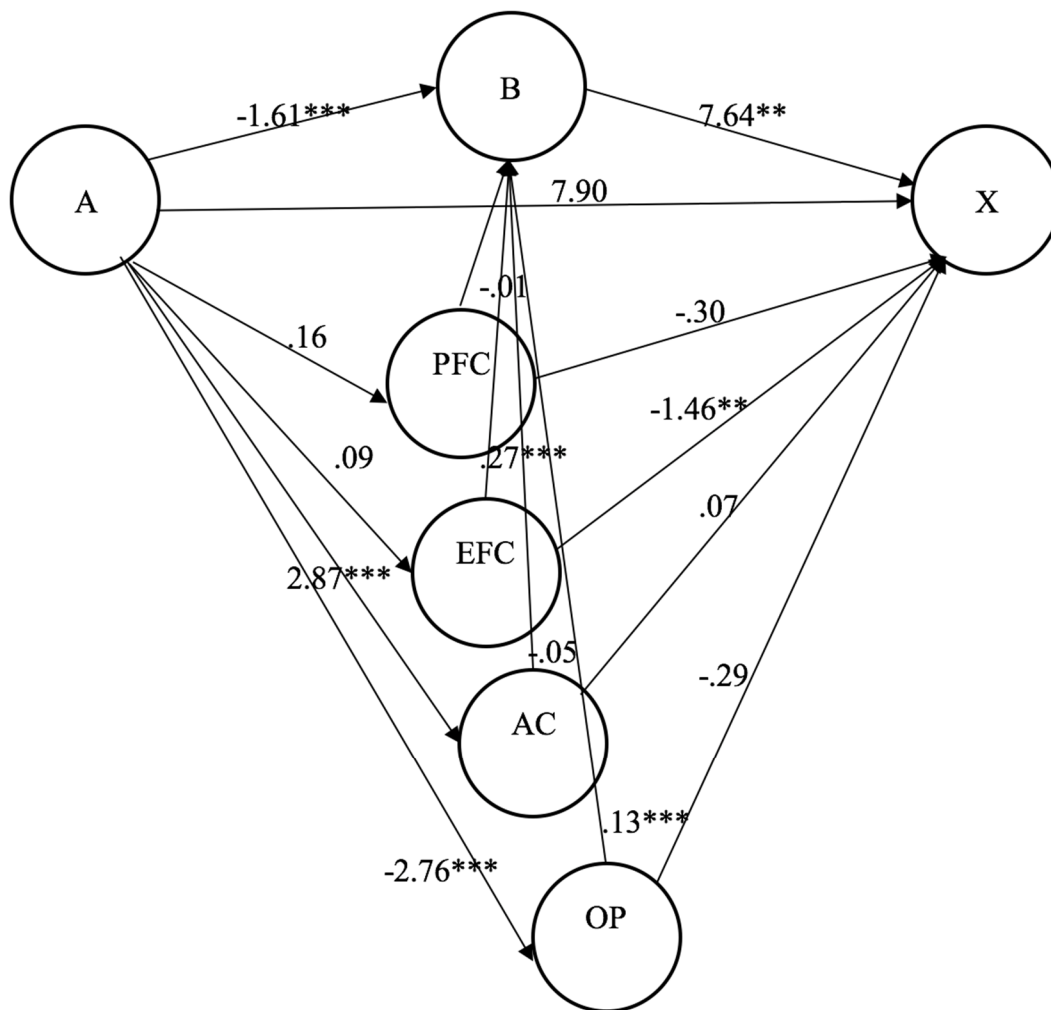


Figure 5.7. Model 2; +=.05; =<.5; **=<.03; ***=<.001; A= Stressors; B=Resources; PFC=Problem-focused coping; EFC=Emotion-focused coping; AC=Avoidance coping; OP=Optimism; X=Parents' transition outcomes.

Model 2.1

The trimmed Model 2 found adequate fit with the data, $\chi^2(91, N = 226) = 166.61$, $p < .001$; RMSEA=.06; CFI=.95; TLI=.92; NFI=.91; AIC=326.62; BIC=600.26. Overall, the fit indices suggest good model fit. See Figure 5.8.

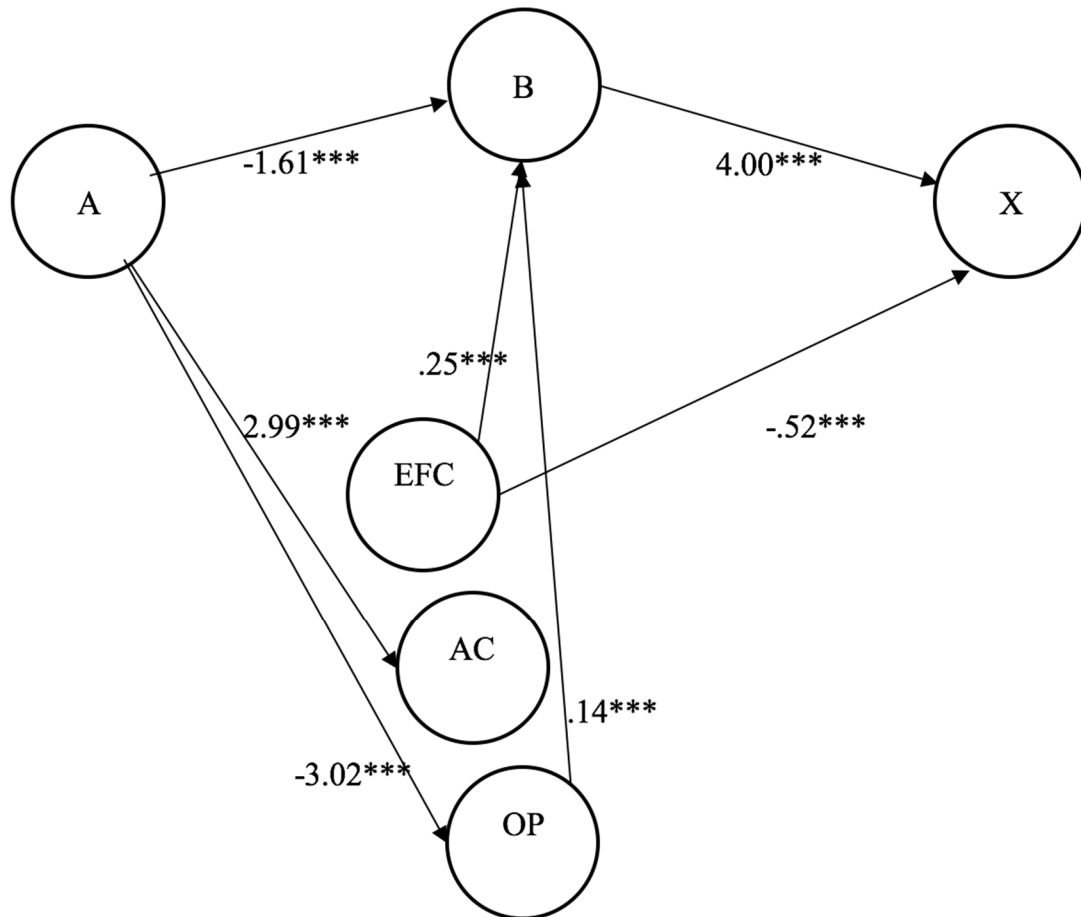


Figure 5.8. Model 2.1; +=.05; =<.5; **=<.03; ***=<.001; A= Stressors; B=Resources; PFC=Problem-focused coping; EFC=Emotion-focused coping; AC=Avoidance coping; OP=Optimism; X=Parents' transition outcomes.

Model comparison

Despite the apparently good model fit indices of the two models, Model 2.1 is closer to the “true model” compared to Model 1.1 based on the lower AIC and BIC scores. Also, the Model 2.1 is more parsimonious with two fewer paths. Additionally,

Model 2.1 is aligned with the ACBX Model (i.e., with A, B, C, X connected and B and C as mediators; Nachshen, & Minnes, 2005) and thus is interpretable. I selected Model 2.1 as the final model and reported details of the results of Model 2.1 in the following section.

Model 2.1 as the final model

A (Stressors) predicted B (Resources; $\beta = -1.61, p < .001$), passive-avoidance coping ($\beta = 2.99, p < .001$) and optimism ($\beta = -3.02, p < .001$). That is, parents who are more stressed tend to have fewer resources, use more passive-avoidance coping, and are less optimistic.

B predicted X ($\beta = 4.00, p < .001$). That is, more resources also led to better parent outcomes.

Optimism ($\beta = .14, p < .001$) and emotion-focused coping ($\beta = .25, p < .001$) predicted B. Emotion-focused coping also predicted X ($\beta = -.52, p = .002$). That is, parents who used more emotion-focused coping and are more optimistic tend to have more resources. Also, when resources are controlled, those who use more emotion-focused coping tend to have worse parent outcomes.

Next, the mediating effect in Model 2.1 was examined. The bootstrapping estimate showed a significant indirect effect between A and X through two paths (i.e., $A \rightarrow B \rightarrow X$, $A \rightarrow \text{Optimism} \rightarrow B \rightarrow X$; $\beta = -8.28, 95\% \text{ CI} = -13.65 \text{ to } -5.74; p = .002$). That is, overall, parents who are stressed tend to have poor adaptive outcomes. This relationship is mediated by the amount of resources and optimism.

There was also a significant indirect effect between emotion-focused coping and X through B ($\beta = .99, 95\% \text{ CI} = .68 \text{ to } 1.37; p = .003$). The positive indirect effect

was strong enough to override the negative direct effect between emotion-focused coping and X, resulting in a positive, significant total effect ($\beta = .99$, 95%=.68 to 1.37, $p = .003$).

Discussion

This study analyzed a relatively large set of variables and their relationships with four important family and parents transition outcomes. It provided a clearer picture of both the weight of each predictor at the indicator level and the mediating mechanism between A and X at the structural level.

Direct effect of ABC on X

The regression analyses provided a detailed picture of the total effects of the 15 predictors on parents' burden, transition experience, family quality of life, and parent subjective health.

Stressors (A)

Consistently with a previous meta-analysis (Hayes & Watson, 2013) and a large body of findings (e.g., Baghdadli, Pry, & Michelon, 2014; Rattaz, Michelon, Roeyers, & Baghdadli, 2017), mental health crisis/ challenging behaviors were the most significant predictors of parents' burden among all the selected stressors.

Different from parents' burden, the parent transition daily rewards and worries questionnaire (TDRWQ) measures the transition rewards and worries which are more specific to parents' perceptions on future and family relationships during the transition from adolescence to adulthood (Jobe & Glidden, 2008). The severity of autism is a detrimental factor of the transition experience. Parents of children with more severe autism symptoms worry more. Similarly, Blacher and colleagues' findings (2010) also found that autism, when compared to Down's syndrome, cerebral palsy, and other

learning disabilities, causes more worries and restrictive expectations in parents during transition. This worry may be valid because positive transition outcomes, such as competitive employment and independent living, are more prevalent among those with fewer autism symptoms (Eaves & Ho 2008; Howlin et al. 2004, Talory & Selter, 2011).

Surprisingly, more filial obligation led to a more positive parents' transition experiences and family quality of life. Aging parents of adults with ASD have their own aging parents too. It is not uncommon for parents to face the stress of taking care of their adult children with disabilities and their own parents in decrepitude (Grundy & Henretta, 2006; Wong, 2017). However, the current study also pointed out that this double duty might not be totally detrimental. Instead, this result is largely consistent with studies in the area of family science that taking care of one's own parents or caregiving in general does cause stress, but it also enhances subjective well-being and other positive personal outcomes (Silverstein & Giarrusso, 2010). This result suggests the complex and multi-faceted nature of family-level stressors.

Resources (B)

Transition planning quality emerged as an important predictor of three parents' transition outcomes, parents' transition experience, family quality of life, and parents' health. Transition planning quality measures whether schools implement evidence-based or recommended practices by the IDEA, Indicator 13, and existing research literature. Other than more structured school-based transition support, parent-teacher alliance was also found to predict family quality of life. Without doubt, schools' services and parent-school relationships are important during transition, yet they were often neglected as a source of support in studies predicting parent adaptive outcomes (e.g., Boehm, Carter, &

Taylor, 2015). There are 6.6 million youths in special education, with 10% between the age of 14 and 21 (US Department of Education, 2011). The vast majority of these transition-age youth in school highlights the critical role of schools as support hubs and training avenues for families. Unfortunately, the existing literature suggested that the transition support and educational programs fail to support the unique needs of students with ASD or include parents as the core decision makers (Kucharczyk et al., 2015; Snell-Rood et al, 2017). Even more so, many parents reported negative experiences with school systems (Wong, 2017). The need to train school personnel to support families of youth and young adults with ASD is paramount (Schall, Wehman, & McDonough, 2012), Many call for more transition training for school professionals, such as school psychologists (Schall et al., 2012; Talapatra, 2014). However, more than half of school psychologists reported not being involved in the transition process (Lillenstein, Levinson, Sylvester, & Brady, 2006).

These results highlight the importance of both quantitative (e.g., compliance with standard practices) and qualitative (e.g., parent-teacher relationship) aspects of school-based transition planning in family-centered transition support and family outcomes and calls for transition interventions that help school professionals implement quality transition planning and build positive collaboration with families.

Other than school-based support, general social support is also a vital predictor of family quality of life. This study replicated the importance of informal social support to parents' well-being (Bishop et al., 2007; Ekas, Lickenbrock, & Whitman, 2010). Overall, both formal and informal support predicted better parents' outcomes.

On top of external support, internal support appears to matter too. Consistent with previous research with parents, parenting efficacy, (Carter, Martinez-Pedraza, & Gray, 2009; Raikes & Thompson, 2005) predicted both parents' transition experiences and parents' health. This finding provides one of the pieces of evidence for the continual importance of parenting efficacy and its role in transition planning. It also encourages future researchers to consider this construct as a potential mechanism of change for effective interventions (Weiss, Tint, Paquette-Smith, & Lunsy, 2016; Keen, 2010).

Contrary to a previous study (Boehm et al., 2015), we found that religion did not significantly predict family quality of life despite a positive trend. This divergent finding may be due to the fact that, in our model, the other stronger predictors absorbed more of the variance than religion.

Coping Strategies and Perceptions (C)

Passive-avoidance coping and optimism were the two most predictive C factors of parent outcomes across the board. Consistent with previous literature studying parents of younger children with ASD, passive-avoidance coping predicted a lower family quality of life (Dardas & Ahmad, 2015; Hastings et al., 2005) and provided evidence for the continual detrimental effect of passive coping on family outcomes during the transition period (Yu, 2017). Similarly, the current results also replicate the positive effects of optimism on positive parents' outcomes (Ekas, Lickenbrock, & Whitman, 2010; Greenberg, et al., 2004)

Conversely, the current study found mixed results with regard to problem-focused and emotion-focused coping. Interestingly, higher levels of problem-focused coping predicted lower stress but a poorer transition experience. This finding is somewhat

aligned with a relatively large study that found that higher levels of problem-focused coping were associated with better mothers' outcomes (Smith et al., 2008), but contradicts a study that found a positive relationship between task-oriented coping and stress among parents of young children with ASD (Dabrowska & Pisula, 2010). The negative effect found between problem-focused coping and parents' transition experiences may be explained by the contextual characteristics of coping, meaning that coping is not innately good or bad but is based on the context in which it expresses (Folkman & Moskowitz, 2004). For instance, it is known that schools' transition practices are often not up-to-standard despite parental efforts (Kucharczyk et al., 2015; Snell-Rood et al, 2017). The gigantic, ineffective educational transition system often negates the effect of strong parental efforts, which may aggravate the negative experiences among parents who actively try to tackle problems. Further research is needed to confirm such claim.

Similarly, the effect of emotion-focused coping is mixed (Aldwin & Revenson, 1987). Some researchers found a positive relationship between emotion-coping strategies and parental stress (Manning et al., 2011), while others did not (Benson, 2010). The current results suggest that emotion-focused coping does not have a direct effect on the selected parent outcomes using regressions, similar to Benson (2010)'s findings. Contrarily, the current results suggest that, at a structural level, emotion-focused coping has a negative direct effect on parents' adaptive outcomes (Beasley, Thompson, & Davidson, 2003; Solomon, Mikulincer, & Flum, 1988). More discussion with regard to emotion-focused coping is presented in the following section.

Overall, the results support some general components for practices, such as

strategies to enhance parenting capabilities, quality family-professional relationships, active parent involvement, and a family-centered approach (Dunst & Trivette, 1996). The results provided evidence for the predictability of A, B, and C factors on adaptive outcomes (McCubbin & McCubbin, 1993) as described in the introduction section. The current study also provides a more detailed picture on the predictors of good family outcomes during the transition process, which might shed light upon the further development of family-centered transition interventions.

Indirect effect of ABC and X

To advance our understanding of the predictability of A, B, and C on X, I examined a partially latent structural regression model. The model revealed a significant full mediation effect between A and X through two paths ($A \rightarrow B \rightarrow X$ and $A \rightarrow \text{Optimism} \rightarrow B \rightarrow X$). The implications are two-fold. First, the current study showed that resource and optimism mediated the relationship between stressors and parent outcomes. There is a debate about the directional effect between resources and optimism and the reciprocal relationship (Carver, Scheier, & Segerstrom, 2010). The current results supported the claim of optimism leading to more resources. For instance, optimistic individuals are more liked by others and are more likely to seek out social resources (Carver et al., 2010). Optimistic individuals also demonstrated higher goal engagement and attainment for high-priority goals (Geers, Wellman, & Lassiter, 2009). In the context of transition, it is possible that optimistic parents not only have more social support, but they are also able to solve prioritized problems with persistence through available support. However, the full mediation contrasts a study with parents of young children with ASD (Ekas et al., 2010). In this study, the discrepant results may be due to the

different selection of B and X indicators and the limited measure of A in Ekas' study. The overarching effect of resources highlights the potential of interventions that connect parents with resources during transition (Ruble et al., 2017; Trainor, 2008; Tylor, Hodapp, Burke, Waitz-Kudla, & Rabideau, 2017).

Second, the current results support the ACBX model (Nachshen, & Minnes, 2005) instead of the ABCX model because of the $A \rightarrow \text{Optimism} \rightarrow B \rightarrow X$ path. This not only provides additional evidence for the sequence of change between A and X among parents of children with ASD, but also to the general literature on optimism (Carver et al., 2010).

Another indirect effect was found between emotion-focused coping and parent adaptive outcomes through resources. Unlike optimism, emotion-focused coping had a negative direct effect on adaptive outcomes, but such a negative direct effect was itself negated by the positive indirect effect through resources. It is consistent with some previous findings that show emotion-focused coping led to positive outcomes, such as lower stress levels, among parents of children with ASD (Manning et al., 2011; Hastings et al., 2005; Stuart & McGrew, 2009), but in the meantime this also supports the paradoxical, negative effect of emotion-focused coping on mental health as summarized by Aldwin and Revenson (1987). The mixed results found in the literature may be due to the buffering, countering indirect effect, implying that emotion-focused coping is a double-edged sword – it leads to desirable outcomes if resources are available and obtainable, but has a detrimental effect if used without resources.

Together, the positive total and indirect effects of optimism and emotion-focused coping on parent outcomes through resources raised an interesting question: Under the gigantic, seemingly unchangeable transition system, what coping strategies help parents

access necessary resources in order to obtain good family and parent outcomes? These results showed that emotion-focused coping might be more effective in solving unsolvable problems (Folkman & Moskowitz, 2004; McGrew & Keyes, 2014, Yu, 2017). It appears that instead of tackling all transition-related stressors directly, staying optimistic is the key for acquiring support from an ineffective system.

Limitations

Due to the malleability of SEM models (MacCallum & Austin, 2000), I encourage readers to interpret the linear regressions and SEM results together. Also, in order to avoid power issues and overloading, the current study did not include some important variables, such as repetitive behaviors (Smith et al., 2008), use of psychotropic medication (Lounds et al., 2017), the presence of fragile X syndrome (Abbeduto et al., 2004), marital relationship (Kersh, Hedvat, Hauser-Cram, & Warfield, 2006). In order to untangle the reciprocal relationship between B and C, longitudinal studies are needed. Continual research efforts are needed in pursuance of a clearer picture of family-level proactive factors.

Chapter 6 Combined Discussion

As a whole, the current project provided insight to the understanding of the stressors, external and internal support, coping strategies, and family adaptation outcomes, as well as the predictors of parents' transition outcomes. Chapter 2 laid the groundwork for the project by providing a general review of the literature and a systematic review identifying the predictors and parents' outcomes within the ABCX model. The first step informed the development of the questions for participants in the qualitative study and the selection of the variables in the quantitative study. Chapter 4 contained a qualitative study in order to explore factors that contribute to the stressors, resources, perception/coping strategies, and desirable outcomes for parents of adolescents and young adults with ASD. Together, the first and second steps provided a clearer picture of the potential factors that predict desirable parents' transition outcomes. Chapter 4 described results from linear regressions to investigate the predictors at an indicator level and found that autism severity, mental health crisis/challenging behaviors, filial obligation, general social support, transition planning quality, parent-teacher alliance, parenting efficacy, problem-focused coping, avoidance coping, and optimism were important predictors of at least one of the four parents' outcomes (i.e., parents' burden, parents' transition experience, parents' subjective health, and family quality of life). Structural equation modeling was also used in Chapter 5 to confirm the loadings of the indicators on the A, B, C, and X factors respectively, and then investigated their relationships. At a structural level, the study provided the literature with new information about the validity of the ABCX model and obtained a deeper-level picture of the relationships among the variables. At the structural level, optimism, emotion-focused coping, and resources

predicted parents' transition outcomes and were mediators in the ABCX model. The three main indirect effects were sequenced as the following: $A \rightarrow B \rightarrow X$; $A \rightarrow \text{optimism} \rightarrow B \rightarrow X$; and $\text{emotion-focused coping} \rightarrow B \rightarrow X$. That is, overall, stressors led to poorer adaptive outcomes because parents with more stressors were less able to obtain the necessary resources to cope, resulting in poorer adaptive outcomes. Additionally, stressors also made parents less optimistic, which in turn led to a lower ability to acquire resources, and thus also resulted in poorer adaptive outcomes. On the other hand, even though stressors did not predict the use of emotion-focused coping, parents who used more emotion-focused coping were better able to obtain necessary resources, which improved their adaptive outcomes. The final stage of the study gave some insight into the predictability of the child-and parent-related predictors on parents' transition outcomes, as well as the model validity. Overall, the results generally supported the importance of the A, B, and C factors on X; however, the sequence of the effect was more aligned with the ACBX model instead of the ABCX model (Nachshen & Minnes, 2005).

Factors Influencing Parents' Transition Outcomes

Stressors (A). The current study delineated the stressors experienced by parents of adolescents and young adults with ASD. These stressors were believed to be detrimental to the family adaptive process during transition (Sanders & Morgan, 1997). In the qualitative study, parents identified an array of parent-and child-related factors that burden them. The five themes included parent's deteriorating health, normative changes and strains, continual deficits, changes in the child's demands, and having more than one child with disabilities. These themes nicely captured the complexity of the stressors experienced by parents of adolescents and young adults with ASD during transition. First,

the stressors are changing in their quantity, expressions, and impact. Despite the known autism symptom abatement among a large number of adolescents and young adults with ASD, the needs of these individuals might change or even increase over time (Volkmar, Lord, Bailey, Schultz, & Klin, 2004). For instance, an adolescent with ASD might want to learn more about romantic relationships, while a toddler does not. Also, the aggressive behaviors of a young adult and those of a toddler poses different levels of danger to the family. Such changes in symptom manifestation and impact concomitant with developmental stages require parents to act differently and acquire new resources and skills (Seltzer et al., 2003).

Nevertheless, the changes in the needs of adolescents and young adults with ASD are not the sole source of stress. These child-related stressors should be interpreted with the normative stressors experienced by parents. Aging itself can be stressful. Rowe and Kahn (1997, p.433) defined successful aging as a non-pathological stage that contains three components - “low probability of disease and disease-related disability, high cognitive and physical functional capacity, and active engagement with life.” While aging poses risks to the three components of successful aging, it is possible for the older individuals to proactively reserve, to a certain extent, their capacity through healthy lifestyle and training (Shephard, 1993). However, the aging processes of parents of adolescents and young adults with ASD interact with those of their aging children. The continual caregiving responsibilities interfere with the parents’ normative aging process. As a result, many aging parents of adolescents and young adults with ASD experience depression, physical health issues, financial strains, and so on. (Abbeduto et al., 2004; Hare, Pratt, Burton, Bromley, & Emerson, 2004).

In addition to the qualitative study, the quantitative study added information about the factors that impact parents' transition outcomes to the literature. At the indicator level, all six stressors were correlated with at least one of the parents' transition outcomes. Among all the variables, two child-related factors (i.e., autism severity and mental health crisis/challenging behaviors) and one parent-related factor (i.e., filial obligation) predicted at least one of the parents' transition outcomes.

Autism severity. The current result replicated Rattaz and colleagues (2017)'s findings that autism symptomology was not associated with parental quality of life among older parents. This may be due to parents' acceptance of their children's differences and their accommodation of their children's autism symptoms (Futagi & Yamamoto, 2002). This may also imply that autism symptomology itself, different from challenging behaviors, may not have direct impacts on parents' overall satisfaction with their life because their children may not pose immediate danger to themselves or others. However, for this group of parents of transition-age youth, their children's autism symptom severity negatively predicted their daily transition experiences. For instance, parents who have children with more autism symptoms displayed more worries or dissatisfaction towards their children' future, access to community resources, financial independence, and family relations. That is, even though autism symptomology does not impact the global well-being of parents, it might at least influence the local, day-to-day experience during transition.

Challenging behaviors continue to be the most detrimental child-related factor of parental stress (Baghdadli, Pry, & Michelon, 2014; Hayes & Watson, 2013; Rattaz, Michelon, Roeyers, & Baghdadli, 2017). The Mental Health Crisis Assessment Scale

(MCAS; Kalb, Hagopian, Gross, & Vasa, 2017) specified a score of 18 as the cut-off for identifying a mental health crisis. In the current study, approximately 60% of parents indicated that their children were having a mental health crisis. This study not only echoes some previous studies that showed severe behavioral problems and co-morbidity among adolescents and adults with ASD, but also singles these factors out as the main child-related source of parental stress during transition. Professionals who work with parents of adolescents and young adults with ASD need to be aware of the toll that challenging behaviors takes on parents' mental health. Similarly, stress reduction programs and counseling for parents of adolescents and young adults with ASD should also prioritize assistance for parents to handle their children's challenging behaviors, if there are any.

Filial obligation. Undeniably, taking care of one's aging parents can be a stressful experience for parents (Robinson & Thurnher, 1979). The current study showed a non-significant, negative trend between filial obligation and parents' subjective health. In the meantime, filial obligation positively correlated with other stressors (i.e., mental health crisis/challenging behaviors and accumulated stressful life events). However, the current findings also demonstrated the positive side of filial obligation – it positively predicted parents' transition experience and family quality of life. This result is largely consistent with family science studies that report that while taking care of one's own parents or caregiving in general does cause stress, it also enhances subjective well-being and other positive personal outcomes (Silverstein & Giarrusso, 2010). Also, the qualitative results might give us some hints with which to interpret the seemingly contradicting results. While parents mentioned that taking care of their own parents and their adult children

with disabilities was stressful, they also reported that they received tangible (e.g., child care) and emotional support from their own parents. That is, there might be some potential mediating or moderating factors that influence the impact of filial obligation. For instance, even though a grandparent who stays in the same household might need help with his or her daily living, he or she can also play a role in taking care of the adolescent or young adult with ASD when the parents are not available. This result highlights the fact that different kinds of stressors might function differently at the family levels. Also, it is important for researchers to remember that stress is a double-edged sword – excessive stress can lead to detrimental effect, but optimal stress is also motivating and prompts individuals to solve problems (Thoits, 1995). Currently, we only have a limited understanding of the complex and multi-faceted nature of family-level stressors among families of adolescents and young adults with ASD.

An additional explanation for the seeming contradictory effects of filial obligation (i.e., positive correlations with other stressors; negative predictability towards parents' transition outcomes) is the suppression effect. That is, the inclusion of other A, B, and C variables in the regression strengthens the relationship between filial obligation and the two parents' transition outcomes (i.e., parents' transition experience and family quality of life) because the irrelevant variances are controlled for (Conger, 1974). Again, potential mediating or moderating effects are of interest for future research.

At the structural level; however, stressors as a whole did not have a direct effect on parents' transition outcomes. Rather, the effect of stressors was fully mediated by resources and optimism. This finding has two implications. First, researchers should consider potential indirect effects when studying the impacts of stressors on family

adaptive outcomes. Without doing so, one would oversimplify the complex picture of the effects of stressors. Second, a positive message from the finding is that the detrimental effect of stressors on parents' transition outcomes can, to a great extent, be buffered. Indeed, future replication is needed in order to confirm such an indirect effect at a structural level.

Resources (B). In the qualitative study, parents identified an array of tangible, emotional, information, and internal resources that had helped or would help them go through the transition process. The majority of these sources of support were provided by other parents of children with ASD, formal support agencies (i.e., vocational rehabilitation agencies, religion, and schools), local or national ASD organizations, spouses, other family members, and parents themselves. These resources are believed to be a buffer against stressors (Duarte, Bordin, Tatzigi, & Mooney, 2005; Wheeler & Frank, 1988).

The regression analyses further confirmed the effect of resources on parents' transition outcomes. General social support, transition planning quality, parent-teacher alliance, and parenting efficacy significantly predicted at least one component of parents' transition quality.

General social support. Social support is often regarded as “the information leading the subject to believe that he is cared for and loved, esteemed, and a member of a network of mutual obligations (Cobb, 1976).” It is well known that social support is important for the well-being of a person. The needs for interpersonal attachments are fundamental needs (Baumeister & Leary, 1995). Consistent with the literature, the current results found that social support predicted parents' transition outcomes (Aschbrenner et

al., 2010; Chou, Pu, Lee, Lin, & Kroger, 2009). However, the current qualitative results also found that, unfortunately, parents of children with ASD received relatively limited social support (Sharpley et al., 1997). When studying transition-age youth with ASD, it is important to consider the impact of social support at the family level through informal channels. The current results continue to encourage clinicians and researchers to help parents cultivate social support within and outside the family (Boyd, 2002).

Transition planning quality. This emerged as an important predictor of three parents' transition outcomes, including parents' transition experiences, family quality of life, and parents' health. As mentioned in Chapter 4, transition planning quality evaluates whether schools implement evidence-based or recommended practices by the IDEA, Indicator 13, and existing research literature. The overarching predictability of transition planning quality is an important finding that suggests the procedural quality of transition planning, as mandated by the law and recommended by the literature, has clinical significance in parents' transition experience and family quality of life. The known inadequacy of transition support and educational programs as support systems for families of students with ASD (Kucharczyk et al., 2015; Snell-Rood et al., 2017) not only implies noncompliance issues but also a big hole in the service delivery system. Without improving the service delivery at the system level, the currently dismal outcomes of young adults with ASD and families will likely remain the same.

Parent-teacher alliance. Other than more structured school-based transition support, parent-teacher alliance was also found to predict family quality of life. The importance of parent-school collaboration is reflected in the model of comprehensive and integrated school psychological services (NASP, 2010). Home-school collaboration and

parent-teacher relationships have long been found to be influential on the learning outcomes of children, such as children's classroom engagement (Hughes & Kwok, 2007), children's achievement (Hughes & Kwok, 2007), children's social emotional functioning (Izzo, Weissberg, Kasprow, & Fendrich, 1999), and fewer behavioral problems (Kim et al., 2012).

Together, the current study calls for more research attention to formal support at a system level. Despite the significance of schools' services and parent-school relationships during transition, these were often neglected as sources of support in studies predicting parent adaptive outcomes (e.g., Boehm, Carter, & Taylor, 2015). The current study also encourages school personnel and administrative staff to rethink the impact of the quality of their work. Many school professionals might not have enough opportunities to collaborate with parents for a variety of reasons, such as a lack of administrative support, lack of time, and ambivalence about parental involvement (Miretzky, 2004). However, it is clear from the literature that home-school collaboration leads to positive student's outcomes. The current study even adds to the literature by providing evidence for the impact of school practices and parent-teacher alliances on parents' outcomes.

Parenting efficacy. Parenting efficacy has long been found to be an important factor that predicts parent outcomes (Carter, Martinez-Pedraza, & Gray, 2009; Raikes & Thompson, 2005). The current study showed that parenting efficacy predicted both parents' transition experience and parents' health. Among all the variables, it is the strongest predictor of parents' transition experience. This finding might imply that empowering parents with knowledge, skills, and confidence would largely improve the parents' transition experiences. The overarching effect of parenting efficacy also

highlights the importance of internal resources, in addition to outside resources, as protective mechanisms during the transition period (see Taylor, Hodapp, Burke, Waitz-Kudla, & Rabideau, 2017). On the upside, parenting efficacy is generally trainable (e.g. Sanders & Woolley, 2005), but currently there is still a lack of programs that target parenting efficacy for aging parents.

Overall, one can see that the support needs for parents are with breadth (services for multiple domains and from multiple sources) and depth (services are often intensive and long-term). The current results also highlighted the importance of the quantity and quality of support from formal agencies (i.e., school). However, a number of accounts (Kucharczyk et al., 2015, Snell-Rood, 2017), including the current results, pinpoint how formal agencies fail to support families of adolescents and young adults with ASD during transition. These results highlight the urgent need to develop interventions that facilitate positive changes at a systemic level and collaboration among systems (e.g., families, vocational rehabilitative agencies, schools, and other professionals of interest).

Even more importantly, at the structural level, resources are such important mediators that buffer the negative effects of stressors. They also act as mediators between coping strategies (i.e., optimism and emotion-coping strategy) and parents' transition outcomes. That is, the current findings supported the suggestion that resources might, to a great extent, be the "ultimate" variable to make a positive impact on parents' transition outcomes. Thus, these findings also reinforced the development of interventions that connect parents with resources during transition (Ruble et al., 2017; Trainor, 2008; Taylor et al., 2017).

Perception/coping strategies (C). The current dissertation project detailed parents' use of coping strategies and perception. The qualitative findings showed that avoidance, emotion-focused, and problem-focused coping were three types of commonly used coping strategies. Additionally, the results also provided information about the reasoning behind the use of these coping strategies. In particular, parents think of their own mortality, responsibility, and family meaning of transition when they cope with the ups and downs during transition. We are in need of effective interventions and strategies that target the unique needs of aging parents of chronic disabilities. A meta-analysis showed that, generally, parenting programs are effective on parents' outcomes (Barlow, Coren, & Stewart-Brown, 2002). A follow-up review showed that the existing interventions for parents of children with intellectual disabilities mostly included cognitive-behavioral techniques (CBT) (Hastings, & Beck, 2004). One commonly used strategy in CBT is a change in cognition in order to change one's behaviors and emotions (Butler et al., 2006). The results might provide additional information for CBT therapists about the potential cognitive processes behind the parents' coping actions (Lustig, 2002).

Using regressions, passive-avoidance coping and optimism were found to be the two most predictive C factors of parent outcomes across the board. Consistent with previous literature about parents of younger children with ASD, passive-avoidance coping predicted a lower family quality of life (Dardas & Ahmad, 2015; Hastings et al., 2005) and provided evidence for the continual detrimental effect of this approach on family outcomes during the transition period (Yu, 2017). Similarly, the current results also replicated the effects of optimism on positive parental outcomes (Ekas, Lickenbrock, & Whitman, 2010; Greenberg, et al., 2004).

At the structural level, optimism and resources also acted as sequential mediators between stressors and outcomes. That is, at a structural level, optimism did not impact parents' outcomes directly, but through resources. Stressors made parents less optimistic, which also led to a lower ability to acquire resources, and thus resulted in poorer adaptive outcomes. This result not only highlights the importance of dispositional optimism, but also has some implications for the potential of training for optimism (Behrad, Kalantari, & Molavi, 2009; Fresco, Moore, Walt, & Craighead, 2009; Schulman, 1999). To elaborate on the previous paragraph about using CBT for aging parents of adults with developmental disabilities, the current results particularly support the use of some common strategies used in some previous optimism trainings that target positive thoughts/optimism, such as positive reframing and deferring automatic negative thoughts (Behrad et al., 2009)

However, similar to the existing literature, the current findings also continue to show mixed results with regard to problem-focused and emotion-focused coping. We found that higher levels of problem-focused coping predicted lower stress, but a poorer transition experience. This finding is somewhat aligned with a relatively large study that found that higher levels of problem-focused coping were associated with better mothers' outcomes (Smith et al., 2008), but contradicts a study that found a positive relationship between task-oriented coping and stress among parents of young children with ASD (Dabrowska & Pisula, 2010). The negative effect found between problem-focused coping and parents' transition experiences may be explained by the contextual characteristics of coping, meaning that coping is not innately good or bad but is based on the context in which it is expressed (Folkman & Moskowitz, 2004). For instance, it is known that,

despite parental efforts, schools' transition practices are often not up-to-standard (Kucharczyk et al., 2015); Snell-Rood et al, 2017). The gigantic, ineffective educational transition system often negates the effect of strong parental efforts, which may aggravate the negative experiences among parents who actively try to tackle problems.

Similarly, the effect of emotion-focused coping has been found to be unclear in the current literature (Aldwin & Revenson, 1987). Emotion-coping strategies were often confused with self-deprecation or other distress-causing coping strategies (Austenfeld & Stanton, 2004). However, with many efforts trying to separate "good" emotion-focused coping strategies from "bad" emotion-focused coping strategies, it is generally believed that emotion-focused coping can be potentially positive for health-related outcomes (Austenfeld & Stanton, 2004; Manning et al., 2011; Hastings et al., 2005). At the indicator level, the current results suggest that emotion-focused coping does not have a direct effect on the selected parent outcomes using regressions, similar to Benson (2010)'s findings. However, when looking more broadly and at a structural level, emotion-focused coping had a negative direct effect on parents' outcomes (Beasley, Thompson, & Davidson, 2003; Solomon, Mikulincer, & Flum, 1988). but a positive total effect on outcomes because of the powerful positive indirect effects through resources. That is, parents who used emotion-focused coping had more positive outcomes because the use of these emotion-focused strategies allowed the parents to access more resources. This result suggests that researchers need to pay extra attention to the mediating effect when studying emotion-focused strategies and parents' transition outcomes. The mediating effect might be altered when a different set of mediators are used. More detailed studies should examine the mediators more systematically in order to create a

clearer picture of the effects of emotion-focused coping. Also, more research is needed in order to confirm such an effect, but this finding may also shed some light into the mixed results found in the literature.

ACBX Model for Parents of Adolescents and Young Adults with ASD

As mentioned in Chapter 4, there is a debate about the directional effect between resources and coping (i.e, ABCX or ACBX models; Nachshen & Minnes, 2005); Orr & colleagues, 1991). There is also a long-standing debate in the general literature with regard to optimism, which discusses the directional effect between resources and optimism and the reciprocal relationship between them (Carver, Scheier, & Segerstrom, 2010). While the current study supports the $A \rightarrow \text{Optimism} \rightarrow B \rightarrow X$ (ACBX) path as proposed by Nachshen and Minnes (2005) and Orr and colleagues (1991), many results also support the $A \rightarrow B \rightarrow C \rightarrow X$ path in the fields of industrial psychology (Ito & Brotheridge, 2003), cancer research (Kin et al., 2010), and autism research (Ekas et al., 2010) . The following section considers these discrepancies within the context of time, measurement, and ease of change.

First, even though the current study supports the $A \rightarrow \text{Optimism} \rightarrow B \rightarrow X$ path, it is commonly accepted that resources and coping strategies reciprocally predict each other across time (e.g., resources at time one predict perception/ coping at time two, while perception/ coping at time one predicts resources at time two; Carver et al., 2010). Currently, there are only limited longitudinal studies untangling the relationships between B and C factors. it is still early to make a definite conclusion of the direction of such relationships. However, the current results supported the ACBX model over the ABCX

model based on model fit indices when all the indicators were measured at the same time point.

Second, it is likely that other researchers might find a contradictory result when there is a different selection of A, B, C, and X indicators. The ABCX model is not a theory but a framework that guides conceptual thinking and variable selection when studying family adaptive processes (McCubbin & Patterson, 1983). In fact, not a single study investigating the same variables used the same measures as the current study. For instance, Ekas and colleagues (2010) and the current study used the LOT (Scheier & Carver, 1985), but the former study only investigated the mediating effect of informal social support. Another example is that Kim et al. (2010) used four items to measure positive reframing and self-blaming to represent the C factor. It is possible that, when measured at a lower level instead of a higher construct level (e.g., optimism, emotion-focused coping), the specific coping strategies are more responsive to the change in resources. The lack of consistency in the use of measures and variable selection of measures pose difficulty comparing studies. However, with more studies investigating the ABCX or ACBX models using structural equation modeling, it is believed that analyses at a structural level will continue to generate a more coherent picture of the directional effects.

Third, the decision of the direction of the relationship between B and C (either $B \rightarrow C$ or $C \rightarrow B$) are also related to a larger discussion of the malleability of perception and coping strategies. Before 1970, coping strategies were largely treated as a trait, meaning that they were not responsive to external variables. However, such schools of thoughts were challenged by a later wave of ideas that treated coping strategies as

processes, meaning they change in response external environment (Lazarus, 1993). The sequence of mediators gives insight into the causal order (Wongpakaran et al., 2016). The $A \rightarrow B \rightarrow C \rightarrow X$ path implies that perception and coping strategies are malleable and can be changed by resources, whereas the $A \rightarrow C \rightarrow B \rightarrow X$ implies that perception and coping strategies are one of the driving forces and are less malleable to resources. Even though both models posit that C is somewhat changeable, the level of malleability differs in the two models (Kim et al., 2009). In fact, Segerstrom (2009) found that although optimism has a certain level of malleability reacting to the outside world, it is a trait-like construct that is relatively stable across time. Since the current findings supported the $A \rightarrow C \rightarrow B \rightarrow X$ path. This might imply that, in a snapshot, C might be less malleable to B at least at a set point in time.

Limitations and Future Research

The quantitative-phase study was recruited through MTurk. Even though measurement was taken in order to ensure the integrity of the data, the current study might be contaminated by less-than-quality data (e.g., dishonest MTurk users not have a child with ASD). Also, the use of MTurk may have restricted participation to parents who only have access to internet and own an MTurk account. As the popularity of online recruitment grows, more research studies and guideline should be developed in order to ensure the reliability and validity of online data obtained by MTurk and other platforms.

Due to limited time and power issues, the current study did not treat demographic variables as predictors. For instance, Krauss (1993) found that social support predicted lower maternal stress, but not paternal stress. However, the current study did not study

mothers and fathers separately. Also, race and culture might play important roles in access to and attitude towards care (Mandell, Listerud, Levy, & Pinto-Martin, 2002). Future research should continue to examine the effect of demographic variables.

Even though the current study strived to include as many indicators as possible in order to capture the breadth of the latent variables, these indicators are by no means comprehensive. Due to limited power and research resources, the second phase of the current study was not even able to capture all the important variables found in the first phase. For instance, future research should continue to build on the literature. It is hoped that the current results shed some light on the important predictors of desirable parents' transition outcomes and the mechanism of change between stressors and parents' transition outcomes, which provide a list of predictors of interest for future research.

The current study follows the ABCX model on construct development and analyses in the qualitative study, and variable selection and model development in the quantitative study. However, it is also possible that A is not the ultimate predictor but a response to B and C. Without a longitudinal data set, the bidirectional, reciprocal relationships among A, B, C, and X factors remain unclear.

Transition is an ongoing process. Due to limited resources, the current study was only able to capture a static picture of the transition process from a parent's perspective. When measuring transition outcomes, the current study only included three transitional parent outcome measures (i.e., parents' burden, family quality of life, parents' subjective health) and one transition-specific parent outcome measures (i.e., parents' transition experiences). Even though the purpose of the current study was to examine parents' transition outcomes, the absence of child-related transition outcomes as dependent

variables does not generate a full picture of how parent-related A, B, and C factors impact overall transition outcomes. Even more so, child-related transition outcomes might account for some of the variables in the parent-related transition outcomes. It is worth noting that the current study is just a snapshot rather than a comprehensive picture.

The current study treated optimism and the three coping styles (i.e., problem-focused, emotion-focused, avoidance) as parallel mediators. However, Stranton and Snider (1993) found that coping styles mediated the relationship between optimism and adaptive outcomes (Stranton & Snider, 1993), meaning that the current study might oversimplify such relationships. Future research should consider building micro models within the A, B, C, and X factors.

An exploratory sequential design first involves the qualitative phase then the quantitative phase. The purpose of this method is to use qualitative data to guide the development of quantitative studies when there is a lack of a guiding framework and the variables of interests are unclear (Creswell & Clark, 2011, p.80). This approach served the purpose to help the variable selection process for the quantitative phase. However, the current study lacks a qualitative study after the quantitative phase to help explain the results. For instance, an additional explanatory sequential study would help answer the nature of filial obligation and the causal order or $A \rightarrow C \rightarrow B \rightarrow X$. Future researchers are encouraged use explanatory sequential methods in order to generate explanations of the observed phenomena related to transition.

A multilevel approach is ideal when analyzing family adaptation as family members are nested under families (Lazarus & Folkman, 1984; Pottie & Ingram, 2008). For instance, a two-level model, which allows for grouping of the outcomes of family

members (e.g., parent, child) within families, would include residuals at the family member and family level, enabling us to understand the overarching effect of higher-level variables on lower-level variables. However, no study that used the ABCX model used a multilevel approach. Thus, there is a lack of understanding about the effects of the predictors of outcomes at different levels. Also, the literature does not provide a straightforward answer about how to organize the outcome variables with consideration of “level”.

The current study is also limited by a two-level measurement model. In particular, the measures at the item level were not analyzed. A three-level measurement model, with items as the first-level indicators while the measures as the second-level indicators, might yield more useful information with regard to the usefulness of measures at the item level. This method might also shed some light on way to remodel the “C” latent variable. Future researchers are encouraged to investigate the “C” latent variable using a measurement model. More efforts are needed in order to understand the measurement of coping strategies and perceptions, and the conceptual and empirical relationships among them (Schwarzer, R., & Schwarzer, 1996).

Overall, this project as a whole contributed a deeper understanding of the predictors of parental outcomes during transition and the transition process. Future research is warranted to contribute to the development of enhanced family-centered policies, interventions, and services to support the families of adolescents and adults with ASD.

Appendix A

Interview Protocol

Questions:

Welcome, and thank you for your participation today. My name is Venus Wong and I am a graduate student at the University of Kentucky conducting my study in partial fulfillment of the requirements for the PhD research. Thank you for completing the survey, and this follow-up interview will take about 45-60 minutes and will include questions regarding your and your child's experiences of transition from high school to adult life in the community. The ultimate goal of the project is to get valuable information to promote a better transition experience for families of students with autism. I would like your permission to tape record this interview.

Do you have any questions or concerns before we begin? Then with your permission, we will begin the interview.

1. What does transition mean to you?
 - a. Your family?
 - b. Your child?
2. Can you tell me what you and your child have experienced during the transition process?
 - a. What has happened to your child (e.g. academic, psychological, behavioral, job-wise, social)?
 - b. What has happened to your family (e.g. financial, marital, family relationship, mental and physical health)?
 - c. If the family does not talk about the role of school – ask how does the school help your child through the transition process? (e.g. IEP meeting, learning support)?
 - d. Summarize the family stressors and ask following-up questions.
3. When you hear the words family transition outcomes, what first comes to your mind? When I said family transition outcomes that mean the results of the transition process from the family perspective.
 - a. *[If parents only talk about the transition outcomes of their child, clarify the concept]* Usually, when people talk about transition outcomes, they focus on the children. However, parents or caregivers are often the ones who go through the process with their child. Sometimes, siblings may have their needs during their siblings with disabilities' transition. With that in mind, what areas should mental health or school professionals pay attention to at the family level (your outcomes)?
 - b. What are good family transition outcomes (your outcomes)?
4. What types of support have you already had that have helped you and your child through the transition process? +What types of support do you wish you had for you and your child during the transition process that you don't have now?
 - a. Internal (e.g. coping style, personality), tangible (e.g. money), emotional, informational (e.g. information regarding services)?

5. Is there anything else you would like to tell me in order to help me understand the transition process?
6. Can you use three words/ adjectives to conclude your transition experience?

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Professional publications

PAPERS

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- Wong, W. H., Ruble, L. A., & McGrew, J., & Yu, Y. (2017). COMPASS consultation and multidimensional fidelity: An empirical study. Accepted by School Psychology Quarterly on 4/13/2016
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BOOK CHAPTERS

Ruble, L., Wong, W. H., & McGrew, J. (2016). Data collection in education and
measurement of progress. In R. Jordan, K. Hume, & J. Roberts (Eds.), *Autism &
education*. Thousand Oaks: SAGE Publications.

PRESENTATIONS

Oral/ Paper Presentations

International/ National

Wong, W. H., & Ruble, A. L. (2018, Feb). How consultation works? A perspective of
multidimensional fidelity. Oral session going to be presented at the Annual Meeting
of the National Association of School Psychologists, Chicago, IL.

Arballo, J., Wong, W. H., & Ruble, A. L. (2018, Feb). Parent and teaching rating of skills in students with ASD. Oral session going to be presented at the Annual Meeting of the National Association of School Psychologists, Chicago, IL.

Findley, J., Rodgers, A. L., Wong, W. H., & Ruble, A. L. (2018, Feb). IEP quality for transition age youth with autism. Oral session going to be presented at the Annual Meeting of the National Association of School Psychologists, Chicago, IL.

Wong, W. H., & Ruble, A. L. (2016, Feb). Teacher burnout: Impacts, detection, and interventions. Oral session presented at the Annual Meeting of the National Association of School Psychologists, New Orleans, LA.

Uzuegbunam, N, Wong, W. H., Cheung, S. C., & Ruble, A. L. (2015, July). MEBook: Kinect-based self-modeling intervention for children with autism. Paper presented at the IEEE International Conference on Multimedia and Expo 2015, Torino, Italy.

Regional

Wong, W. H., Rodgers, A. D., & Ruble, L. A. (2015, Sep). Common elements of effective teaching for students with autism spectrum disorders. Oral session presented at the Kentucky Association for Psychology in the Schools Conference, Louisville, KY.

Ruble, L. A., Rodgers, A. D., Wong, W. H., & McGrew, J. (2014, Sep). Implementation science and autism. Oral session presented at the Kentucky Association for Psychology in the Schools Conference, Louisville, KY.

Poster Presentations

National/ International

Wong, W. H., Yu, Y., McGrew, J., & Ruble, A. L. (2017, May). The impact of teacher burnout on students with ASD: Mediating mechanism. Poster session accepted at the International Meeting for Autism Research, Baltimore, MD.

Abraoll, J., Wong, W. H., McGrew, J., & Ruble, A. L. (2017, May). The self-determination skills of students with ASD: A comparison study. Poster session accepted at the International Meeting for Autism Research, Baltimore, MD.

Findley, J., Wong, W. H., McGrew, J., & Ruble, A. L. (2017, May). The IEP quality of students with ASD. Poster session accepted at the International Meeting for Autism Research, Baltimore, MD.

Wong, W. H., & Ruble, A. L. (2017, Feb). How school psychologists should monitor intervention fidelity in school. Poster session accepted at the Annual Meeting of the National Association of School Psychologists, San Antonio, TX.

- Wong, W. H. & Ault, M. (2017, Feb). Using the system of least prompt to teacher self-determination skills. Poster session accepted at the Annual Meeting of the National Association of School Psychologists, San Antonio, TX.
- Wong, W. H., Yu, Y., McGrew, J., & Ruble, A. L. (2016, May). Prediagnostic and diagnostic stages of autism spectrum disorders: A parent perspective. Poster session presented at the International Meeting for Autism Research, Baltimore, MD.
- Ruble, L. A., Jackson, M. W., Rodgers, A. D., Snell-Rood, C., Wong, W. H., Yu, Y., Odom, J. A. & McGrew, J. H., (2016, May). COMPASS revisions. Poster session presented at the International Meeting for Autism Research, Baltimore, MD.
- Jackson, M. W., Ruble, L. A., Rodgers, A. D., Snell-Rood, C., Wong, W. H., Yu, Y., Odom, J. A. & McGrew, J. H., (2016, May). Adapting an evidence based intervention using an implementation science framework. Poster session presented at the International Meeting for Autism Research, Baltimore, MD.
- Hastings, K.C., Ruble, A. L., & Wong, W. H., (2016, Feb). Measuring social group outcomes using the TSSA. Poster session presented at the Annual Meeting of the National Association of School Psychologists, New Orleans, LA.
- Wong, W. H., & Ruble, A. L. (2015, Aug). Applying social network analysis as a clinical measure: A case study of evaluating the effectiveness of social interventions. Poster

- session accepted at the Annual Meeting of the American Psychological Association, Toronto, Canada.
- Ruble, L. A., Rodgers, A. D., Wong, W. H., & McGrew, J. (2015, May). Teaching quality and common teaching sequences for students with ASD. Poster session presented at the International Meeting for Autism Research, Salt Lake City, Utah.
- Uzuegbunam, N, Wong, W. H., Cheung, S. C., & Ruble, A. L. (2015, May). A newly developed social-narrative computer program – Mebook. Poster session presented at the International Meeting for Autism Research, Salt Lake City, Utah.
- Wong, W. H., Rodgers, A., Ruble, A. L., & McGrew, J. (2015, Feb). The Theory of Planned Behavior and influences of special education teachers' intentions to collect data. Poster session presented at the Annual Meeting of the National Association of School Psychologists, Orlando, FL.
- Wong, W. H., Fisher, S., & Yang, H. W. (2015, Feb). Perceived safety, social problem solving skills, and the nature of bullying. Poster session presented at the Annual Meeting of the National Association of School Psychologists, Orlando, FL.
- Ruble, A. L., McGrew, J., & Wong, W. H. (2014, May). Validity and reliability of the parent activation measure for developmental disabilities. Poster session presented at the International Meeting for Autism Research, Atlanta, GA.

Rogers, A., Ruble, A. L., Wong, W. H., & McGrew, J. (2014, May). Examining the effects of COMPASS on the self-efficacy of teachers of students with autism. Poster session presented at the International Meeting for Autism Research, Atlanta, GA.

Venus Wing Hang Wong