CULTURAL ADAPTATION OF THE TRANSITIONING TOGETHER® PROGRAM FOR CAREGIVERS OF ADOLESCENTS WITH AUTISM IN ACCRA, GHANA.

By

Danielle Dede Ami-Narh

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ABSTRACT

CULTURAL ADAPTATION OF THE TRANSITIONING TOGETHER® PROGRAM FOR CAREGIVERS OF ADOLESCENTS WITH AUTISM IN ACCRA, GHANA.

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For adolescents with autism and their families, transitioning to adulthood often means overcoming several social, systemic and environmental barriers (Lehman et al., 2002). In Ghana, misconceptions, limited knowledge and non-categorization of autism have contributed to delays in early detection, diagnosis, treatment and unavailability of supports for individuals and their families, which are three essential components for optimal outcomes (Danquah-Brobbey, 2018). These barriers put strenuous pressure on the caregivers who have found themselves at the center of their child's transition planning process.

The purpose of this study is to address a service gap for Ghanaian families and their adolescent children with autism by culturally adapting an existing evidence-based program, *Transitioning Together* ® (Smith, Greenberg, & Mailick, 2012). Specifically, the researcher sought to develop a set of culturally appropriate program curriculum modules, that address the suitable demographics and unique caregiving needs of families of adolescents with autism in Ghana. This study was designed to explore the central research question: What changes need to be made to the *Transitioning Together*® program for Ghanaian caregivers, to increase its cultural relevance, content applicability, and user friendliness?

The researcher developed a methodological framework using the Cultural Adaptation Process Model (CAPM) (Domenech- Rodriguez & Weiling, 2004) and the Ecological Validity Framework (EVF) (Bernal, Bonilla, & Bellido, 1995) in a Participatory Action Research. This methodology included focus group discussions with practitioners and individual interviews with eight caregivers to provide input on what and how they want the program to be presented. In adapting the *Transitioning Together* ® program, content changes were integrated throughout the program instead of simply adding cultural factors to individual sessions. Changes were made to the program manual to reflect the length of the program, questions for discussion, appropriate goals for caregivers and medium of communication for facilitators and caregivers. A methodical review with nine experts to review and provide feedback on the developed program was solicited after changes were made.

The results of this study show that caregivers and practitioners in Ghana will benefit from the program if implemented seamlessly. Additionally, Transitioning *with Autism, Growing Up, Autism and Family* and, *Behavior Management* are the specific topics caregivers deemed important and beneficial to discuss during group sessions. Implications for practice, policy, and future research are discussed.

Keywords: Cultural Adaptation, Autism, Caregivers.

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CHAPTER ONE

INTRODUCTION

When a child is born, families often look forward to witnessing the transition of their child across different stages of life. With so much excitement, families celebrate these stages and hope for success. In the United States, one of the most exciting and traditionally significant points of transition is from high school to adulthood (King, Baldwin, Currie, & Evans, 2005; Russell, 2002). Most families are excited but also worried as to whether their child is ready to navigate the world. In Ghana, a traditionally significant point of transition for most families is preparing their child at the age of 15 to leave home for high school, conventionally boarding school. Similarly, most families are excited but worry if their child will be able to endure living independently successfully.

Regardless of the cultural context, the excitement and joy of watching children transitioning between stages of their life can also be overshadowed by anxiety, fear, and stress when they reach a stage where they have to attain some form of independence. This stage is certainly more stressful for families of children with a disability, (Cheak-Zamora, Teti, & First, 2015) and even more so for families of children with disabilities in areas where access to resources is limited.

Though struggling during the transition to adulthood is common, individuals with autism are at a higher risk (Taylor, Hodapp, Burke, Waitz-Kudla, & Rabideau, 2017). Adolescents with autism experience significant challenges as they transition to adulthood, with less than 25 percent living independently or have social interactions (Billstedt, Gillberg, & Gillberg, 2005; Levy & Perry 2011; Seltzer, Shattuck, Abbeduto, & Greenberg, 2004). They experience more transition difficulties mainly because of social and communication deficits associated with their disability

(Forest, Horner, Lewis-Palmer, & Todd, 2004). Specifically, social and communication deficits affect the child's interactions with peers and caregivers, thus making transitions to new social, academic, and physical settings stressful (Forest et al., 2004).

Scholars have identified that caregivers of these adolescents have elevated stress, as well as poor mental health, poor quality of life, and overall poor health (Jellett, Wood, Giallo, & Seymour, 2015; Smith, 2012). Additionally, low-income family outcomes, low-income family dynamics, and cohesion were reported due to a combination of the inability to assist their child overcoming their challenges, and possible neglect on other family obligations, thus causing the family as a unit to suffer (Boehm, Carter, & Taylor, 2015). Summarizing the role of parents during the transition and early-adult years, Timmons, Whitney-Thomas, McIntyre, Butterworth, & Allen, (2004) concluded that parents also experienced difficulties managing regular, daily family obligations. Bello-Mojeed & Bakare (2013) reported that, apart from the psychosocial stress to families, the physical strain of autism that is brought on by the lack of facilities or services to provide relief to families is often overlooked. Due to limited system support in rural locations, and fears for uncertain service, caregivers have found themselves at the center of their child's transition planning process.

Statement and Significance of the Problem

Autism is a neurodevelopmental disorder which typically presents symptoms from early stages of development and continues to evolve throughout the individual's life (National Institute for Health and Clinical Excellence guidelines, 2013; National Institutes of Health, 2017). It is a childhood neurodevelopmental disability, characterized by deficits in social, communicative, as well as repetitive and restricted interests (American Psychiatric Association, 2013). Research has indicated that symptoms of autism can impede one's functioning including school, work, independent living, social, and community integration (Tincani & Bondy, 2014; Volkmar, Siegel, Woodbury-Smith, King, McCracken, & State, 2014). According to the National Institute of Health, every 1 in 45 children has autism in the United States (Zablotsky, Black, Maenner, Schieve, & Blumberg, 2015). A recent review of epidemiological surveys of autism worldwide suggests prevalence estimates of 62/10,000 (Elsabbagh, Divan, Koh, Kim, Kauchali, Marcín, et al., 2012). The results of this study did not support systematic differences in autism by geographical region, ethnic group, or socioeconomic factors (Dixon, Badoe, & Owusu, 2015).

It is, however, important to take account that, the ability to detect such differences is severely limited due to unreliable and nonexistent data sets, particularly in low and middle-income countries (LMIC) (Elsabbagh et al., 2012). Ghana, which is the location of this study, has not had any published autism prevalence studies yet. This limitation, similar to other health-related issues, may be due to reasons including lack of funding, lack of suitable screening and diagnostic tools, and lack of expertise. Based on comparisons of other global studies, there is no reason to presume estimates would differ dramatically in Ghana.

The World Health Organization (WHO) has acknowledged autism as a significant public health issue worldwide (Abubakar, Sewanyana, de Vries, & Newton, 2016; Franz, Chambers, von Isenburg, & de Vries, 2017; Guler, de Vries, Seris, Shabalala, & Franz, 2017). Though the majority of people with autism live in LMIC (Dawson-Squibb, 2018), there has not been researched, and clinical work conducted to create an environment where the individual and their families are supported. Furthermore, persons with autism who live in LMIC receive minimal services from health education and social welfare systems to support their families (Franz et al., 2017; Guler et al., 2017). For these reasons, appropriate first actions need to be taken after an individual is diagnosed with autism. These actions include the conveyance of relevant information and psychoeducation provided to parents and caregivers. Education must focus on the meaning of autism, the data about autism, what can be done to support the child’s learning and development, and how to prepare for their role as parents or caregivers of a child with a developmental disability in the community (Dawson-Squibb, 2018).

There is ample evidence that proves the functioning and quality of life of a person with autism is highly dependent on family and parental factors such as parental knowledge, stress, and family support (Eapen & Guan, 2016; Vasilopoulou & Nisbet, 2016). However, there has been relatively limited research on parental/caregiver education and training programs for parents/caregivers, particularly in low resource communities. The transition years are a critical time during which supports and training of adolescents with autism and their families can directly affect their outcomes (Carter, Austin, & Trainor, 2012). With an increase in diagnosis and prevalence, an increase in service provision is necessary for addressing the needs associated with autism. The availability of adequate services for children with autism is imperative to allow them to function better in their transition stages, but such services for adolescents are often not as available in the community, and if existing, are challenging to navigate (Tincani & Bondy, 2014; Volkmar et al., 2014).

The relevance of parent/caregiver interventions. Families play an essential role in providing care and support as their children transition from one stage to another. With many anticipated and unanticipated changes, expectations, and challenges for both the children and the caregivers, caregivers are overwhelmed with a lack of knowledge, resources, and support to help their children with autism; inevitably worrying about their future (Glidden & Jobe, 2007). Their stressful and challenging life can significantly affect parental and familial adjustments such as physical health, mental health, stability and functionality of the family (Smith, Greenberg, &

Mailick, 2012). These negative impacts and lack of resources must be addressed to alleviate the detrimental outcomes for caregivers and their entire family. More importantly, adverse caregiver outcomes have a direct impact on the quality of care and support they can provide for their children, which in turn affects their success.

It is clear that much is needed to prepare families and caregivers for the transition to adulthood. Though less established, there are a few existing evidence-based interventions for families of adolescents with autism. Although services for younger children with autism have been better established, services to aid adolescents with autism transition between stages successfully have been inadequate. As a result, many caregivers and adolescents are needlessly struggling. This limited service implies that more research needs to go into developing programs for families that have adolescents with autism. In developed countries, such as the United States, the United Kingdom, and Canada, some research has been conducted on the development of evidence-based services and interventions to support caregivers and families of adolescents with autism. However, microscopic studies have focused on LMIC or the more narrowed Ghanaian setting.

To improve the current situation of autism in Ghana and Africa as a whole, it is essential to address the factors that impede its diagnosis, treatment, and management (Bakare, 2014). Kumpfer, Alvarado, Smith, Bellamy, (2002) suggest that the most straightforward and least costly way to provide effective interventions and services is by culturally adapting existing interventions rather than by developing new culturally specific intervention manuals and materials (Bernal & Adames, 2017).

Purpose of the Study

This study addressed a service gap for Ghanaian families and their adolescent children with autism by culturally adapting an existing evidence-based program, Transitioning Together ® (Smith, Greenberg, & Mailick, 2012). This study aimed at developing a set of culturally appropriate program curriculum modules that address the suitable demographics and unique caregiving needs of families of adolescents with autism in Ghana.

Objectives

This study attained three significant goals;

1. Information on the unique needs and service gaps were solicited from caregivers of adolescents with autism and practitioners serving families and adolescents with autism in Ghana.
2. A set of culturally appropriate program curriculum modules for caregivers of adolescents with autism was developed based on the needs.
3. Feedback from experts who reviewed and evaluated the program curriculum modules were solicited.

Summary of Study

This study employed both the experience and expertise of an interdisciplinary team of experts and researchers in autism, and related disciplines (rehabilitation counseling, social work, special education, family and child development, mental health counseling), as well as end-users (caregivers and practitioners) to identify needs, and to review and provide feedback on a series of program curriculum modules. The program is developed and modified based on 1) The Transitioning Together® program guide; 2) The Ecological Validity Framework; 3) Guidelines and other family psychoeducation programs and; 4) Needs that we identified by end-users.

Research Question

Given the purpose of this study, the central research question of the study is; what changes need to be made to the Transitioning Together® program for Ghanaian caregivers, to increase its cultural relevance, content applicability, and user friendliness?

Theoretical Framework Guiding the Study

The Ecological Systems Theory (EST) (Bronfenbrenner, 1977), was used as an overarching framework for understanding unique needs, challenges and service gaps of caregivers/parents and practitioners of adolescents with autism in Ghana. The ecological systems approach provides a structure for understanding the importance of cultural adaptation (Marsiglia & Booth, 2015). In this theory, the development and functioning of a person are influenced by four interconnected environmental systems (Shogren, 2013). Bronfenbrenner conceptualized four different systems in which individuals exist: (a) the microsystem consists of the individual's primary environment, these may include elements such as the family, friends, school, and church; (b) the mesosystem refers to the interconnections between the microsystems; for example, a connection between the individual's family and school); (c) the exosystem reflects interaction of systems that indirectly impact the individual: for instance the governmental agencies; and (d) the macrosystem which encompasses the individual's cultural environment, including customs, beliefs, social systems, and resources (Bronfenbrenner, 1977). In this approach, the relationships among individuals, institutions, and the broader cultural context within the ecological framework are bidirectional, creating a dynamic and rapidly evolving system (Marsiglia & Booth, 2015).

This framework was used as the guiding lens in this study to explore the lived experiences of parents/caregivers raising children with autism in Ghana to understand how challenges, needs, service gaps, and systems in their environment have influenced their experiences. Additionally, this framework was used as a guide to design a program curriculum module that will accommodate the systems in which parents/caregivers exist.

Methodological Framework Guiding the Study

A Participatory Action Research (PAR) approach was utilized to ensure that local end users' needs, world views, and local contexts were included throughout the development of the program curriculum modules. Specifically, the researcher employed the Cultural Adaptation Process Model (CAPM) (Domenech- Rodriguez & Weiling, 2004) and the Ecological Validity Framework (EVF) (Bernal, Bonilla, & Bellido, 1995) to develop a set of culturally appropriate program curriculum modules for caregivers of adolescents with autism. More information about the methodological framework will be provided in Chapter two.

Researcher Role and Positionality

A Participatory Action Research (PAR) approach requires a researcher to build collaborative, productive, and communicative relationships with various stakeholders. As a result, it is essential for researchers to examine their perspective and backgrounds, especially the ones that focus on the research. Understanding positionality is crucial to understanding the subjectivity of researchers. Sage Publication (2017) suggest that it is vital for a researcher conducting PAR to have an open mind, flexibility, creativity, non-judgmental attitude, humble demeanor, aspects of cultural competence (i.e., an awareness of identity and power differentials and sensitivity to contexts), and different communication styles. Researchers need to be aware of how their backgrounds and identities make them an insider and outsider to the topics, settings, and participants. As such, the identities of both researcher and participants have the potential to impact the research process. Identities come into play via our perceptions, not only of others but of how we expect others will perceive us. Our own biases shape the research process, serving as checkpoints along the way (Bourke, 2014).

Definitions

Autism. Autism is a childhood neurodevelopmental disability that is characterized by two significant deficits, social-communicative, as well as repetitive and restricted interests (American Psychiatric Association, 2013).

Caregivers. Caregivers are in various forms, and they range from the actual parents of the child with autism to professionally trained personnel who are well versed in the art of caregiving. In this project, the researcher defines a caregiver of a child with autism as an individual who identifies themselves as having, providing for and or being the legal guardian of a child with autism.

Cultural adaptation. Cultural adaptation is a systematic process whereby an intervention or treatment that has been developed for a group of people who show similar traits is taken and modified for a different group based on the specific traits of that group of people. The cultural adaptation process may include but not limited to modification of language, context, values, geographical location to reflect the actual needs of the group (Bernal, Jiménez-Chafey & Domenech-Rodríguez, 2009).

CHAPTER TWO

LITERATURE REVIEW

To provide a comprehensive understanding of the concepts and constructs involved in this study, this chapter is divided into four overarching sections. The first section will give a contextual overview of Ghana's disability culture as it pertains to education, healthcare access, employment, and social welfare. The second section will provide a review of the literature underlining the experiences of parents/caregivers who have a child with autism. In this section, the role of parenting and caregiving, challenges and needs of caregivers in western cultures and, challenges and needs of caregivers in the African cultures are discussed. The third section is dedicated to discussing family interventions. Here, a general overview of interventions for caregivers of adolescents with autism is introduced with the Transitioning Together® program discussed in detail. Finally, the fourth section discusses cultural adaptations. This section will provide a background of what cultural adaptation is, discuss frameworks, models and, guidelines, and give information on ethical considerations, which leads to the methodological framework of the study.

Ghana's Disability Culture

In 2006, Ghana passed a Disability Rights Bill, which proposed that, by 2016 Ghana would provide individuals with disabilities a variety of services and equal employment opportunities. Like other proposed policies, the disability culture that exists in present-day Ghana is still problematic (Danquah-Brobbey, 2018). Historically, individuals with disabilities in Ghana have been said to have originated from a spiritual realm, the forest, or the river (Avoke, 2002; Badoe, 2014). Additionally, children with specific disabilities were killed in certain communities (Avoke, 2002; Reynolds, 2010). Though these practices are not as prevalent due to education and western influence, scholars have suggested that fear and stigmatization of children with developmental delays are still regular (Anthony, 2011; Baffoe, 2013; Salifu & Mate-Kole, 2014; Thomas et al., 2015).

The Ghanaian culture promotes collectivism, mutual dependency, and essential contribution to community and family. This, therefore, places communication and interpersonal experiences at the core of Ghanaian culture (Stephens, Owusu, Parchment, & McKay, 2015). An individual's ability to participate successfully in the community is based on his or her ability to communicate and socialize “normally” like everyone else. This implies that individuals with disabilities that affect his or her ability to participate and contribute are likely to encounter increased stigmatization and isolation (Salifu & Mate-Kole, 2014; Stephens et al., 2015). Individuals with autism are therefore often misunderstood and face isolation and stigmatization.

Education and disability. The Ministry of Education Youth and Sports (MEYS) has complete responsibility for all educational policies, monitoring, and evaluation (Republic of Ghana, 2004). Within the ministry, the Ghana education service (GES) implements the basic and high school education components including technical and vocational training institutions through regions, districts and institutions throughout the country (Republic of Ghana, 2004). GES is therefore responsible for all K-12 education. Additionally, the MEYS has a Special Education Division (SPED), whose mission is to increase access to quality education and to train young individuals with disabilities and children with special learning needs. This division strives to make educational environments accessible by removing any barriers to ensure full participation and integration of individuals with disabilities into the mainstream community (Slikker, 2009). However, there are very few facilities available for the number of people who need them. Even though there is inclusive education policy, there are still a large number of children and youth with disabilities who are prevented from attaining basic education in regular schools (Avoke, 2002). Additionally, other children drop out and are unable to attain basic education due to damaging teaching practices that some teachers use (Avoke, 2002).

For educational purposes, the government labels individuals with autism as having an intellectual disability or a mental disorder (Salifu & Mate-Kole, 2014).Yekple (2014) conducted a study to explore the impact of traditional practices, belief systems, and perceptions on educating children with intellectual disabilities in Ghana. Results of this study showed that traditional practices and belief systems harmed accessibility to quality education for children with intellectual disabilities in Ghana (Yekple, 2014). The inclusion of individuals with disabilities into educational settings, the need for increased teacher education, advocacy for educational rights, and educational policy reform are dominant themes within the literature on autism, developmental delays, and other nonspecified disabilities occurring in Ghana (Anthony, 2011; Baffoe, 2013; Stephens et al., 2015, Dixon et al., 2015; Yekple, 2014).

Healthcare access and disability. The limited availability of healthcare specialist and resources has created a prominent barrier for individuals with disabilities and their families to access healthcare (Salifu & Mate-Kole, 2014). Notably, the inadequacies of healthcare professionals who are knowledgeable about autism in Ghana have compounded delays in early detection, early diagnosis, and early intervention; all of which are essential for positive outcomes (Danquah-Brobbey, 2018). Though the government has put in place policies and programs to help increase access to healthcare, financial difficulties have made it challenging for some individuals. The government established the National Health Insurance scheme in 2005; however, there are still individuals in impoverished communities that are unable to afford the premium (United Nations Development Program, 2007). This insurance covers the most common illnesses and some accidents; however, rehabilitation services, appliances, and prosthetics are not included (Slikker, 2009). The unavailability of these services, therefore, makes this health insurance less beneficial to individuals with disabilities who seek rehabilitation and specialized services (DSI Mini-Program Agreement, 2007).

Employment and disability. Formerly, there were policies and quotas in place so that businesses that have a certain number of workers were required to employ a certain percentage of individuals with disabilities (Slikker, 2009). The government discarded the policy due to poor management taking away the benefit of integrating individuals with disabilities into society through meaningful jobs (Ghana Federation of the Disabled, 2008). Employment opportunities for individuals with disabilities are limited due to negative attitudes from society and institutional barriers. Thus, most individuals with disabilities who are employed in an integrated work setting face many constraints. These constraints include the quality and conditions of their jobs. As a result, many individuals with disabilities who have meaningful jobs are self-reliant. Equipping individuals with disabilities with appropriate employable skills and competence to make them self-reliant is what most families are striving to do.

Social welfare and disability. The Department of Social Welfare is responsible for providing social welfare services to vulnerable populations. This department collaborates with people in their communities to improve their social wellbeing and success by promoting development with equity (Slikker, 2009). They are responsible for the general social welfare of individuals with disabilities, which includes counseling and reference; provision of vocational training; job placements; and integration into society. They also serve as an advocacy institute that provides recommendations to the Ministry of Employment and Social Welfare on disability issues. With regards to rehabilitation, only individuals with severe disabilities are referred to a rehabilitation center. Leaving other individuals with less severe disabilities seek services from private agencies which are mostly very costly. For individuals with autism, it is even harder for them to get governmental assistance for their specific needs as there is currently no distinct or official label for autism in Ghana (Badoe, 2014; Salifu & Mate-Kole, 2014.)

Unfortunately, due to the minimal support and care for individuals with disabilities, the overall wellbeing and success of individuals with disabilities in Ghana fall on the shoulders on the family. For individuals with autism, the families have become the hope of them succeeding and becoming meaningful individuals in society. The lack of support from the government puts strenuous pressure on the families as they encounter many barriers and challenges. The next section will review the literature on the experiences of these caregivers. Since there is minimal literature on autism in Ghana, the section is broader in scope to include study findings from Western cultures and African cultures (Nigeria and South Africa).

Experiences of Caregivers of Children with Autism

With the rapid increase in the diagnosis of autism (Gerber, 2014), it is surprising that autism is still poorly understood by the general public. Autism is a spectrum of which different individuals have different symptoms and behaviors, some individual may exhibit behaviors such as tantrums, self-mutilation or inappropriate social skills (Bishop, 2012; Koudstaal, 2011), all of which are behaviors that are perceived as not acceptable in society. This becomes stressful for parents because, due to the seemingly normal appearance of their child, receive insensitive and judgmental reactions from the public when their child exhibits these inappropriate behaviors (Gerber, 2014).

Role of parenting and caregiving. In order to better understand the experiences of parents/caregivers of individuals with autism, it is important to be aware of the norms and social constructs of parenting/caregiving. Parenting or caregiving in our society is a social construct (Parchomiuk, 2014). This implies that the society we live in influences or determines how parenting/caregiving should be assumed, to form values and norms which become the basis for its evaluation, and to prepare individuals to become parents/caregivers (Parchomiuk, 2014). For instance, in Sub-Saharan Africa, caring for the person with disability or elderly relatives is usually regarded as the responsibility of family members (Evans, 2010). Therefore, unlike the United States and other western cultures, putting an elderly in a home is not an option for families.

A parent/caregiver's ability to live up to this construct of ideal parenting/caregiving can be impacted by factors such as children's developmental needs, parent/caregiver's capability, and availability of resources to fulfill these needs; a broader social and economic context where parents/caregivers function, amongst other factors. This particular viewpoint on parenting/caregiving has become useful in evaluating how parents/caregivers who have a child with a disability function (Parchomiuk, 2014).

Challenges and needs of caregivers in western cultures. Parents/caregivers raising a child with specials needs, including those with challenging behaviors, experience higher levels of stress than parents raising a typically developing child (Estes, Munson, Dawson, Koehler, Zhou, & Abbott, 2009; Gupta, 2007; Spratt, Saylor, & Macias, 2007). Sufficient studies on caregiving of individuals with autism in western cultures (i.e. United States, United Kingdom and Canada) have demonstrated themes, including poor adjustment outcomes (Jellett et al., 2015; Lee, Berry-Kaizmien, Volker, Lopata, Nida, Thomeer, & Rodgers, 2009), and ineffective coping (Lee, Bain et al., 2012; Pozo, Sarria & Brioso, 2014) indicating that adequate formal and informal resources, interventions and social support can alleviate associated stress and improved caregiver's quality of life (Khanna et al., 2011; Lee, Bain et al., 2012; Lee, Lopata, Volker, Thomeer, Nida, Toomey et al, 2009)

Woodgate, Ateah and Secco (2008) conducted a study in Canada on the experiences of 21 parents of children with autism. The main challenge reported by parents is that they felt they are living in a world of their own just like their children: isolated from society and sometimes even their own families. In order to fight the isolation that they and their children had, authors identified three themes; *Vigilant Parenting*, *Sustaining the Self and Family*, and *Fighting all the Way* as things that all the parents shared in common.

Additionally, several studies showed that the symptoms of stress and depression are much more prominent in parents of children with autism compared to parents of children with other disabilities (Montes & Halterman, 2007; Roberts & Graff, 2011; Tunali & Power, 2002). Sharpley, Bitsika and Efremidis (1997) related the prominence of stress and depression to the permanency of the disorder, as well as receiving very little social support.

Challenges and needs of caregivers in African cultures. Even though not as established as scholars in the western cultures, several scholars have conducted studies to understand the experiences of parents/caregivers of individuals with autism in Africa. Swanepoel, (2003) conducted a study to understand, explore and describe the lived realities and experiences of primary caregivers raising their children with autism in South Africa. Using a phenomenological approach, the researcher conducted four individual interviews with women who were biological mothers of children with autism between 31-39 years of age. Two broad categories and subthemes resulted from content analysis. The first category related to the challenges surrounding the diagnostic process. Themes identified under the first category include: *Being a New Parent and Making Sense out of Chaos*; *Responsibility and Blame*;

Confusion and Disillusionment during Early Experiences with Helping Professionals; and *Mixed Feelings about the Diagnosis* as recurring challenges of the Caregivers. The second category related to challenges surrounding the pervasive influence of autism on different areas of family life. Under this category themes identified included: *Strained Family Relationships; Challenges of Behavior Management and Disciplining the Child with Autism; Challenges of Finding Suitable Resources for Education and Day-Care;* and *Maintaining the Family Unit and Doing Things as a Family*.

Swanepoel recommended that primary caregivers of children with autism may benefit from professionally run support groups that they can share challenges, experiences and learning the difficult task of raising children with autism. Furthermore, he recommended specific attention to be given to the attribution of blame and responsibility within the family, as well as possible spillover effects in the marriage relationship, parent-child relationships, and/or sibling relationships (Swanepoel, 2003).

Lagunju, Bella-Awusah and Omigbodun (2014) also highlighted that increasing public awareness and creating special programs will help improve the condition of families of children living with the autism in Nigeria. Lagunju et al. made their recommendation after participants in their study reported low awareness and understanding, late diagnosis, lack of structured healthcare or supportive services, and lack of special education programs as challenges they face.

Comparable to Woodgate et al's study in Canada, Ulofoshio (2017) conducted a study in Nigeria and reported mothers feeling isolated by society. The researcher used transcendental phenomenological approach to explore the perceptions and lived experiences of 10 mothers raising children with autism in Nigeria. She also sought to gain understanding of how negative opinions and beliefs about autism within the Nigerian culture and community impacted the experiences of these mothers. Using Bronfenbrenner's (1977) ecological systems theory, Ulofoshio reported challenges experienced by participants as: *Difficulties Getting a Diagnosis, Low Acceptance, Negative Treatments or Attitudes from Family, Friends and the Public, Inadequate Services, and Poor Government Support.* She added that despite these challenges, participants had to struggle to learn how to provide the intervention to their children needed, educate the society about autism, and be at the center of their child's world. Participants further reported that having a place where they can share challenges, experiences and learning the difficult task of raising children with autism will be beneficial for them and help alleviate the isolated feeling.

Nwanze (2012) reported that in urban areas of Nigeria most parents depend on schools or paid care providers to care for their children while they work; however, for children with challenging behaviors such as those associated with autism, it is a challenge to find care providers who would agree to care for their children. Mothers in most cases end up leaving their jobs to care for their children. The scarcity of qualified staff and programs to assist families affected by autism poses challenges to the management of the disorder in Nigeria (Lesi, Adeyemi, Aina, Oshodi, Umeh, Olagunju, et al., 2014; Nwanze, 2012).

Dixon, Badoe, and Owusu, (2015) conducted a study to explore the perspectives of autism disorder in urban Ghana. Using structured interviews to gather information from 25 families of children and young adults with autism (19 male, 6 female, and age range 3-30 years), caregivers expressed significant concerns about challenges they face in managing difficult behaviors of their young adult with autism. Participants highlighted the need for additional parent training to be able to help their children. Personal correspondence with a director of an autism school in Tema, Ghana (Hopestters Autism Center) confirmed that the inadequate access to training, education and support for parents/caregivers adds more stress to the already stressful lives of the parents/caregivers (Baaba, personal communication, December 27, 2017). She indicated that having several support groups where caregivers and parents can attend and learn how to manage difficult behaviors and tasks will be very helpful for both the caregivers and service providers.

Issues concerning disability are not at all a priority for policy makers in Low- and Middle-Income Countries LMIC (Okasha, 2002), even though there has been ample evidence of challenges and needs of caregivers of children with autism in the various countries. Even if policy makers in these areas inspired to make these issues a priority, other barriers like resource allocation, inadequate social safety nets, and inadequate fiduciary power to actually implement the infrastructure and inadequate highly qualified professionals. The struggle to meet basic daily needs makes it difficult to focus on other needs (Levers, 2012). Ghana is considered a LMIC and is faced with the reality of poverty. This creates a gap in parents' access to specialized (and often costly) services necessary for early intervention, such as vocational rehabilitation, speech therapy and occupational therapy, as well as the appropriate school placement for children with autism.

In conclusion, the overall increase in the diagnosis of autism (Luther, Canham & Young Cureton, 2005) and the growing pressures and challenges parents experience in raising a child with autism will continue to rise. Realizing the amount of stress and challenges, research in western cultures has been conducted on the development of evidence-based services and interventions, to support caregivers and families with adolescents with autism. However, research about parent/caregiver groups for autism in Ghana seems to be non-existent. This research could contribute significantly to the gap in knowledge and interventions about Ghanaian parents' experiences and the region.

Though there are similarities in the challenges facing caregivers in western and African cultures, it is noticeable that, caregivers in African cultures reported challenges such as getting a diagnosis, lack of structured health-care or supportive services, and lack of special education programs which are not major challenges reported by caregivers in western cultures. Additionally, caregivers in western cultures reported challenges associated with expressed emotions however, though it can be implied that caregivers in African cultures experience same, issue s of stress and depression were not explicitly reported. It is therefore very important to consider the differences in needs between cultures when developing, adapting or implementing an intervention.

Family Interventions

Family intervention is the process of involving the family in the treatment of an individual's disability. The goal is to improve outcomes for the person with the disorder or illness by improving family engagement and effectiveness in handling the challenges associated with the problem, as well as by improving the well-being of the parent/caregiver by identifying strategies to reduce stress and negative outcomes of caregiving (American Psychological Association, n.d). Bearss and colleagues (2015) provided a useful framework for family interventions involving parents/caregivers. They discussed two parent programs, parent support programs, and parent/caregiver-mediated interventions. In parent support programs, the parent /caregiver is the object of focus and the child is an indirect beneficiary. In parent/caregiver-mediated interventions, on the other hand, parents/caregivers are trained to work directly with their children and the child, thus, the child is the direct beneficiary of the intervention.

Acknowledging Bearss et al (2015) framework, Dawson-Squibb (2018) used the term 'parent education and training' (PET) when referring to the programs that combine provide both parent support and parent/caregiver-mediated interventions. He defined PET "as the passing on of information or skills to parents using a range of modalities (didactic, role-play, discussions, video-guidance) in a context where parents/caregivers and trained facilitators are the direct participants" (Dawson-Squibb, 2018, p. 17). This study aims at culturally adapting the *Transitioning Together*® Program (Smith, Greenberg, & Mailick, 2012) and will be under the PET umbrella.

Interventions for caregivers of adolescents with autism. Though not a lot of them exist, interventions for parents/caregivers that have a child with autism are gradually becoming common. Over the past years, programs such as The ASCEND (Autism Spectrum Conditions – Enhancing Nurture and Development) program, Son- Rise, EarlyBird, and Parent Management Training-Oregon have been widely used for parents of children who have autism, however, there has been very few programs available for parents of adolescents.

Picard, Morin, and De Mondehare (2014) conducted a study in Canada to develop and evaluate a psychoeducational program that would provide information to parents of adolescent with Intellectual and Developmental Disabilities (IDD), on the support services available to them. This 10-week program addressed areas that were most often expressed by parents in a survey previously conducted with a large sample of parents of people with IDD in order to make the support more accessible to them, foster a sense of well-being and a positive parental experience. Participants attended weekly sessions of two hours each on specific information sessions that covers topics on the basic information on IDD, government services and financial assistance, associations and regional organizations, school, parenting skills, adolescence, love, and sexuality, family relationships, life after school, and legal aspects. Compared to treatment as usual, both groups reported overall satisfaction, suggesting that early intervention is beneficial for parents to learn about resources to help their children.

***Transitioning Together*® program.** The *Transitioning Together*® program (Smith, Greenberg, & Mailick, 2012) involves eight weekly education and support group sessions for parents/caregivers as well as eight weekly social skill group sessions for teens with goals to: a) provide education and support for parents; b) provide opportunities for social interaction and learning for adolescents; and c) emphasize positivity and problem solving (Szidon & Kraemer 2015). The *Transitioning Together*® program has two stages of intervention; 1) two individual family joining sessions, and 2) eight multifamily group sessions (Smith et al., 2014). The joining sessions allow the family to meet with the program staff before the group meetings to develop rapport and clarify family goals. Group sessions involve education on a variety of topics relevant to autism and guided practice with problem-solving for individual family problems. The parent group sessions cover transition planning topics including autism in adulthood, post-secondary education, employment, family, legal issues, risk to adult independence, community integration and mental health. Adolescent group sessions involve a variety of games and activities to target skills such as engaging in conversation, recognizing social cues, and using problem solving strategies. An important part of the parent sessions is the problem-solving process.

A pilot evaluation of the program included 10 families of adolescents with autism (aged 15–18 years; *M*=16.2; *SD*=1.1). Results showed a significant positive change from pre intervention to post intervention in parents' understanding of their child's disability and of the service system (Smith et al., 2012). There were also significant improvements in the parent-child relationship domain. Although researchers did not find significant changes in autism symptoms or in parental report of stress in the pilot sample, parents increased in their ability to predict when their child would have a behavior problem from pre intervention to post intervention (Smith et al., 2012).

After the pilot findings, researchers refined the *Transitioning Together* ® program to include a highly homogenous group of families (Smith et al., 2014). The initial program included families of adolescents with a wide range of verbal and intellectual abilities, including individuals with intellectual disability along with individuals with IQs in the gifted range (Smith et al., 2014). The evaluation study of the refined version comprised of families that have adolescents between the ages of 14 and 17 years who are verbal (speak using complex sentences) and who participate in general education settings at least 50% of the time (Smith et al., 2014).

DaWalt, Greenberg & Malick, (2018) presented an evaluation of the intervention using a randomized waitlist control design ($n = 41$). Their aim was to explore the program's impact on parental stress and well-being, family empowerment and expressed emotion, and adolescent behavior and community involvement using psychosocial, behavioral, and biological strategies to measure change in child behavior, parent stress, and family functioning from pre- to post-intervention.

Findings indicated significant improvements in parental depressive symptoms and problem solving from pre- to post-intervention for parents in the intervention condition but not for parents in the control condition. Social interactions also improved for adolescents in the intervention condition relative to controls. Parents reported satisfaction with the program and particularly valued the opportunity to interact with other families. Despite a pressing need for research and interventions during this transition period, there currently are very few empirically validated programs for adolescents with autism or their families. The *Transitioning Together* ®

program a promising intervention to support caregivers who have an adolescent with autism during the transition to adulthood (DaWalt et al, 2018).

A cultural and linguistic adaptation of the program for Spanish-speaking families is being conducted (Szidon et al, 2015). The authors advise that in transporting the intervention to a different setting, it is important to truly adapt the model and curriculum and not just translate it into a different language.

Franz, Guler, Seris, Shabalala, and de Vries, (2016) explored contextual factors relevant to the adaptation of a caregiver early autism intervention in South Africa. Results reported by both caregivers and service providers indicated that the importance of matching provider to family by spoken language, cultural sensitivity to traditional parenting practices and family customs, affordability of treatment, the importance of immediate and extended family acceptance and support, the effects of community-based stigma, the importance of religion and faith as a form of support and feeling financially exploited by autism service providers are concepts that need to be considered in adapting a caregiver intervention. In order to conduct research for populations of culturally diverse background, it is imperative to understand the concept of cultural adaptation. The last section of this chapter is devoted discussion of cultural adaptation in general and the proposed methodological framework of this study.

Cultural Adaptation

Background. Across the literature, it has been documented that a person's culture, or simply put, a person’s way of life, has an influence on how he or she interacts with himself or herself and the society. Initially developed for psychological treatments three decades ago (Domenech- Rodriguez & Bernal, 2012), cultural adaptation refers to “the systematic modification of an evidence-based treatment or intervention protocol to consider language, culture, and context in such a way that is compatible with the client's cultural patterns, meaning, and values" (Bernal, Jiménez-Chafey & Domenech-Rodríguez, 2009, p. 362). The most common example of cultural adaptation being done is changing a program material into the native language of the intended population (Kumpfer et al, 2008).

The practice of cultural adaptation research provides an ethical bridge between the large-scale dissemination of Evidence Based Interventions (EBIs) and competent service delivery to ethnic minorities, particularly because diverse populations continue to be overlooked (Bernal, 2006; Bernal & Domenech-Rodriguez, 2009). Cultural adaptation is a necessary action to consider in the adoption of EBIs with ethnic and other minority groups. It proposes a roadmap to choose existing interventions and a specific approach to evaluate prevention and treatment interventions for cultural relevance (Marsiglia, & Booth, 2015). Theories provide a fair idea of what to consider when implementing and evaluating a program, it is important, however, to understand why people, populations and communities make choices and then plan accordingly using theories or strategies that best fit to improve their status (Raingruber, 2014).

The value of scientific rigor over cultural conformity may be a limitation in applying EBIs (Marsiglia & Booth, 2015). This standard, however, should not be maintained when working with real communities, both must be satisfied to the highest degree possible (Regehr, Stern & Shlonsky, 2007). Despite the progress that has been made, most EBIs are developed for and validated with middle-class White Americans, with the assumption that evidence of efficacy with this group can be transferred to non-majority cultures, which may or may not be the case (Kumpfer, Alvarado, Smith, & Bellamy, 2002). One solution to the tension between using culturally relevant practices and EBIs is locating interventions that have been designed for and tested with a given cultural group. However, the limited availability of culturally specific interventions with strong empirical support may create barriers to this approach.

Critics of cultural adaptation question the fidelity, efficacy and effectiveness of culturally adapted interventions (Marinez-Lora & Atkins, 2012). They argue that adapting EBIs compromises the fidelity and effectiveness of rigorously studied interventions (Castro, Barrera & Martinez, 2004). Balancing fidelity and adaptation have therefore, been highlighted as one of the primary issues around cultural adaptation of EBIs (Castro et al., 2010; Elliott & Mihalic, 2004)

As research stands now, there is a lack of studies that examine fidelity in culturally adapted interventions. However, several studies have provided support and results for positive outcomes of cultural adaptation; for example, Poulsen et al (2010) conducted a cultural adaptation study on the *Parents Matter!* program for use in rural Kenya. This program is an EBI originally developed for African American parents to promote effective parent-child communication about sexual risk reduction and parenting skills. Pilot data of the adapted program showed it retained its effectiveness, successfully increasing parent-child sexual communication and parenting skills.

The Strengthening Families Program (SFP) is a nationally and internationally recognized parenting and family strengthening program for high-risk and general population families. Studies with the SFP with different ethnic populations have also suggested that culturally adapted interventions improve retention and recruitment by about 40 % (Kumpfer et al., 2002). In these studies, the culturally adapted programs maintained the same level of effectiveness as the original intervention (Kumpfer et al. 2002).

Hall and colleagues (2016) conducted a meta-analysis of culturally-adapted psychological interventions in 78 studies for psychopathology outcomes, with 13,998 participants and 95% non–European Americans. Using a random effects multilevel regression model, the overall effect size ($g = 0.67$, $p < .001$) favored the effectiveness of culturally adapted interventions over other conditions (no intervention, other interventions).

In summary, culturally responsive adaptations can increase participant engagement and satisfaction, and improve participant recruitment and retention, elements that are challenging when implementing interventions with ethnic minorities (Kumpfer, Alvarado, Smith, & Bellamy, 2002). Promising results from meta-analytic research show more positive outcomes for culturally adapted interventions than traditional interventions (Griner & Smith, 2006; Smith, Domenech-Rodríguez, & Bernal, 2011).

Frameworks, models and guidelines. Scholars have designed models, various guidelines and frameworks as a guide in conducting research that entail culturally adapting EBIs. One school of practice capitalizes the content, focusing on what to adapt, that is, modifying program content and modifying program delivery methods. Another school of practice focuses on the process, that is, how to adapt, thus providing a comprehensive guideline on the process (Ferrer-Wreder, Sundell, & Mansoory, 2012). Some examples of common guidelines include: the Ecological Validity Framework (Bernal, Bonilla & Bellido, 1995), the Cultural Accommodation Model (Leong & Lee, 2006), the Cultural Sensitivity Framework (Resnicow, Soler, Braithwaite, Ahluwalia, & Butler, 2000); the Cultural Adaptation Process Model (Domenech- Rodriguez & Weiling, 2004), the Hybrid Prevention Program Model (Castro, Barrera & Martinez, 2004), the Selective and Directive Treatment Adaptation Framework (Lau, 2006), the Integrated Top-down and Bottom-up Approach (Hwang, 2009), the Cultural Specific Prevention Framework (Whitbeck, 2006), and the Heuristic Framework (Barrera & Castro, 2006).

Frameworks, models and guidelines that focus on what to adapt during cultural adaptations. The Ecological Validity Framework (EVF) developed by Bernal, Bonilla, & Bellido (1995) was originally conceptualized for Latino populations. Ecological validity refers to a congruence of a client's experiences of their ethno-cultural and linguistic properties embedded in a treatment assumed by the clinician, (Bernal &, Domenech- Rodriguez 2012), suggesting that if ecological validity is met, one can assume that the treatment aligns with the worldview of the client. The EVF outlines eight domains for consideration in an adaptation. The table below represents the culturally sensitive elements and the dimensions of treatment for clinical research interventions with Hispanics (Bernal et al., 1995).

Table 1: Culturally Sensitive Elements in the Ecological Validity Framework (Bernal &, Domenech- Rodriguez 2012)

Intervention	**Culturally Sensitive Elements**
Language	Culturally appropriate, culturally syntonic language.
Persons	Role of ethnic/racial similarities and differences between clients and therapists in shaping therapy relationship.
Metaphors	Symbols and concepts shared with the population; sayings or "dichos" in treatment.
Content	Cultural knowledge: values, customs, and traditions uniqueness of group (social, political, economic, and historical).
Concepts	Treatment concepts consonant with culture and context: dependence vs interdependence vs independence; emic (within culture, particular) over etic (outside culture, universal).
Goals	Transmission of positive and adaptive cultural values; support adaptive values from culture of origin.
Methods	Development and or cultural adaptation methods.
Context	Considering changing context in assessment during treatments or intervention; acculturative stress, phase of migration; developmental stage; social supports and relationship to country of origin: economic and social context of intervention.

A similar framework to the EVF is the Cultural Sensitivity Framework (CSF), which distinguishes surface structural versus deep structural adaptations of program content to meet unique cultural values and specific needs of the families (Resnicow, Soler, Braithwaite, Ahluwalia, & Butler, 2000). The CSF was developed to address implementation of substance use prevention and intervention programs with ethno-cultural groups (Bernal &, Domenech-Rodriguez, 2012).

Frameworks, models and guidelines that focus on how to conduct cultural adaptations.

There are many frameworks, models and guideline that focus on how to conduct the adaptation, that is, the processes and stages to follow, with a primary goal of identifying what specific necessary cultural variables are missing from theories and models to enable effective treatment. Leong & Lee (2006) developed the Cultural Accommodation Model (CAM). This model involves a three-step process; the first step is to identify cultural gaps. The second step is to examine relevant literature to inform appropriate content to fill the gap. The final step is to introduce or carry out the intervention and check for validity.

In 2004, Domenech-Rodriguez and Weiling proposed the Cultural Adaptation Process Model (CAPM). This model includes a three-phase approach. Phase 1 guides pre-intervention steps including understanding community need via focus groups and evaluating the intervention fit for the targeted population. Phase 2 involves implementing procedural, measurement, and content adaptations and revising based on the community and interventionists' feedback. Phase 3 encompasses finalizing adaptations, piloting materials, and formulating future plans (Domenech Rodríguez et al., 2011).

Hwang (2009) also described a community-based developmental approach, the bottom-up approach involves a five phase approach which include: (a) generating knowledge and collaborating with stakeholders, (b) integrating generated information with theory and empirical and clinical knowledge, (c) reviewing the initial culturally adapted clinical intervention with stakeholders and revising the culturally adapted intervention, (d) testing the culturally adapted intervention, and (e) finalizing the culturally adapted intervention.

The current study was guided by the Cultural Adaptation Process Model (CAPM; Domenech Rodríguez & Wieling, 2004) and the Ecological Validity Model (EVM; Bernal et al., 1995). CAPM is designed to be used in conjunction with the EVM, which details eight areas to address during cultural adaptation process: language, persons, metaphors, content, concepts, goals, methods, and context (Hurwich-Reiss et al, 2014). The combination of these models allows for a thorough adaptation method with CAPM modeling the process for delivering and evaluating an intervention. The EVM guiding systematic adaptations for intervention content (Domenech Rodríguez et al., 2011).

Ethical Considerations

An ethical behavior for a community intervention is not just simply following professional codes. It involves keenly doing what is right for the community and individual participants. This involves applying the basic idea of protecting the person's rights from treatments or interventions that may intrude or disrupt their cultural norms and values (Bernal & Adames, 2017).

Trimble et al. 2010 identified ethical dimensions of culturally sensitive research as using an approach that provides respectful and culturally informed consent procedures regarding confidentiality. The practical implication here is to inform potential participants of research studies as well as clinical practice of the values and norms that are implicit in the intended interventions to be delivered (Bernal & Adames, 2017). Ethical considerations are very important in cultural adaptations because, a program that that is implemented unethically is ignoring its mission and risking its credibility and effectiveness in the community (Rabinowitz, 2015).

In conducting cultural adaptations, the risks of imposing of western values, norms and beliefs on others, particularly subordinating groups is high (Domenech- Rodriguez & Bernal, 2012). Because ethical issues are not always clear, community programs should ideally have standards for primary ethical issues, including confidentiality, consent, disclosure, competence, conflict of interest, grossly unethical behavior, and the overall ethical stance and actions of the program. More importantly, such programs should have policies which will help in upholding the standards. This will promote community respect and excellent service delivery of the program (Rabinowitz, 2015).

In the University of Kansas Community toolbox, Rabinowitz (2015) outlines what it means to be ethical in developing a community intervention. He emphasizes on the following as guidelines to follow: 1) Respecting people as ends, not means; 2) Respecting participants' ability to play a role in determining what they need; 3) Not assuming that professional staff or program planners necessarily know what's best for a community or individual; 4) Respecting everyone's human, civil, and legal rights; 5) Doing what is best for everyone under the circumstances; 6) Not abusing your position or exploit a participant to gain a personal advantage or to exercise power over another person; 7) Not attempting an intervention in areas in which you're not trained and/or competent. This guideline takes into account the fact that but it is not always possible, however in instances where this rule needs to be bend the researcher may have to learn during the process, getting all the help he/she can and hoping he/she does not do anything harmful; Actively strive to improve or correct, to the extent possible, the situations of participants in the program and the community (Rabinowitz, 2015).

Methodological Framework

This section introduces the systematic adaptation framework developed for the current study. This framework supports and examines the cultural adaptation process of the *Transitioning Together* ® program to reflect values, norms, needs and experiences of caregivers of adolescents with autism in Ghana.

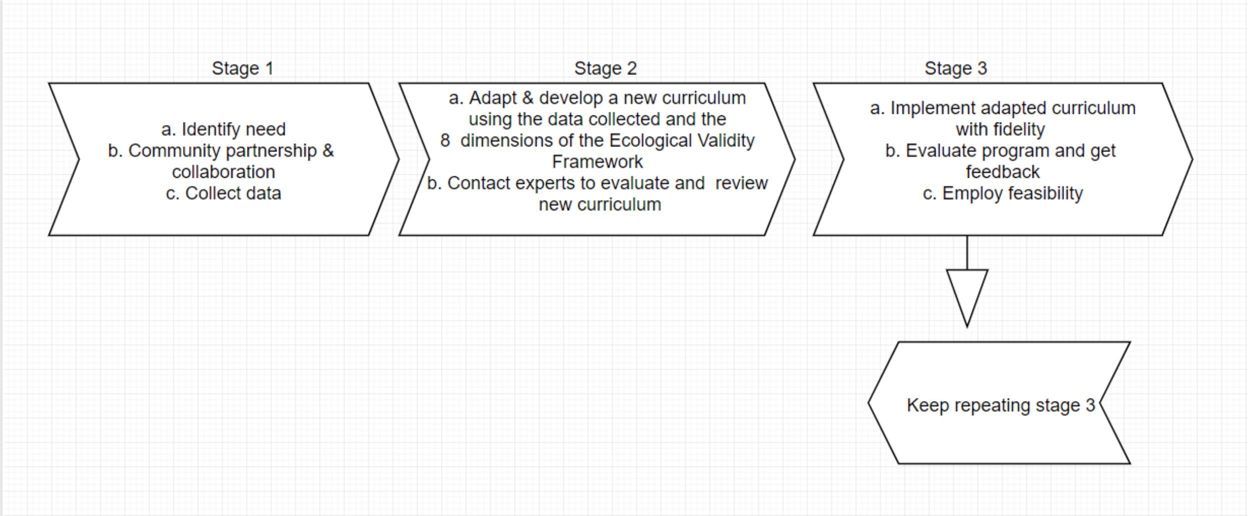


Figure 1: Methodological Framework

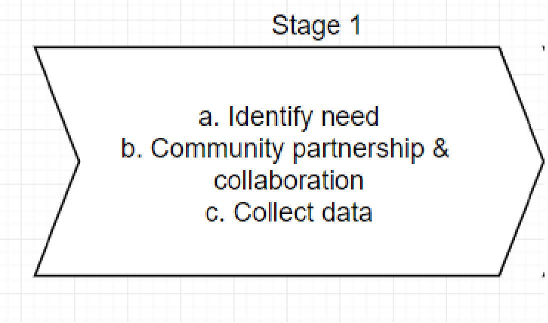


Figure 2: Stage 1 - Collaboration to Find a Balance Between Community's Needs and Scientific Integrity.

The primary purpose of culturally adapting interventions is to develop interventions that will benefit the community in question. In doing so, it is important that the people it is being created for find the intervention useful. This helps to eliminate issues of imposing what the researcher thinks the community needs to what is actually needed. During this stage, the researcher will: a) Identify needs; b) Build community partnership and collaboration; c) Collect data.

Step a, the identification of needs, scholars in cultural adaptation suggest this to be done through extensive review of literature or conducting a needs assessment. A viable partnership must then be formed with the stakeholders of the community and the researcher in Step b. It is imperative in soliciting if the intervention is a good fit for the community that is being adopted into. This allows for easy identification of informants, collaborators and other stakeholders who are willing to provide input by way of in-depth interviews or focus group discussion.

Step c is to collect useful data that will help to inform what and how to modify the intervention. It is important to collect data on what program content needs to be modified, as well as program delivery methods that may also need to be modified. The content of the EVF provides guide to the specific elements for this step.

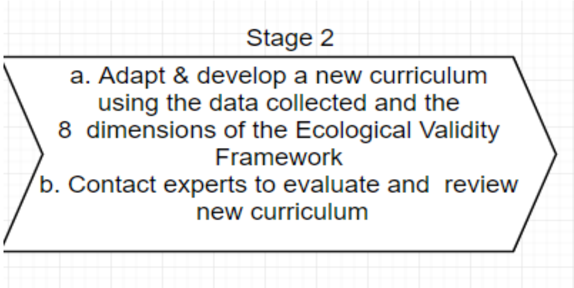


Figure 3: Stage two - Developing and Evaluating a New Curriculum

The second stage consists of two steps. Step a) requires the researcher to adapt and develop a new curriculum using the data collected in stage 1 and the eight dimensions of the EVF; Step b) requires the researcher to contact experts to evaluate and review the new curriculum.

This stage requires using the eight domains of the Ecological Validity Framework

(Bernal, Bonilla, & Bellido, 1995) as a step-by-step guide in considering specific aspects to modify when developing the new curriculum. Lastly, in depth feedback on potential outcomes, methods, cultural relevance and sustainability of program should be solicited.

Table 2: Culturally Sensitive Elements for Current Study

Domain	**What to Consider**
Language	What is the appropriate language to use both written and verbal?
Persons	Role assignment: who is seen as an acceptable person to deliver content etc.
Metaphors	What are familiar symbols, sayings, and concepts that will be relatable?
Content	Cultural knowledge: What are important values, customs, and traditions that makes this particular group unique and how will this influence the kinds of issues that will be pressing.
Concepts	What is the congruence between concepts in the intervention and cultural context of families?
Goals	What are the intervention goals created within context of family values, customs, and traditions?
Methods	What methods or ways will be employed to make sure that intervention goals are achieved?
Context	Changing social, political, economic, acculturative, and other contexts of families.

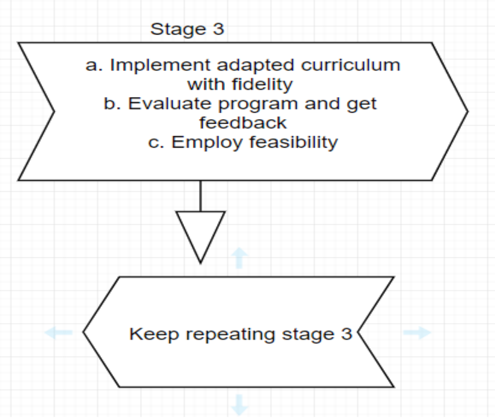


Figure 4: Stage three - Implementing curriculum and program evaluation

Stage 3 requires that the culturally adapted intervention program is implemented and evaluated. In evaluating the program, caregiver/parent and family outcomes should be measured, (Karst, 2012). This includes assessing the functionality and well-being of the family, the parent–child relationship, parenting efficacy and sense of competency, parenting stress, parent mental health (specifically, anxiety, and depression), and any other factors (Karst, 2012).

It is important to implement with fidelity (meeting requirements of fidelity checklist) and quality as well as solicit feedback from participants. This feedback will be helpful for revising the curriculum.

Another step in this stage is to employ feasibility. Feasibility of a study provides feedback on whether the intervention can be shaped to be relevant and sustainable, additionally it can help identify what and how changes need to occur (Bowen, et al., 2009).

CHAPTER THREE

METHODOLOGY

This chapter describes in detail, the research design and methodology selected for this study, as well as its utility. It is followed by a description of the participants, data sources, procedures, measures and data analysis for each of the stages and steps involved. Finally, an overview of the validity and reliability is discussed followed by the research bias and ethical assurances.

Research Design

As stated earlier, the researcher's purpose of the study is to culturally adapt the *Transitioning Together* ® program for Ghanaian caregivers who have an adolescent with autism. The program will address the service gap for Ghanaian families and their adolescent children with autism by providing support group sessions for caregivers that emphasize on positivity and problem-solving. A Participatory Action Research (PAR) approach was used to gather feedback about how each module can be tailored to meet the specific needs of this population. To achieve this goal, the researcher interviewed Ghanaian caregivers and conducted focus group discussions with practitioners in a qualitative study.

Participatory Action Research PAR has been defined by Baum, MacDougall and Smith, (2006) as an approach that:

"Seeks to understand and improve the world by changing it. At its heart is a collective, self-reflective inquiry that researchers and participants undertake, so they can understand and improve upon the practices in which they participate and the situations in which they find themselves. The reflective process is directly linked to action, influenced by the understanding of history, culture, and local context and embedded in social relationships. The process of PAR should be empowering and lead to people having increased control over their lives." (p. 854).

The main goal of PAR is to provide workable, sustainable solutions that address pressing concerns and develop local human capacities; this begins with the identification of a problem facing a group of people (Ozanne & Saatcioglu, 2008). In this study, identification of the problem was done through extensive literature reviews and personal communication with stakeholders in Ghana. In PAR it is vital that researchers seek to improve the well-being of the population of interest to reduce inequities (Baum et al., 2006). This process can be fully attained by involving persons in the population of interest. In this study, Ghanaian caregivers, as well as practitioners, participated in the cultural adaptation process by providing feedback on what to adapt in the program. The purpose of the interview and focus group discussions was to bring out insights by having caregivers and practitioners tell stories about their lives as caregivers or practitioners and discuss their various needs.

To increase the likelihood that cultural contexts were accounted for in the cultural adaptation of the program, the central question "What changes need to be made to the *Transitioning Together*® program for Ghanaian caregivers to increase its cultural relevance, content applicability, and user-friendliness?" was asked. This question was first addressed with a qualitative design that entailed discussions, interviews, field notes, and specified demographic information. Using a semi-structured interview guide, participants provided useful feedback on each of the program modules. The data collected from the participants helped to further develop and modify the modules to meet their specific needs.

Overview. This study employed two of the three different stages in the methodological framework to achieve its purpose. In stage 1, interviews and focus group discussions were conducted to get feedback from participants. In stage 2, the researcher analyzed and used the data from the interviews to modify and localize the *Transitioning Together*® program curriculum to suit the specific needs of caregivers of adolescents with autism in Ghana. The researcher used other resources to inform the development of the new curriculum. After the new curriculum was developed, the researcher contacted caregivers, practitioners, and researchers to review and evaluate the newly developed curriculum. The researcher revised the program materials based on comments and recommendations provided by the participants who evaluated the curriculum.

Table 3: Summary Table of Stages, Steps and Activities Involved

Stage	**Step**	**Activity Involved**
1. **Soliciting initial information**	a. Conducting focus groups	Recruitment of potential participants
		Data collection
		Data analysis
	b. Conducting individual interviews	Recruitment of potential participants
		Data collection
		Data analysis
2. **Developing and evaluating a new curriculum**	a. Modify the curriculum	Use data in stage one to modify the curriculum
	b. Review and Evaluation of curriculum by experts	Recruitment of potential participants
		Data collection

Before any data collection took place, the researcher applied for approval by the Michigan State University Human Research Protection Program and the Institutional Review Board (IRB) in order to assure all proposed procedures would be ethical and protect the participants involved in the study. The researcher applied for an Exempt IRB review, given that there will be no or minimal risk to human subjects involved, and is therefore exempt from federal regulations under 45 CFR 46.101(b) (2).

Stage 1: Soliciting Initial Information

This stage comprised of two steps; step 1a. Conducting focus group discussions, step 1b. Conducting individual interviews.

Step 1a. Conducting Focus Groups. There are intends for conducting focus groups (Creswell, 2007). For instance, focus groups can be beneficial when participants are likely to be cooperative with one another, have the experience, when there are time constraints, or when individuals may be hesitant to speak alone (Luse, 2012). For this study focus group discussions were beneficial for the researcher because it allowed for: 1) recruiting more participants; 2) talking to more people within a short time frame; 3) exploring consensus or lack of; 4) understanding commonalities within and differences between suggested comments; and 5) assessing potential bias.

Recruitment of participants. The inclusion criterion for this study was that all participants were providing services at the time of data collection. The sample was recruited from two autism centers in the Greater Accra region of Ghana. Creswell (2007) stated, “the more diverse the characteristics of the individuals, the more difficult it will be for the researcher to find common experiences, themes, and the overall essence of the experience for all participants” (p. 122). It was therefore essential to locate individuals who were associated with the same organization to attain a higher likelihood to find a shared experience or consensus across participants. This step recruited practitioners who provide direct services for families of children and adolescents with autism in Accra, Ghana. Due to the limited availability of services for adolescents and youths with autism, participants included practitioners who work with children as young as two years old and youth up to the age of 18 years old. Practitioners included applied behavior analysis (ABA) technicians and service providers. Three focus groups with a total of 16 participants were conducted. For this research, recruitment and focus group discussions were carried out until saturation was reached. Saturation is based on successive interviewing until sources yield redundancy, and the data is complete and integrated. No limits on demographics such as gender, age, or ethnicity were used. Demographic information for members of each of the three groups was presented in Tables 4, 5, and 6.

Table 4: Pre-Interview Questionnaire Summary of Participant Responses – Focus Group 1

	Gender	**Age**	**Marital status**	**Educational level**	**Degree/Training**	**Job title**	**Years in field**	**Area of service expertise**	**Client population**	**Age range of clients**
	M	20	S	High school	None	Caregiver	2	Education	Individuals with autism	5-15
	F	35	M	Tertiary	Certificate in Marketing	Administrator	3	Education	Individuals with autism, Families, guardians, advocates	3-17
	F	22	S	High school	None	Assistant Administrator	3	Education	Individuals with autism and down syndrome	3-17
	M	27	S	Tertiary	Psychology/ Board certified Autism Technician	Behavior therapist	4	Behavior intervention	Individuals with autism	2-10
	F	44	M	Tertiary	Special Education tutor	Director	9	Education, independent living, social skills	Individuals with autism and down syndrome	4-18

Table 5: Pre-Interview Questionnaire Summary of Participant Responses – Focus Group 2

	Gender	**Age**	**Marital status**	**Educational level**	**Degree/Training**	**Job title**	**Years in field**	**Area of service expertise**	**Client population**	**Age range of clients**
	M	25	S	Tertiary	BSc Agricultural science	Junior ABA therapist	1	Behavior and social skills	Individuals with autism	2-10
	F	27	S	Tertiary	Psychology/ Board Certified Autism Technician	Senior Behavioral therapist	4.5	Behavior intervention	Individuals with autism	2-11
	F	26	S	Tertiary	Psychology/ Board Certified Autism Technician	ABA therapist	3	behavior intervention	Individuals with autism	2-10
	M	27	S	Tertiary	MPhil Population and health	Junior therapist	1	Community integration, social skills. mental health, independent living	Individuals with autism	2-10
	M	30	S	Tertiary	BSc Fisheries and aquatic sciences	Junior therapist	1	ABA	Individuals with autism	3-10
	M	26	S	Tertiary	BSc Psychology	Junior therapist	1	Mental health Education	Individuals on the spectrum	2-10

Table 6: Pre-Interview Questionnaire Summary of Participant Responses – Focus Group 3

	Gender	**Age**	**Marital status**	**Educational level**	**Degree/Training**	**Job title**	**Years in field**	**Area of service expertise**	**Client population**	**Age range of clients**
	M	26	S	Tertiary	BSc Earth Science	Junior ABA therapist	1	Mental health	Individuals with autism	2-12
	F	26	S	High school	none	Facilitator	4	Education and Independent living	Individuals with autism	12-15
	F	32	M	Tertiary	B. Ed Special education	Facilitator	5	Community integration, Social skills training, Independent living	Individuals with autism and Cerebral Palsy	12-18
	F	37	F	Tertiary	Dip Education	Teacher	4	Education and social skills training	Individuals with autism and cerebral palsy	10-18
	F	21	F	High school	None	Caregiver	3	Education	Individuals with autism and cerebral palsy	3-15
	M	26	S	Tertiary	BSc Psychology	Junior therapist	1	Mental health, Education	Individuals on the spectrum	2-10

Data collection procedures. Before the focus group discussions occurred, participants filled out a demographic form and submitted to the researcher in person or via email. Each focus group discussion began with friendly interactions, a brief explanation of the study purpose, and informed consent. Focus groups lasted on an average of 40 minutes. All discussions were audio recorded to ensure that all information was captured with accuracy. Following each discussion, the researcher labeled each recording with the pseudonym and date of the discussion. Participants had the right to end the discussion at any point for any reason and could leave whenever they wish to. The researcher also stated that arrangements for referrals could be made if a participant needed counseling. The researcher first provided a presentation on the *Transitioning Together*® program that the current study was based on, followed by the solicitation of feedback that was developed to capture the eight dimensions of the EVF (See appendix B for the interview protocol).

The nature of semi-structured questions was intended such that other questions often emerge in fieldwork and may add to or replace pre-established ones (Glesne, 2015). The interview guide was modified throughout the focus group discussion to accommodate new insights as they emerged. The researcher consciously assessed the value in pursuing this, making sure that areas that were not of interest to the primary research question were tactfully and gently directed back on topic. Before and during discussions, the researcher practiced noticing her feelings, but not being captured by them (Glesne, 2015). This analytical technique helped in assessing the researcher’s feelings and impressions, while also staying present and listening mindfully to the participant.

Step 1b: Conducting Individual Interviews. Individual interviews were conducted with eight caregivers to attain detailed and in-depth information from the end-users. These interviews allowed the researcher to explore susceptible, embarrassing, controversial or “personal” topics that caregivers may otherwise not share in a group.

Recruitment of potential participants. This step involved caregivers of adolescents with autism. Selection of participants was guided by their relationship with an adolescent with autism. Potential participants were sought out through autism centers in Accra and personal recommendations. For this research, the researcher recruited and interviewed eight participants. No limits on demographics such as gender, age, or ethnicity were used; however, all participants had to be living in the same household with their child at the time of data collection.

A secondary source of data for this study was field notes and a reflective journal. Throughout the research process, these pieces were continually updated with the researcher’s emotions, stances, values, and perspectives, which helped to contextualize the primary data source (Glesne, 2015).

Summaries of participants in the individual interviews.

Participant 1. Participant one is the mother of a 15 years old female who has been diagnosed with autism by a medical doctor. She reported her age as being between 46 and 55 years and being married. She has a master’s degree; however, due to her daughter’s disability, she has only been working part-time. She reported that her daughter receives speech therapy as well as special education services. Together with her husband, their household income per year is about GHC60, 000. She also reported having an 18 years old daughter who has not been diagnosed with any disability.

Participant 2. Participant two is a father of a 16 years old male is who has been diagnosed with autism by a medical doctor. He reported his age as being between 36 and 45 years and being married. He has a master’s degree and is employed full time an engineer. He reported that at this time his son is receiving special education in speech therapy from the disability center that he attends. His wife is a stay at home mom to help take care of the children especially because they have a son with autism.

Participant 3. Participant three is a single mother who has a set of twin boys with autism she reported being a high school graduate and a self-employed trader at the central market. She also reported being 36 years and not having her sons formally diagnosed. She reported that the staff at the disability center assessed her sons and said that they might have autism because of the symptoms. Her sons are currently 14 years and have no other siblings.

Participant 4. Participant four is a 25 years old woman who takes care of her nephew that was brought to her from Canada by her sister. She reported that her nephew was diagnosed at age two by a clinical psychologist and currently at 12 years shows signs of Attention Deficit Disorder (ADD). She has a full-time job and with support from her nephew's mom who is his sister their household income pay year is about GHC75, 000.

*Participant 5***.** Participant five is a self-employed single mother and a high school graduate. She is 36 years old and currently has a son with autism who is 14. She reported that her son was diagnosed by the disability center staff at age 10. She also reported that her son has some speech delays and is receiving services with a speech therapist. She reported her son receiving some special education services as well as. She recounted having two other children 16 years and seven years who do not have any form of disability.

Participant 6. Participant six is a father to a 12-year-old son who has autism. He has an undergraduate degree and is employed full-time. He is married, and his wife is also employed full-time. He reported being 36 years old and his son being diagnosed by the disability center staff at age 7. Together with his wife, their household income is about GHC 70,000.

Participant 7. Participant seven is a stay at home mom who has a son aged 17 diagnosed by a medical doctor with autism. She is married, and her husband is working full-time. She has an undergraduate degree and worked before her son being diagnosed with autism. Currently, the household income is about GHC75, 000.

Participant 8. Participant eight is a mother to an 11-year-old son who was diagnosed with autism by a social worker. She reported her age as being between 25 and 35 years, she is married and works full-time. Her husband also works full-time their household income is about GHC100, 000 per year. She reported that her son receives speech therapy from the speech therapist and some special education services from the disability center.

Table 7: Summary of Participant Demographic Characteristics - Individual Interviews

Characteristics	Frequency
Gender	
Male	2
Female	6
Age	
18-25	1
25-35	1
35-45	5
45+	1
Education	
High school	2
Tertiary	2
Graduate school	4
Marital Status	
Married	3
Not married	5
Employment Status	
Full time	4
Part-time	1
Self-employed	2
Unemployed	1

Data collection procedures. Before interviews, participants filled out a demographic form and submitted to the researcher in person or via email. Each interview began with a friendly interaction, a brief explanation of the study purpose, and informed consent. The researcher conducted interviews in a private location of the participants' choosing. Each interview lasted about 30 minutes, and second interviews were scheduled for some of the participants to obtain clarifying information and or greater depth of insights.

All interviews were audio recorded to ensure accuracy. Following each interview, the researcher labeled the recording with the pseudonym and date of the discussion. Participants have the right to end it at any point for any reason. The researcher also stated that arrangements for referrals could be made available if a participant needed counseling. Participants had the right to end the discussion at any point for any reason and could leave whenever they wish to. The researcher also stated that arrangements for referrals could be made if a participant needed counseling. The researcher first provided a presentation on the Transitioning Together® program that the current study was based on, followed by the solicitation of feedback that was developed to capture the eight dimensions of the EVF (See Appendix C for the interview protocol).

The nature of semi-structured questions is such that other questions often emerge in fieldwork and may add to or replace pre-established ones (Glesne, 2015). The interview guide was modified at certain times during the interview to accommodate new insights as they emerged. The researcher consciously assessed the value pursuing this, making sure that areas that were not of interest to the primary research question were tactfully and gently directed back on topic. Before and during interviews, the researcher practiced noticing her feelings, but not being captured by them (Glesne, 2015). This analytical technique helped in assessing the researcher’s feelings and impressions, while also staying present and listening mindfully to the participant.

Data Analysis

Using semi-structured interviews, participants provided feedback about the program. Analysis commenced alongside data collection. After each focus group or individual interview, the researcher reflected on the experience and wrote field notes. Strauss and Corbin (1998) stated that the process of data analysis in qualitative research involves working with the data, organizing it, breaking it down, synthesizing it, searching for patterns and discovering what is essential. A third-party transcription service transcribed all the audio recorded interviews. The analysis included an initial listening to the audio recordings and taking notes until the transcripts were available. After the researcher received the transcriptions, she reviewed them by listening to the recording to ensure the accuracy of the transcription.

Coding. Creswell (2017), highlights that coding is the process of organizing the data by bracketing chunks and writing a word representing a category in the margins. The researcher utilized manual coding techniques for analysis. The rationale for choosing to code manually was based on the sample size being relatively small, comprising of 23 participants and 11 transcripts. Specifically, open and evaluation coding procedures were employed (Saldaña, 2009).

Open Coding. The researcher employed open coding, which is the analytic process through which concepts are identified, and their properties and dimensions are discovered through the data (Lawrence & Tar, 2013). Here the researcher identified significant and minor themes, to gain a better understanding of the data. The researcher analyzed each transcript line by line to obtain significant statements made by participants regarding reasons for deciding if a topic is important to participants or not. The researcher then listed and developed preliminary groups of reasons. An important consideration for this stage is that “coding is not simply just labeling; it is linking” (Glesne, 2015, p. 195). Data was densely coded, without attempts to condense or summarize the content in just a few themes (Delamont, 2002).

Evaluation coding. Evaluation coding is best suited for researchers who are trying to ascertain the value of a program, policy, or action plan (Saldaña, 2009). Evaluative judgments can help researchers make decisions about what modifications are needed to improve the quality or effectiveness of a program for future use (Saldaña, 2009). Analysis of evaluation data allows the researcher to achieve three things: a) describe field observations or participant responses that assess the value of the program in question; b) understand how the program compares to others; and c) make predictions that offer recommendations on program adaptations and how to go about executing them (Saldaña, 2009). The researcher re-coded several times to confirm themes. The use of evaluative coding tactics and engaging in multiple coding phases contributed to the validity of the data analysis process. Evaluation coding usually consists of or is supported by other manual coding techniques (Saldaña, 2009). For this study magnitude coding was employed under the umbrella of evaluation coding to analyze the data.

Magnitude coding. Magnitude coding is a supplemental technique that denotes frequency, direction, extent, absence or presence of data, and evaluative information (e.g., statements that have positive or negative meanings; Saldaña, 2009). Words, symbols, or abbreviations can be used with this coding process (Saldaña, 2009). In order to identify what end users thought were useful or not useful in the program, magnitude coding was used to identify positive and negative statements made by participants and to count the frequency of occurrence of all positive and negative statements (Saldaña, 2009).

The researcher maintained a codebook through the entire research process, which included each code, along with a definition and short description. This codebook assisted in avoiding meanings drifting, or changing, as codes are applied to the data. Throughout the analysis process, the researcher wrote analytic memos as often as possible to record what was done, why it was being done and what needs to be done next (Delamont, 2002). This practice was essential for the organization, and to ensure reliability and validity of the work.

Stage 2: Developing the New Curriculum

Modifying the curriculum. The researcher used the data from the information solicited from caregivers and practitioners to modify and localize the Transitioning Together® intervention curriculum to suit the specific needs of caregivers of adolescents with autism in Ghana. Based on extensive literature conducted in the preparatory phase on existing evidence-based family intervention, as well as input from the data collected and analyzed, the researcher prepared a set of program curriculum materials. Using the criteria outlined in the Ecological Validity Model (Bernal, Bonilla, & Bellido, 1995), needs that were identified by more than 50% as important were included in the intervention. The weighting of different topics was determined based on the frequency with which the needs were expressed (a need mentioned 100% as important was allotted twice as much time as a need expressed 50%).

Recruitment of participants. After developing the curriculum modules, the researcher contacted an interdisciplinary team of researchers, practitioners, and caregivers for review and input on the materials. For the purpose of the review and evaluation, participants had to meet at least two of the following criteria;

1. Have acquired a masters or doctorate in related areas.
2. Have worked with adolescents with autism in Ghana for at least three years.

3. Is Currently working with adolescents with autism in Ghana
4. Possess knowledge and experience in conducting research.
5. Possess expertise in family-related intervention areas.
6. Have an adolescent child with autism in Ghana.

15 participants were invited through personal recommendation however, nine participants were selected. Participants comprised of individuals specializing in autism and family intervention, as well as related disciplines and expertise (e.g., counseling, social work, special education, family and child development, mental health counseling).

Summary of participants.

Participant A. participant A is a practitioner who works at a private autism center. She currently works in the capacity of a facilitator and has been working at the center for three years now.

Participant B. Participant B is a practitioner who works at a private autism center. She currently works as an administrator and a facilitator at her center. She has been working with individuals with autism for five years.

Participant C. Participant C is a special needs educator who owns an autism center. She works directly with students at her center as well as does training for parents and other practitioners in the area. She has been working in the field for 11 years.

Participant D. Participant D is a researcher and practitioner with over eight years of experience working with individuals with intellectual disabilities. She has a Ph.D. in rehabilitation science and conducts research in Ghana.

Participant E. Participant E is an Applied Behavior Analysis (ABA) technician with over six years of experience. She currently works as special education needs (SEN) facilitator.

Participant F. Participant F is a rehabilitation counselor and researcher who works with caregivers and individuals on the spectrum. He has over five years of clinical and research experience with this population.

Participant G. Participant G is Board Certified Behavior Analyst with over 14 years of experience. She has clinical and research experience in working with children, adolescents and adults with autism.

Participant H. Participant F is an Applied Behavior Analysis therapist in Ghana. She has worked in this capacity for about four years now.

Table 8: Summary of Participant Demographic Characteristics-Reviewers

	Gender	Educational Level	Degree/Training	Years in the field	Area of expertise
Participant A	F	High School	Special education needs (SEN) facilitator	3	Adolescents with autism
Participant B	F	High school	Special education needs (SEN) facilitator	5	Adolescents with autism, Parents of individuals with autism
Participant C	F	Bachelors	Special Education Tutor	11	Individuals with autism, Parents of individuals with autism, Practitioner Training
Participant D	F	Doctoral	Rehabilitation Science	8	Individuals with intellectual disabilities
Participant E	F	Masters	Applied Behavior Analyst Technician	6	Individuals with autism
Participant F	M	Doctoral	Certified rehabilitation Counselor	5	Caregivers of individuals with autism; Individuals with autism
Participant G	F	Doctoral	Board Certified Behavior Analyst	14	Children, Adolescent and Adults with Autism
Participant H	H	Bachelors	ABA Therapist	4	Individuals with autism

Data collection procedures. The participants were emailed the set of program curriculum materials and the checklist. They were given up to three weeks to review the content and give their feedback in writing via email. Participants had the task of examining the entire program overview and curriculum to provide comments on specific content and method of delivery. During the review, comments, and suggestions on the content, possible outcomes, processes and procedures, as well as its applicability and feasibility were provided by filling out the evaluation checklist. After submitting the checklist, the researcher contacted the participants to ask clarifying questions and get more insights on the responses given. In this latter process, four participants were engaged.

Measure. The PET checklist (Dawson-Squibb & de Vries, 2018) is an evaluation framework that was developed to evaluate and serve as a guide in the selection of programs best suited to specific needs and communities. Primarily developed for evaluating programs in low-resource communities, this framework emphasizes the importance of both implementation and process factors in addition to outcomes when evaluating parent education programs. The 37-item scale is divided into three sections. The first section evaluates parent-focused outcomes as well as outcome in a broader context such as the impact on child, family, siblings and the community. The second section evaluates processes and procedures. Elements of acceptability and accessibility are evaluated. The third section is the implementation landscape, evaluating if the program has the potential for scale-up and sustainability especially in areas of integration coordination, scalability, monitoring, and evaluation. For this research, the researcher modified the checklist to suit the purpose of the study better (See Appendix D).

Validity and Reliability

The primary validity criterion for qualitative work is credibility, or “the extent to which the data, data analysis, and conclusions are believable and trustworthy as based on a set of standard practices” (Lather, 2007). The main issue in this area is determining what the “set of standard practices” are, and how to measure one’s work against them. Addressed in the following paragraphs are some approaches for addressing reliability and validity in the context of this study.

Rich data. First, clarity was ensured. This study clearly defined and described precisely what is being researched and how it is being done. Each definition is clear enough to allow multiple observers to agree on where with whom and how to reliably code data with these definitions in mind. The second approach was data saturation. According to Guest, Bunce, and Johnson (2006), data saturation occurs when no new data is needed because additional data collected does not result in new themes or codes participants in this study were recruited till data was saturated.

As a component of validity, the researcher continuously self-reflected through journaling, memos, field notes, self-recordings, and peer discussions. This self-reflection and meticulous record-keeping were critical to understanding one’s self as a researcher to one’s work and keeping records of the research process. These methods helped the researcher better understand the influence she may have on the research. To address credibility (or internal validity), the researcher was sure to spend enough time actively engaged with participants, provide a full description of the research conditions and maintain accurate delineation of the research process. Dependability also relied on high-quality field notes and tracking of the process employed throughout the study.

Triangulation. Triangulation is a technique used to increase the validity of qualitative research (Maxwell, 2013). Multiple coding practices to address inter-rater reliability was carried out between the researcher and a colleague who is an experienced qualitative researcher. This process is a form of triangulation, (investigator triangulation) which relates to confirmability, where the researcher worked closely with the colleague and with two other peers to review the data and check the consistency of the findings (Noble & Smith, 2015).

Researcher Bias

Creswell (2014) mentions that the researcher should keep in mind their biases, values, and personal background (i.e., gender, history, culture, and socioeconomic status) that could shape the interpretations formed during a study. Due to the previous work experiences working closely with practitioners and caregivers of children with autism in Ghana, the researcher considered how this background and experiences might influence the data collection procedure, as well as how the data collected was coded.

Ethical Assurances

The identities of those who agreed to take part in the study have been kept confidential. Outside of general demographic information, no personal identifying information was collected throughout the study. Informed consent was obtained. The document described the purpose of and procedures involved in the study. The consent process also explained expected participation duration times, risks and benefits, payments, participants’ rights, and the researcher’s contact information. Consent related information was conveyed in simple, easy to understand language (English) and avoided the use of technical or overly complicated jargon. Participants had the opportunity to ask questions before agreeing to participate.

Furthermore, the names and locations of the study sites were kept confidential. All study data and materials, including responses from questionnaires and interviews, were kept in a password-protected computer file. All hard copies of study material were stored in a locked file cabinet that remained locked when not in use by the researcher.

CHAPTER FOUR

RESULTS

The purpose of this study was to culturally adapt the *Transition Together* ® program for caregivers of adolescent children with autism in Ghana. Two overarching stages were used in achieving this purpose. The central question "What changes need to be made to the *Transitioning Together*® program for Ghanaian caregivers to increase its cultural relevance, content applicability, and user friendliness?" was asked. This central question was asked to increase the likelihood that cultural contexts were accounted for in the cultural adaptation of the program. A qualitative, semi-structured interview methodology was used to provide participants the opportunity to describe their needs and preferences. This semi-structured methodology was designed to capture the eight domains of the Ecological Validity Framework (Bernal, Bonilla, & Bellido, 1995).

This chapter presents the findings from the study which includes feedback obtained from the participants on the *Transitioning Together* ® program modules on what they deemed as important topics or not to be included in the revised curriculum. It also provides results on additional topics they would like to see added. These were addressed based on stage 1 of the methodological framework. Additionally, evaluations results from experts are reported in this chapter, which was addressed in stage 2 of the methodological framework.

Stage 1: Soliciting Initial Information

The focus of the first stage of this study was to solicit information from participants on what changes the researcher needed to make to the *Transition together* ® program to increase its relevance to them. This stage involved seven semi-structured questions. Findings of this stage are reported in order of which the questions were asked.

The first question was specifically inquiring on which of the already existing topics in the program participants thought were relevant or important to them with reasons to support why they thought it was an important topic of discussion. The second question supported the first question by asking participants if they had additional topics that they thought was relevant. These two questions fulfilled the *content* and *metaphor* domains of Ecological Validity Framework (EVF; citation). The researcher employed evaluation coding, which was supported by magnitude coding. The magnitude coding process was to help identify statements that showed a positive or negative reaction towards the topic (Saldaña, 2009). The researcher rated the topics as important, somewhat important and not important.

In analyzing the sub-question why? or why not? the researcher objectively identified patterns in the data by placing significant statements into broad themes. Additionally, reminders about nonverbal communication and emotions prompted during the interviews were also taking into consideration during the coding process. Salient ideas expressed by participants in various forms were also coded. Finally, triangulation methods to ensure validity were employed by examining and cross-checking previous research that outlined needs for the population in the study to the needs reported by participants of the study. Thick, rich descriptions of statements made by participants are also reported.

Content and Metaphor. The *Transitioning Together* ® program has eight topic areas that parents meet over an eight-week period to discuss: Autism in Adulthood, College Planning, Employment Planning, Family Issues, Community Integration, Risk to Adult Independence, Legal Issues, and Health and Wellbeing (DaWalt, Greenberg & Malick, 2018). Participants of the study reported six out of the eight topic areas as important and relevant to them. Additionally, participants reported Behavior Management as a topic that will be relevant to them.

Autism in adulthood. This topic was coded as important as all eight caregivers and participants in all three focus groups reported it as useful topic to discuss. It was coded as important also because participants reported that it will increase their knowledge in what autism is. Autism in Adulthood was therefore included as a topic in the adapted program. Participant 1 and 6 expressed;

> *"Yes, it will be good to learn more"*
>
> *"It is important for us to learn more about our children"*

Participants in FG1 also expressed;

> *"I think there is a need to really talk to them and make them understand that yes their children are with autism and are growing, they are transitioning into adulthood"*

College planning. With regards to college planning, participants did not express interest in wanting to discuss it as a topic. Six parents did not see it as important,

> Participant 7*: "At this point that is a little too late for him don't you think haha"*
>
> Participant 2: *"Not necessary for my child"*

One parent saw it as important stating;

> Participant 1: *"Well, it is important ...there are autistic children who are able to achieve that, so it is important"*

Another was indifferent.

Additionally, nine out of the 15 participants in the focus group discussions expressed no interest in it; a participant in FG3 expressed;

> *" I think parents should look past school because quite frankly not all our children will get an office job, so let's make sure that our kids are independent as possible, they understand work ethics, they understand they have to go to work, they understand that*

> *they have to save, all these things, the parent has to make sure they put steps in place for their kid because parent talk like, 'he is my child, she is my child I am going to take care of him' you are not going to be alive forever, so make sure you put steps in place to take care of this child."*

A total of two FG participants reported this topic as important with a participant in FG1 stating;

> *"Could be important for some parents elsewhere but not our children here."*

The researcher therefore coded this topic as not important. College Planning was therefore not included as a topic in the adapted program.

Employment planning. Participants in both focus group discussions and individual interviews unanimously identified employment as an important topic to discuss. It was reported as important because discussing it will provide caregivers with available options to help children. The topic employment planning was added to the adapted program.

> Participant 1: *"It is also important, I mean, how are they going to support themselves when we are gone? So, it is also important."*
>
> Participant 2: *"That will be good, I tried to get him involved in the things I do but he is sometimes reluctant so let me see what my options are".*
>
> Participant 7: *"Yes he started going to the shop with his father, I do not know what he does there though but he always comes home tired haha… I would like to know what else he can do so I can let him try new things."*

Practitioners in focus group discussions as well as caregivers stressed on the importance of discussing employment in relation to caregivers' future absence:

FG2: *"… yeah Because after all we hope that a child will get to the point when they are independent of you and that is when maybe you can find your fulfillment so that is the main thing that we are always in for."*

FG3: *"…I believe parents should also be able to look in to that because they are not going to be around for the kid's entire life, so they need to make decision as to what kind of life is their child is going to live after they are gone."*

Family issues. All participants listed family issues as important; however, some individuals stressed on discussing behavior management practices they can adhere to. The topic family issues was added to the adapted program.

Participant 1: *Yeah… I think every member of the family needs to understand what Autism is about in the first place and how to relate to persons like that and then you know, (laughs) how to defend yourself when they get aggressive and all that. She has a bigger sister, she is much smaller in size than she is,…during her meltdown time, she can just beat her, pull her hair, you know, if she understands what it means to have Autism, if she understands…how to relate when she gets like that, it will go a long way to help all of us, sometime she behaves as if she understands, sometimes she is just down, she just breaks out and cries, sometimes she just wishes she has a bigger or smaller sister, you know, she is also quite anxious and I don't even know what to do."*

Participant 2: *"It will be important especially for my wife haha"*

Participant 6*: "Haha oh yes, that is if you are referring to the various family dynamics with the other kids too"*

Participant 7: *"Oh very important for all of us especially how to deal with the younger ones"*

Practitioners also reported their happenstances with parents as a reason why this topic is important:

FG1: *"Yes that is right because I think years back, I dealt with parents who tried to blame each other for the child's disability …"*

FG2: *"In some other cases you realize that ok, the parents are really not going to be consistent, they will rather give a child what he wants or just to prevent the child from the tantrum or just to keep or just let someone else take care of the child that is yeah quick… I also believe the role of the family is super key from all angles they look at it from because first of all, right from even identifying that your child could be autistic we need a family who has a fair idea of some of the signs we need to look out for, mostly what happens here is we have most parents in denial or did not even identify early"*

Legal issues. Participants did not seem to be interested in this topic as none of them gave a positive yes or showed interest in wanting to know about it. The topic legal issues was not added to the adapted program. Participants reported;

Participant 2: *"oh we don't really do those things here in Ghana."*

Participant 3: *"I don't think it is as important as some of the other topic."*

Participant 6: *"errmmm that is not something I per se worry about haha."*

FG1: *"umm doesn't really seem like an issue here."*

FG2: *umm can't talk to that*

Risk to adult independence. All participants reported risk to adult independence as important linking its importance to their adolescents' ability to live independently. The topic risk to adult independence was added to the adapted program.

Participant 6: *"That will be good to explore especially because my child is growing"*

FG2: *“These kids are growing so it will be important to discuss what the possible risks could be.”*

FG3: “ Yeah definitely, because a child at a point in time should know how to cross the road by himself, should know not to get in to a stranger’s car, should not give their numbers too strangers, should basically know how to go to a shop pick stuff up that he or she wants and pay for it and know that, this money I have to get change and stuff, so this basically, we do teach some of these things in ABA, but if the child does not have access to ABA, I think this is also something really important that the parents should…teach their kids.”

Community integration. Participants regarded community integration as an important topic to discuss. Practitioners and caregivers acknowledged this topic as important because it provides them the opportunity to expose their children to the community without being anxious. The topic community integration was added to the adapted program.

Participant 3: *“Very Important, I think I need to understand how to involve him in our family activities.”*

Participant 5: *“Yes it will be important.”*

Participant 8: *“Yup we would like to learn more about the community here and how to get involved.”*

FG: *“I think community involvement is important for parents to learn how to involve their children in community activities. Some of these parents are even afraid to take their children to church ooo.”*

Health and wellbeing. Participants in the study acknowledged health and well-being as a topic that should be discussed in the program. Participants reported this as being important to discuss to help with stress. Health and wellbeing was added to the adapted program.

Participant 2: *"Yes but very basic things because some of the things you teach us are impossible to execute haha."*

Participant 6: *"Haha oh this one will be important, it gets so stressful, and it will be interesting to see how others cope."*

Participant 7: *"I am especially stressed out haha need some tips on how to cope you know. Especially now that I am a stay at home mom"*

Participant 8: *"For now we are both doing well because we have my husband's mother living with us and helping us out, but like I was saying earlier, he is growing up so who knows what other stressors may arise. It would be very good to be prepared"*

FG3*: "Very important because most of these parents are stressed"*

Tables 7 and 8 below show a summary of what topics participants in both focus group discussions and individual interviews reported as important, somewhat important and not important.

Table 9: Summary of Focus Group Discussion Codes

	Important			**Somewhat Important**			**Not Important**		
	FG1	**FG2**	**FG3**	**FG1**	**FG2**	**FG3**	**FG1**	**FG2**	**FG3**
Autism in Adulthood	5	6	5	0	0	0	0	0	0

Table 9 (Cont'd)

College Planning	**1**	**2**	**1**	**2**	**1**	**0**	**3**	**3**	**3**
Employment Planning	5	6	5	0	0	0	0	0	0
Family Issue	5	5	5	0	1	0	0	0	0
Legal Issues	0	1	0	1	2	0	4	3	4
Community Involvement	5	6	5	0	0	0	0	0	0
Risk to adult Independence	5	6	5	0	0	0	0	0	0
Health and Well being	5	6	5	0	0	0	0	0	0

Table 10: Summary of Individual Interview Codes

	Important	**Somewhat important**	**Not important**
Autism in Adulthood	8	0	0
College Planning	1	1	6
Employment Planning	8	0	0
Family Issue	7	1	0
Legal Issues	0	1	6
Community Involvement	8	0	0
Risk to adult Independence	7	1	0
Health and Well being	6	1	1

Across the eight interviews and three focus group discussions, a major theme on behavior management emerged as a common topic participants wanted to be added to the adapted program. This topic was regarded as important by all participants. Some participants explicitly said behavior management while others used other terms to reflect behavior management.

Behavior management. Swanepoel (2003) amongst other scholars have reported that behavior management and disciplining the child with autism as a challenge that caregivers face in Africa. It was not news that this was the most reported topic of interest when participants were asked for additional topics. In this study caregivers used the key phrases 'how to handle my teenager" and "how to reprimand my child" to refer to behavior management.

> Participant 1 expressed *". Behavior Management Hmm… some of their behaviors are quite unpredictable, so you just need to prepare for anything, and I think the school whichever school a child is going to really needs to understand what it means to admit an Autistic child…and that is what were are lacking here."*
>
> Participant 3 expressed *"Hmm…you know if you have a teenage child, it means, you are far advance in age (Laughs) so it means if you are not as strong as your child probably, so what to do when they get aggressive or what are some of the calming techniques and then…that is it basically."*
>
> Participant 4. *"Definitely need more ways of how to handle my teenager"*
>
> Participant 7. *"Ermm how to handle the siblings, sometimes I just do not have the words to explain their older brother's behavior to them"*

Practitioners also focused on aspects of boundaries in relation to managing behaviors:

> FG1. *"I think there is a need to also talk about boundaries to parents so that they can teach the children boundaries because you can't go on hugging everybody* all over the *place, there is a need for parents to know that and also knowing specifically what to engage them with in the house so they can have a plan for the day so that they know that in the morning should do this in the morning he will do that in the morning"*
>
> FG2. "*I know that some times what also happens is they come for the trainings, they know what behaviors, I mean the fashions of each and every behavior requires, but when they come home, they are tired, parents are tired to follow through and then they say "I*

> *am not an ABA therapist, when you cry for toffee, I will give it to you…. Let the therapists do it that is their job", forgetting that we all need to be very consistent in making this kid grow…all those are important for behavior management and for behavior management*"

The next three questions, questions three, four and five of the interview protocol solicited information on the organization of the *Transitioning Together* ® Program. This question fulfilled the *Languag*e, *Methods, Context and Person* domains of the Ecological Validity Framework (Bernal, Bonilla, & Bellido, 1995). Participants were asked to give their opinion on the organization of the program including, language, number of sessions, time of day, and who should facilitate.

Language. Participants unanimously reported that the manual should be in English so that it can be used across different communities since English is the medium of instruction in Ghana. However, caregivers requested that the individual facilitating the program, mix both English and the local dialect during sessions to make it easy for everyone to participate. For instance, participant 7 indicated;

> *"You know that there are certain things that are better explained in Twi so we need to be able to do so if that will enable us get our point across. For instance, I don't know about your church haha but even when I go for English service my pastor will say certain things in Twi, so we get a better understanding of it"*

Practitioners in the focus group also shared the same sentiment as the caregivers. Participants in FG2 said:

> *"If you speak only English in your program it will become a "class thing" as in only the elite will benefit from it. As for the manual we practitioners are using it so it has to be in*

English and anyone who calls themselves a practitioner should be able to read and write English"

Methods and context. A series of questions were asked with regards to the methods. Individuals were asked about a) adolescent group sessions; b) appropriate days and times; and c) joining session.

Adolescent group sessions. All eight caregivers reported that an adolescent group was not very necessary for them since their children already had some type of group and skill training activities from the autism center they attend. Though some of their comments suggested they did not mind it, they did not show a strong interest in having it either.

Participant 1: *I can see how this will be helpful, but it also depends on the time you know. Let's keep it as a caregiver group only for now so we can be free haha.*

Participant 2: *Hmm it depends on my child's mood that day, but anyway if the primary purpose of the program is for us then let us have our time alone.*

The practitioners in the focus groups mentioned that some caregivers may need childcare while they are attending the group so if possible, have that as an option however they did not see the need for a structured group.

FG1. *"You need to think about those parents that do not have any support at home; if you want them to come you will have to provide something for their child too. Maybe a caregiver or an aide to help watch their children will be ideal or even an incentive you know"*

FG3. *"I mean it could be a good idea to have the children also come together as a group so they can also be friends because their parents will become friends ha-ha... but on a more serious note if the parents are recruited from one school chances are that their* *children already know each other... one thing to consider too is the time of the day you know... our children need structure so if that time is scheduled for something else then don't change it ... I am also sure the parents will want to be free haha"*

Appropriate time and day. When asked about days and times there were conflicting responses however all caregivers concluded by saying that they will try to fit whatever works best to their schedule.

Participant 1. *"I am quite flexible, weekday evenings around the time school closes works for me."*

Participant 2. *"I work full time so Saturday early morning will work for me; I can do this for about a month take a break and do it again, take another break you know.... "*

Participant 5. "Oh… I know Fridays are out for religious reasons, Saturdays and Sundays are also busy for my work you know but I have workers so I can make time so far as it's not more than six weeks haha"

Practitioners in the focus groups were concerned about full-time working parents especially those that work in white-collar jobs they expressed weekends as best times for them however in Ghana most weekends are filled with weddings and funerals.

FG1. *"So, all the parent training that I have done have been one on one so we go to their homes at times that are convenient for them... yes... in my experience most of them prefer Saturday mornings or Friday evenings but then again the ones I have worked with are full time workers. Some of them come to the center during the week while their children are here too .... But like my colleague said it really depends on the individuals"*.

FG2. *"Saturdays are for weddings and funerals and celebration haha... but on a more serious note you wouldn't want parents missing sessions so if you can get a solid month*

> *or say six weeks where parents can commit to say Saturday mornings…that would be ideal"*

Persons. The researcher did not make assumptions about the kind of facilitator that would be appropriate for the adapted program. When participants were asked, they expressed a preference for a parent who is an expert in the particular topic of discussion each session. Caregivers especially mentioned that, having another caregiver who has lived experiences of what they are discussing is crucial. Additionally, they reported that having someone who is bilingual would be much more preferred.

> Participant 2: *"…autism is new to us here in Ghana so it is hard to meet people with older children and asked them how they did certain things, sometimes some of these meet ups that we do involve parents who have older children but most of them don't even live here in Ghana oo… me, if this group is able to bring experienced parents to share their experiences on how they survived I will be here every day haha…"*
>
> *FG3: "Definitely have a parent who is older and has experience present the materials haha… a very knowledgeable practitioner will be great as a facilitator too, but definitely get a parent too"*

Questions six and seven which were the final questions, solicited feedback from participants as to what they deemed as potential challenges and benefits of the program. These questions fulfilled the *Concepts* and *Goals* domains of the EVF (Bernal, Bonilla, & Bellido, 1995).

Concepts and goals. Castro and colleagues (2004) suggested that approaching difficult issues from a familiar cultural perspective can minimize behavioral resistance. The researcher did not make assumptions that the program will be well accepted by participants since it was developed based on their inputs. Here participants reported possible challenges of language, length of program, and practicality of the program as a possible challenge.

Challenges of language. Here participants expressed the language in which the group is conducted as a potential barrier to participation. Participant 3 stated;

"If you speak only English the whole time, mix it up with twi ha-ha."

Practitioners in FG2 expressed;

> *"We just have to make sure that every type of parent understands what is going on and make sure it is not too academic like they are in a classroom"*

Length of program. Another possible barrier that participants reported was the length and time of the program. While caregivers showed absolute interest in participating, they mentioned that running the program for a long time may result in them missing some sessions and not benefiting from the program. Participant 1 reported;

> *"I really want to participate if there are too many sessions or if it is over a long period of time, I might miss one due to a funeral or wedding ha-ha… moreover, that might be a crucial one for me you know"*

The practicality of the program. The possibility of the program not being practical and applicable to caregiver' current situation was reported by participants as a potential barrier to participation. Participants 3 and 4 expressed;

> *"Errrm you know some of trainings are not always realistic, so if the things we are talking about every time is not realistic, it will discourage most of us from coming because me especially I do not like my time to be wasted."*
>
> *"I cannot think of any but just make sure that the things we are talking about are practical."*

Participants also reported learning new ideas, strategies and interacting with fellow parents as the main benefits they can see from the program. Participants 2 and 8 reported:

> *"Oh, I can already see plenty of benefits ha-ha.... I mean just listening to other parents talk about their struggles will help me feel like good about myself you know and just learning new things ... they struggle is not easy."*
>
> *"The different friendships and relationships that will come out from this program, the new information that will be learned."*

Stage 2: Developing the New Curriculum

Using the *Transitioning Together* ® curriculum, the researcher adapted and modified based on the extensive feedback from the parents and practitioners in stage 1. The researcher considered comments made by the participants to modify and localize the program curriculum modules. Additionally, the researcher made sure the eight domains of the Ecological Validity Framework was taken into consideration (Bernal, Bonilla, & Bellido, 1995).

The parent group meets for four weekly sessions. Each session involves education on a topic relevant to autism and the transition to adulthood as well as guided practice with problem solving for individual family challenges. Parent group sessions last approximately two hours. Sessions begin with 15 minutes of socializing, followed by 45 minutes of education and 60 minutes of discussion and problem solving. For each problem-solving activity, the group chooses one problem a family is facing. The group works together to select strategies that the family can implement to address that problem. Families are invited to share updates on strategy implementation with the group during subsequent sessions. This process provides an opportunity to gain from the vast experiences of the multiple families present and to focus on addressing problems in a constructive, non-critical way. The group will maintain a WhatsApp group through which parents and facilitators can communicate.

Table 11: Summary of Adapted Program Sessions

Sessions	**Goals**
Session 1: Transitioning with Autism	Meet other families Learn about developmental course of autism
Session 2: Growing Up	Learn about employment services and strategies Finding community activities and social opportunities Discuss safety concerns for adults with autism
Session 3: Behavior Management	Learn strategies for behavior management during adolescence and early adulthood
Session 4: Family Issues and Wellbeing	Learn about impact of autism on family and the environment on individuals with autism Learn about risks to parental health and well-being Learn coping skills and self-care strategies

The manual of the newly adapted program and curriculum modules can be found in the Appendix.

Evaluating the New Curriculum

After participants reviewed the program manual and curriculum modules, the checklist provided them the opportunity to give comments on the potential outcomes, process and procedures, and implementation of the program. Participants gave overall comments of the different sections as well as comments on specific question. The next paragraphs will discuss feedback from participants.

Potential outcomes. This section of the checklist had 11 items. This included caregiver outcome, child outcome, family outcome, and community outcome. Overall, participants provided positive feedback with no changes to the curriculum modules but suggested some more structure to the program implementation will result in positive outcomes. Participant E expressed;

> *"This program provides well laid out, simplified and practical strategies that caregivers can follow to improve the overall quality and well-being of the child with autism and their families. I think the particular section on problem solving as it relates to challenging behaviors of the child will be useful to any care giver. I find the environmental impact, employment services and community involvement you incorporate all be very useful components of the program."*

Caregiver outcome. Participants gave positive feedback for this section indicating that caregivers will benefit greatly from the program. Participant F, however related the success of the caregiver outcome to caregiver engagement. He expressed that that this program will only support the emotional wellbeing of the caregiver including stress reduction, hope, and managing grief where applicable depending on how much the family as a unit is engaged. Additionally, Participant G raised a concern indicating the need for the program to have clear practical skills the parents will learn. She expressed:

> *"This program is primarily knowledge-based, but it is not clear what practical skills the parents learn and whether these are implemented. Modeling problem-solving is great but this program doesn't evaluate the ability for the parents to implement problem solving on their own."*

Child outcome. In reviewing the program on whether it will lead to an improvement in the child's quality of life and wellbeing participants had positive comments. Participant F, however, linked this to the ability of the program to impact the community. He expressed:

"This will depend on how much the bigger community is made aware of autism. The training definitely advocates for parents reaching out to the community members. The extent to which this is a success will determine how accepting the community will be of the child with autism hence improving their quality of life."

Additionally, with regards to whether this program will lead to changes in autism related deficits, Participants F expressed:

"The program is focused more on parental training. Its success in reduction of autism related deficits will therefore depend on how much the parents translate the training into practice. Also, identification of specific resources (both personnel and places) related to communication and social interactions would definitely help."

Participant G expressed:

"The problem-solving activities after each set of topics may lead to some goal setting and some follow-through, it is difficult to know whether the parent goals will actually be worked on. Though check-ins ensure some follow-up, I don't think these are sufficient in changing parent behavior, in my experience with the U.S. version of this program."

Family outcome. All participants suggested that the program will lead to an improvement in the family quality of life. They also reported the programs ability to improve the family's access to receiving supports**.** Participant F and G expressed:

"It will bring parents of children with autism closer together hence offering alternative sources of support."

"This is critical to this program. And a major positive potential outcome"

Community outcome. In this subsection participants generally reported that the program will have a positive impact on the community.

> *“This program will go a long way to help, because when there is enough awareness, society will have adequate knowledge which will reduce stigma drastically.”*

However, participant F linked the success of the program to have a positive impact to the community to parents being able to advocate for their children as discussed in the program. Participant F expressed:

> *“Given that it is parental focused; I am not sure about how it will impact the community. If the parents choose to advocate for and involve their children in community activities, then the community impact will be felt.”*

Process and procedures. This section had eight items in total broken down into acceptability, accessibility and psychological process. Overall participants reported the program to be accessible, acceptable and having a good psychological process. Participant D expressed:

> *“The manual clearly states the various processes and procedures the program and tends to be in as the parents get the opportunity to discuss challenges and find solutions to the problems and challenges this will help strengthen each other”*

Accessibility. In this particular section, participants provided positive feedback and thought the program was accessible. However, participant E was concerned about language literacy, Participant E asked:

> *“My question though centers on caregivers who can neither read nor write. Is there any plan for them? Or is the focus on educated caregivers?”*

Participant C also expressed:

> *“Once we get this program to the appropriate quarters, it should be accessible to the caregivers”*.

Acceptability. Except for participant G who commented that she was not an expert in the culture, all participants suggested the program was acceptable. Participant E expressed:

> *"Caregivers are often looking for solutions and since you provide some useful practical strategies and approaches, I think they will be receptive to it."*

Psychological process. In examining whether the program informs and prepares caregivers of next steps and support after its completion, participants responded positively. Participant B specifically commented on the WhatsApp group:

> *"I like that there will be a WhatsApp group for parents to be able to stay in touch with their group members for a long time"*

Implementation. This section had two items for participants to examine sustainability and replication of the program. Participants provided an overall positive feedback for this section. They, however, expressed the need for structure and attention from program facilitators for the program to be sustainable. Participant D expressed:

> *"As long as the same level of attention and supervision are implemented in all the different centers this program will be sustainable this will reduce preferences of a particular center as a result of lack of resources in the center close to the family."*

With regards to replication of the program Participant C commented:

> *"This program can be easily replicated in different centers across the nation because, families nationwide experience similar challenges."*

Overall comments. After examining the program curriculum modules based on the different sections on the checklist. Participants provided an overall comment on the program. Each participant provided a positive comment on the program. Four Broad themes emerged from the comment. These included *Positive comments, Program Implementation, Literacy and Rural Settings,* and *Behavioral management strategies*.

Positive comments. Generally, all participants provided positive comments. These comments expressed satisfaction with the content, process, procedures and the availability of the program.

> Participant A. "*I really love the topics and her behavior management I am I went through the topics I have discovered one way to manage one of my student's behavior"*
>
> Participant C. "*Over the years a lot of these facts have been discussed, but this is the first time it is documented like this from the caregiver's point of view. This program will go a long way to help have the caregiver, with support, transition and behavior management."*
>
> Participant D. *"I particularly like the aspect of the program which focuses on the family support especially Couple well-being and sibling well-being the emphasis on every family exploring which coping strategy or intervention strategy may be suitable for the needs is also stated clearly finally if this program is successfully implemented it will help improve on the independent skills of adults since on the autism spectrum."*

Program implementation. Apart from providing comments in the implementation section, participants emphasized again on the success of the program to the ability of facilitators to implement methodically.

> Participant A. *"This program I believe strongly will be very beneficial to all if implemented very well…."*
>
> Participant D. *"It looks like it will be a good program if well implement…"*

Literacy and rural setting. Here participants raised concern of replicating the program in rural areas where caregivers do not have the ability to understand or speak English.

Participant E. *"As earlier indicated, I wondered how caregivers who may not be literate in the English language participate in the program."*

Participant F. *"Some parts of the modules will have to be modified if it is to benefit parents in the rural settings…"*

Behavioral management strategies. Participants specifically gave feedback on the behavior management module. Here participants suggested that the researcher include more evidence-based behavior management strategies. They also suggested that facilitators needed to spend more time on that module.

Participant G. "*Even though this is not intended as an applied behavior analytic training. There is some valuable information missing (such as links and resources to available positive behavior strategies, such as the National Professional Development Center for Autism"*

Participant E. "*Often times, care givers do not understand challenging behaviors and interpret these behaviors to "being stubborn". I recommend facilitators of the program to spend more time explaining problem behaviors*."

CHAPTER FIVE

DISCUSSION

In this chapter, the researcher provides an overview of the study, outlining the purpose statement, research question of interest and a summary of the methodology. The discussion focuses on the description of the adapted program outlining the changes made in relations to the original program. The implications and limitations of the study are also addressed.

Overview

The purpose of this study was to address a service gap for Ghanaian families and their adolescent children with autism by culturally adapting an existing evidence-based program, *Transitioning Together* ® (Smith, Greenberg, & Mailick, 2012). Specifically, the researcher sought to develop a set of culturally appropriate program curriculum modules, that address the suitable demographics and unique caregiving needs of families of adolescents with autism in Ghana. This study was designed to explore the central research question: What changes need to be made to the *Transitioning Together*® program for Ghanaian caregivers, to increase its cultural relevance, content applicability, and user friendliness? To address this research question, the researcher employed a participatory action research methodology. This methodology included focus group discussions with practitioners and individual interviews with caregivers to provide input on what and how they want the program to be presented. A methodical review with experts to provide feedback on the developed program was solicited after the set of curriculum modules were modified based on the input, using the *original Transitioning Together* ® program materials as the basis.

The Transitioning Together Adapted Program

In adapting the *Transitioning Together* ® program, content changes were integrated throughout the program instead of simply adding cultural factors to individual sessions. Changes were made to the program manual to reflect the length of the program, questions for discussion, appropriate goals for caregivers as well as medium of communication for facilitators and caregivers. The following provides a description of the curriculum content and the changes made across each of the eight domains of the Ecological Validity Framework [EVF] (Bernal, Bonilla, & Bellido, 1995).

Overall curriculum content change. In comparison to the original program, the current version has the following content session changes. First, in *Transitioning Together* ® program, the first session, “Autism in Adulthood” was retained as is. Second, “Family Topics” and Health and Well-being” in the original program were combined into one session in the Ghanaian version called the “Autism and Family”. Third, two sessions, namely, “College Planning”, and “Legal Issues” were not included in the Ghanaian version. Fourth, three of the original sessions, namely “Risk to Adult Independence”, “Employment”, and “Community Involvement” were combined into one session in the Ghanaian version. Finally, an additional session was included in this version to address behavior management and advocacy. This module titled “Behavior Management” focused on additional behavioral management techniques in the Ghanaian version. In addition, the problem-solving activity were introduction in session 1 of the Ghanaian version while it was introduced in the third session of the original Transitioning Together® program.

Description of revised curriculum changes. Changes made across each of the eight domains of the EVF. The cultural adaptation process occurred throughout the development process (from identifying need through to having experts review the adapted program). The adaptation process included selecting the specific framework to guide the process and making the modification to suit the preferences of Ghanaian caregivers. The *Transitioning Together* ® adapted program was culturally adapted using the Cultural Adaptation Process Model (Domenech- Rodriguez & Weiling, 2004) and the Ecological Validity Framework (Bernal, Bonilla, & Bellido, 1995). The next few paragraphs will discuss the changes made across each of the EVF domains.

Language. Language always carries meanings and references beyond itself: The connotations of a language represent the culture of a specific social group. Language, as defined in this framework, applies to both oral and written communication as well as particular slangs (Bernal, Bonilla & Bellido, 1995). The majority of culturally adapted evidence-based programs have been interventions tailored into the Spanish cultures and have made changes to the language (DaWalt, Greenberg & Malick, 2018; Santiago, Bernal, Reyes-Rodriguez & Bonilla-Silva, 2012; Wallis, Amaro & Cortez, 2012). In this adapted program, the researcher did not change the language of the manual; however, facilitators are advised to deliver the content of the program in both English and the appropriate local language. The rationale behind not changing the language was because participants in the study unanimously reported the manual should be in English so that it can be used across different communities. They suggested this because English is the medium of instruction in Ghana.

Franz et al., (2016) stressed on the importance of carefully matching families with facilitators that speak and understand the same language they feel comfortable. Caregivers requested that the individual facilitating the program, mix both English and the local dialect during sessions to make it easy for everyone to participate. For instance, participant 7 indicated: "You know that certain things are better explained in Twi, so we need to be able to do so if that will enable us to get our point across. For instance, I do not know about your church, haha but even when I go for English service, my pastor will say certain things in Twi, so we get a better understanding of it."

The researcher decided to adhere to not changing the language also because Ghana is a multilingual country in which about 80 languages are spoken (Paul, Simmons & Fennig, 2014). Accra which is the capital of Ghana and the setting of the study is a "salad bowl" which has people from the over 70 different ethnic groups in Ghana. Changing the language of the manual from English to one local language excludes more caregivers. A participant who reviewed the program raised a concern about language and literacy: "As earlier indicated, I wondered how caregivers who may not be literate in the English language participate in the program."

The researcher acknowledged that this might be a potential limitation for the program; however, the manual of the program and the curriculum was maintained in English. The researcher argues that official government documents, assessments, hospital forms and other manuals used in the country are written in English. Though there are documents that are translated into various local languages, this program was developed in English, the official medium of instruction in Ghana.

Person. The EVF defines the person domain as the participant – facilitator dyad. This includes the participants' expectations of the facilitator and ethnic match. For this study, the researcher recommends an experienced parent and an experienced practitioner in the topic of discussion to co-facilitate the sessions. Similar to the Spanish version of the *Transitioning Together* ® program, this was highly recommended by both practitioners in the focus groups and individual interviews. This is an aspect that is different from the requirement of the original program, which prefers that the facilitators should be trained under the original program and holds a professional degree, rather than as a peer-run program.

Metaphors. Metaphors refer to those sayings and dichos (Bernal et al., 1995) shared by the caregivers who have adolescent children with autism. The researcher asked the question, are the sayings, terminologies, and dichos in the program content common to the caregivers in Ghana? The researcher built-in metaphors and sayings that reflect the Ghanaian culture. Because a question on metaphors was not asked in the focus group discussion or individual interviews, end users did not provide inputs. Additionally, none of the experts raised a concern. This domain can be better assessed after the program is implemented and being evaluated.

Content and context. An essential consideration in the cultural adaptation process, according to Bernal et al., (1995), is cultural knowledge: What are essential values, customs, and traditions that make this group unique and how will this influence the kinds of issues that will be pressing. It was imperative to consider contextual issues to increase the practicality of the program. Thus, the researcher made a conscious effort to keep the information in the modules relevant to the setting. In this domain, end users of the program provided information on the kinds of issues and topics that will be useful to them as well as topics that they felt did not apply to them. The next few paragraphs will compare this study's finding on *content* to the literature.

Autism in adulthood. The introductory session entitled "Transitioning with Autism," focused on a discussion of the challenging nature of autism, important things to consider during the transition stage and current positive trends. This session also introduced the problem-solving component of the program. This topic was reported as necessary by end users. A practitioner in FG1 expressed "I think there is a need to really talk to them and make them understand that yes their children are with autism and are growing, they are transitioning into adulthood." This expression of necessity is consistent with the literature on autism in African cultures. Though there are limited studies to document the challenges, barriers, and needs of caregivers who have children with autism, the few studies report that learning the developmental course of autism will be beneficial for caregivers (Swanepoel, 2003; Ulofoshio, 2017 & Lagunju, Bella-Awusah & Omigbodun, 2014). Content of this topic together with other valuable issues are discussed in the session *Transitioning with Autism*.

Growing up. In the second session, three topics in the original *Transitioning Together* ® program were combined and entitled "Growing up." The following topics were discussed. The first one was *Adult Independence*. This topic focused on discussions on promoting responsibilities, helping to address skills, facilitating interest and encouraging the individual. The second one was *Employment Planning*. This focused on things to consider when planning for employment, different ways in which adolescents could generate income and examples of employment avenue are to be discussed. The third one was *Community Involvement* this topic invites discussions on how parents can put themselves out there and advocate for their as well as getting involved in the community.

Behavior Management. Session three entitled "Behavior management" discussed challenging behaviors and strategies to manage them.

Family issues. The final session titled "Autism and the Family" focused on a discussion of the impact of autism and the family, myths, ways of supporting each other and coping strategies. This topic was reported as important by end users. Feedback from this topic indicated caregivers strained family relationships and challenges of behavior management in the family as issues they would like to gain insight. Feedback reported aligns with the literature on challenges caregivers in Africa face. Swanepoel (2003) reported responsibility and blame, parent-child relationship, marriage relationship, doing things as a family and strained family relationships as issues caregivers find challenging and stressful. In the adapted program the topics of family issues and well-being have been combined into one topic to discuss the issues and coping techniques to help with stress.

College planning and legal issues. These topics were reported as not important by end users. For instance, the topic legal issues, participants showed no interested in it as none of them gave a positive yes or rated it as important. Participant 2 outrightly said "oh we do not do those things here in Ghana" to mean that the issue of legal issues and caregiving was not a major concern in Ghana. Participant six also stated "Participant 6: errmmm that is not something I per se worry about haha". With these comments made by participants the researcher argued that, participants did not see the need to discuss these issues. Additionally, this lack of interest aligns with literature as it has not been reported as a need by caregivers.

Methods. This dimension takes into consideration the incorporation of cultural knowledge into the adapted programs' process and procedures. It is imperative that facilitators respond to and are compatible with the participants' culture. The adapted program has several ways in which it offers a different method and delivery of the program. First, while the original *Transitioning Together* ® program is delivered over an eight-week period, the adapted program is delivered over a four-week period. Bernal and colleagues (1995) suggest balancing process and content for program effectiveness of cultural adaptations. While others might argue the fidelity of the newly adapted program because of the shortened time, it is important to bear in mind the possibility of participants not completing the program if left at eight weeks.

Similarities to the Original Transitioning Together ® Program

Adapting a program does not mean doing away with the original program. The researcher maintained the format and portions of the original *Transitioning Together* ® program content which did not comprise the cultural relevance of the program (See Appendix E).

Problem solving. In the revised version, the researcher did not change the content or process of the problem-solving activity. Though the delivery time was changed the content of this section of the original program was maintained as it is in the program manual.

Tips for facilitators. A very important factor that practitioners and participants who reviewed the program reported was proper implementation of the program. In the Ghanaian version, participants indicated that the ability of facilitators to implement the program well will contribute to the success of the program. With the exception of how facilitators communicate with caregivers, the researcher maintained the tips for facilitator in the original *Transitioning Together* ® Program.

Weekly templates. Though the adapted program is a four-week program as against the original eight weeks of the original program. The researcher maintained the templates for the weekly program.

Strengths and Limitations of the Study

A major strength of the current study is that this study represented the first study to systematically identified the service gaps for families of Ghanaian families who have a transition-age child with autism. More importantly, the input from the community, including stakeholders (practitioners, administrators) as well as end-users (families of children with autism) allowed the revision and adaptation of an existing evidence-based intervention to be developed that is culturally responsive to the Ghanaian families, who currently has no formal services available.

This study has incorporated a group of experts who are researchers and practitioners who are well versed in the types of clinical topics and/or the culture to make an attempt to provide feedback on the developed program. The participants that informed the cultural adaptation are the caregivers and practitioners who would benefit directly from the program. Hence, caregivers and practitioners are reporting on their own personal experiences, challenges and needs. Nonetheless, there are limitations to every research study. The current study has several limitations that need to be taken into consideration when considering the results.

First, number of participants in the sample was restricted and may not be representative of caregivers and practitioners in Ghana; however, they provide valuable insights for future research with this group. Additionally, because participants from two autism centers were utilized in the study using nonprobability sampling techniques, care should be taken when trying to apply these findings to the broader population.

Secondly, because of the researcher’s previous work history within the geographic area and because participants were specifically targeted based on their affiliation to the autism centers, participants may have been biased while participating in the study. Further, participants may have responded to questions with a more positive lens when discussing their acceptability of the program. On the other hand, it is important to note that any previous relationships with the researcher and the participants involved also could have allowed for the participant to feel more comfortable in discussing very personal matters.

Furthermore, although evaluation was performed by using a group of experts, a formal field testing on the feasibility and efficacy of the Ghanaian version of the program was not done.

Specifically, Participant F commented on the difficulty of purely evaluating the efficacy of the program without collecting the data of actual implementation.

Finally, the newly developed program was not reviewed by any caregiver. This could have probably yielded some bias in the review results especially because none of the end users were involved in the process.

Implications of the Adapted Transitioning Together Ghana Program

Study findings have implications for a wide variety of stakeholders. Results of this study are important to adolescents with autism and their families, policy makers, practitioners and researchers. This research study advances the field of autism research in Ghana because it is the first to develop a set of program curriculum modules for caregivers who have an adolescent child with autism in Ghana. Though limited research on autism in Ghana exists, most studies have focused on childhood autism spectrum disorder. Hence the present study adds to the limited body of literature of adolescents with autism and caregiving. Scholars of autism and caregiving in Africa have long reported family support groups, parent training and parent education as important ways to support families. (Dixon, Badoe & Owusu, 2015; Nwanze, 2012; Swanepoel, 2003; Ulofoshio, 2017). The results of this study are not only significant because it highlights the need for caregiver training; but also because it shows that there is a desire for increased knowledge about autism and transitions as well as practitioners accepting the parent training program to increase caregiver knowledge and participation in their child's transition process.

Policy Implications

Non-categorization of autism. The current study shows the need for systemic caregiver support and resources and how the non-categorization of autism affects service provision. As evidenced by the results of this study, the caregivers and families of adolescents with autism continue to play a vital role well into adulthood. This aligns with previous research that indicates parental social and financial support determines the success of adolescents with autism during their transition stages (Dixon, Badoe & Owusu, 2015; Nwanze, 2012; Swanepoel, 2003; Ulofoshio, 2017).

With the non-categorization of autism as a disability in Ghana by the government (Salifu & Mate-Kole, 2014), it is rather difficult for caregivers and practitioners to obtain any resources to provide or improve autism related services. The results of this study indicate a need for parental advocacy for proper and official categorization of autism to receive improved services, support and resources.

Research Implications

Though feasible to consider the implication of improved caregiver experiences and outcomes following participation in the newly adapted transitioning together Ghana program, there are certain modifications that need to be made to the newly adapted transitioning together Ghana program. This program is brand new and will necessitate further exploration, and pilot testing. The current study provides justification for the establishment and use of this program however implementation and further testing will be needed in a variety of areas.

Replication of current study. Future research would be necessary to replicate the current study in other geographic locations, especially rural area in order to capture the different experiences that caregivers have as a result of geographical location. This will provide a more culturally appropriate program for caregivers in that area.

Larger sample size. This research had eight caregivers and 16 practitioners in stage one and nine expert reviewers in stage two. Future research should attempt to include more participants. This will allow the results to be more generalizable to the geographic location.

Conducting a pilot study. Conducting a pilot study will provide more information about additional, needed program modifications, and allow for the collection of pre- and posttest data from a larger sample and more diverse study site locations. Doing so will make study findings more generalizable, will provide monitoring and evaluation data, and can offer information on the feasibility of expanding the study to other West African nations. Future studies should also examine the efficacy.

Feasibility and fidelity of the program. In moving toward the goal of implementing evidence-based programs it is important to consider implementation fidelity as part of a process evaluation referring to the degree to which a program is delivered according to protocol (Bragstad, Bronken, Sveen, Hjelle, Kitzmüller, Martinsen, ... & Kirkevold, 2019). With the success of the program being dependent on proper implementation, it is important to conduct implementation fidelity studies to evaluate to what extent the transitioning together Ghana program is being delivered according to protocol.

Another step in the evaluation process is to employ feasibility. Feasibility of a study provides feedback on whether or not the intervention can be shaped to be relevant and sustainable, additionally it can help identify what and how changes need to occur (Bowen, Kreuter, Spring, Cofta-Woerpel, Linnan, L., Weiner., ... & Fernandez, M. 2009). A major change in the program was reducing the eight-week program session of the original transitioning together ® program to a four-week program in the adapted version. Gladding (1994) indicated that a 1.5 to 2 hours of weekly group meeting for 12-16 sessions would be optimal for effective group session. With the focus group data indicating a range of four to six weeks as ideal, it is important to implement and test for feasibility and fidelity to identify an optimal and effective time range for sessions.

Outcome studies with caregivers. The newly adapted program aimed improving the quality of life of caregivers. As part of the evaluation process it is important to use social validity measures via a satisfaction survey and exit interview questions to obtain information on what caregivers learned and what they will do differently as a result of the program. Social validity measures such as adolescent outcomes (Frequency of social interactions, social engagement), caregiver wellbeing, caregiver child relationship amongst others should be considered.

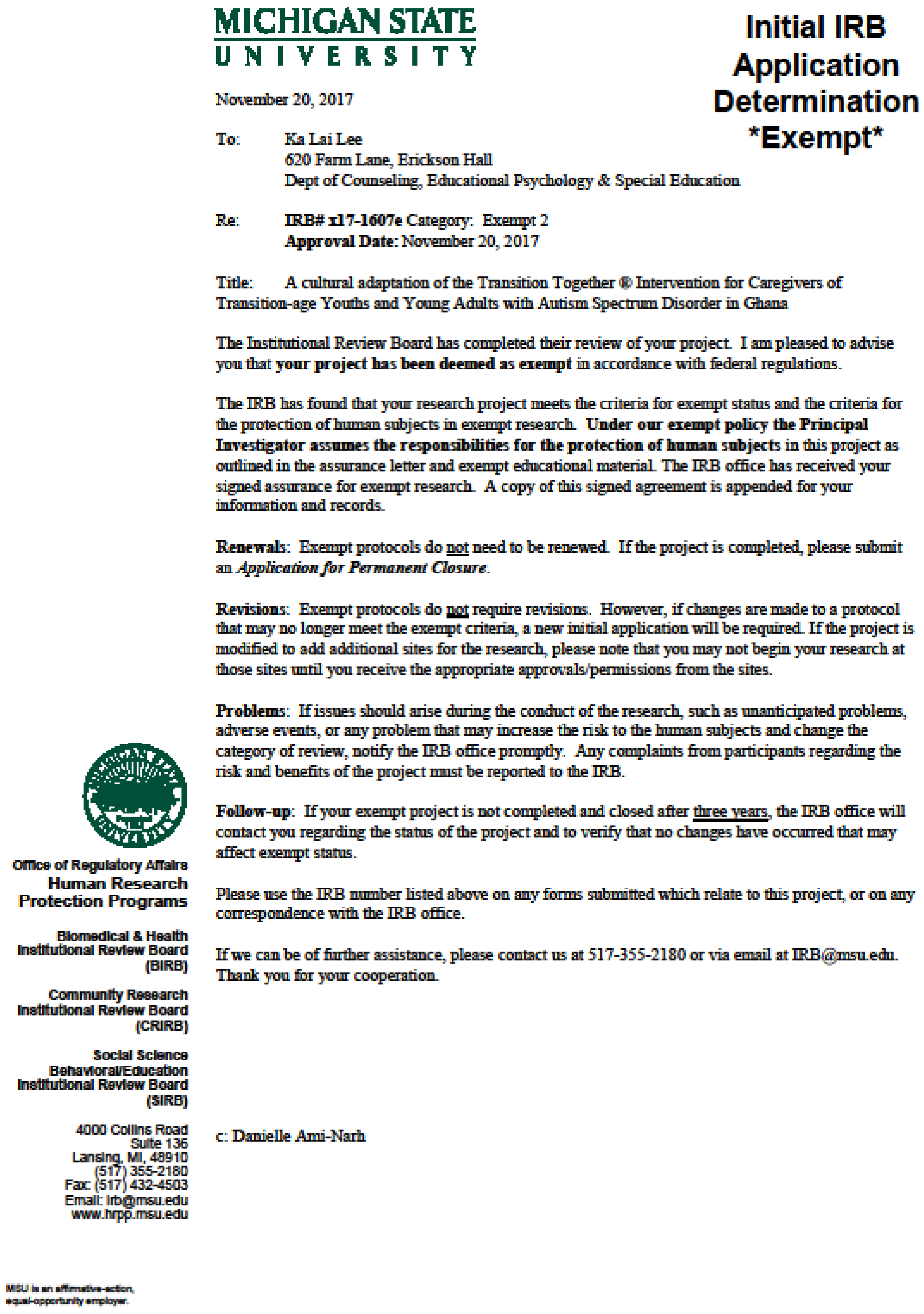
Practice Implications

Though future research needs to examine how the information from the current study can be used in making the program a success, important implications for practice can be drawn from the study. The findings from this study highlights the importance of using the newly adapted Transitioning Together Ghana program to address various family needs and challenges that would have otherwise not been discussed. With the emphasis on the success of the program being seamless implementation, it is imperative that facilitators and parent facilitators are trained with a standard training module. This training procedure will reduce inadequacies and help to ensure that the program is run in a way that can be sustained. As such this training module will have to be developed and delivered to facilitators of the program.

Through the implementation of the Transitioning Together Ghana program, practitioners would be able to work with caregivers on helping them understand various concerns and challenges they may be facing as well as providing a platform for them to find support through other caregivers and ask questions that they otherwise will not have had the opportunity to ask.

APPENDICES

APPENDIX A: IRB DOCUMENTATION



MICHIGAN STATE
UNIVERSITY

Initial IRB Application Determination *Exempt*

November 20, 2017

To: Ka Lai Lee
620 Farm Lane, Erickson Hall
Dept of Counseling, Educational Psychology & Special Education

Re: **IRB# x17-1607e** Category: Exempt 2
Approval Date: November 20, 2017

Title: A cultural adaptation of the Transition Together ® Intervention for Caregivers of Transition-age Youths and Young Adults with Autism Spectrum Disorder in Ghana

The Institutional Review Board has completed their review of your project. I am pleased to advise you that **your project has been deemed as exempt** in accordance with federal regulations.

The IRB has found that your research project meets the criteria for exempt status and the criteria for the protection of human subjects in exempt research. **Under our exempt policy the Principal Investigator assumes the responsibilities for the protection of human subjects** in this project as outlined in the assurance letter and exempt educational material. The IRB office has received your signed assurance for exempt research. A copy of this signed agreement is appended for your information and records.

Renewals: Exempt protocols do not need to be renewed. If the project is completed, please submit an ***Application for Permanent Closure***.

Revisions: Exempt protocols do **not** require revisions. However, if changes are made to a protocol that may no longer meet the exempt criteria, a new initial application will be required. If the project is modified to add additional sites for the research, please note that you may not begin your research at those sites until you receive the appropriate approvals/permissions from the sites.

Problems: If issues should arise during the conduct of the research, such as unanticipated problems, adverse events, or any problem that may increase the risk to the human subjects and change the category of review, notify the IRB office promptly. Any complaints from participants regarding the risk and benefits of the project must be reported to the IRB.

Follow-up: If your exempt project is not completed and closed after three years, the IRB office will contact you regarding the status of the project and to verify that no changes have occurred that may affect exempt status.

Please use the IRB number listed above on any forms submitted which relate to this project, or on any correspondence with the IRB office.

If we can be of further assistance, please contact us at 517-355-2180 or via email at IRB@msu.edu. Thank you for your cooperation.

c: Danielle Ami-Narh

Office of Regulatory Affairs
Human Research Protection Programs

Biomedical & Health Institutional Review Board (BIRB)

Community Research Institutional Review Board (CRIRB)

Social Science Behavioral/Education Institutional Review Board (SIRB)

4000 Collins Road
Suite 136
Lansing, MI, 48910
(517) 355-2180
Fax: (517) 432-4503
Email: irb@msu.edu
www.hrpp.msu.edu

APPENDIX B: CAREGIVER PRE-INTERVIEW QUESTIONNAIRE

Caregiver Pre-Interview Questionnaire

Demographic Information

Directions: Please complete the following form as completely as possible. Please answer all questions truthfully. This information is being collected for research purposes only. Your information will be kept confidential and will not be shared in any way by the research team.

Child Information

1. Please indicate your child’s gender:
    ____ Male
    ____ Female
    ____ Not listed (please specify): ___________________
    ____ Prefer not to respond

2. What is your child’s birthdate? ______________________________

3. At what age was your child diagnosed with ASD? ________________

4. My child was first diagnosed with ASD by a:
    ____ Clinical psychologist
    ____ School psychologist
    ____ Medical doctor
    ____ Other, Please specify: _______________________________

5. Does your child have any other identified delays or disabilities (besides Autism Spectrum Disorder), such as ADHD, speech delay, or other special needs? Yes No

6. If you answered “yes” to #5, please indicate what other delays/disability(ies) your child has been identified as having.
    ____

7. How many children do you have? _________________

8. What are their ages? _____________________________

9. Among all the children you have, how many have a disability? _____________

10. What, if any, specialized services does your child currently receive? (e.g., speech therapy, private counseling, special education)
    ____

____

11. What, if any, specialized services have been provided to your child in the past?
____

____

Parent Information

12. What is your age 18-24___ 25-35____ 36-45_____ 46-55____ above 55 ______?

13. What describes your highest level of education?
______ Some high school
______ High school diploma
______ Some college
______ Some graduate school
______ Graduate degree (master’s level or higher)
______ Other, please specify: ___________________________

14. Please indicate your marital status:
______ Single
______ Married
______ Living with domestic partner
______ Divorced
______ Widowed
______ Other, please specify: ____________________________

15. Thinking about all the sources of income you and your family received, what was the total gross income (before taxes were taken out) for your household **over the past year:**
_____ a) GHS 5,000 or less _____ b) GHS 5,001 to 10,000
_____ c) GHS 10,001 to 15,000 _____ d) GHS 15,001 to 20,000
_____ e) GHS 20,001 to 30,000 _____ f) GHS 30,001 to 35,000
_____ g) GHS 35,001 to 40,000 _____ h) GHS 40,001 to 50,000
_____ i) GHS 50,001 to 75,000 _____ j) GHS 75,001 to 100,000
_____ k) GHS 100,001 to 200,000 _____ l) GHS 200,001 or more

16. Please indicate your employment status:
______ Full time ______ Part time
______ Not working ______ Others, please specify: __________

APPENDIX C: PRACTITIONER PRE-INTERVIEW QUESTIONNAIRE

Practitioner Pre-Interview Questionnaire

Directions: Please complete the following form as completely as possible. Please answer all questions truthfully. This information is being collected for research purposes only. Your information will be kept confidential and will not be shared in any way by the research team.

1. Gender:
____ Male
____ Female
____ Not listed (please specify): ____________________
____ Prefer not to respond

2. Age (years): ______________________________

3. Please indicate your marital status:
____ Single
____ Married/With a partner
____ Separated/Divorced
____ Widowed
____ Prefer not to respond

5. What is your highest education completed (high school, bachelor's, masters):
____

6. What are your degrees in:
Bachelor: ______________
Master: __________________
Doctorate: __________________
Professional degree: ______________________

7. Certification and Licensure Credentials
Please Specify ________________________________
____ None

8. What is your present occupation?

____ Private Not-For Profit (e.g., Corrections Programs, Disability Centers, College/University, Community Mental Health Centers, Community, Rehabilitation Program, Independent Living Programs, Non-Profit, Research Institutions).

____ Private For-Profit (e.g., Corporate Environment, For-Profit Research, Institutions, Forensic, Medical Center or Rehabilitation Hospital, Insurance, Company, Long Term Disability, Workers Compensation)

____ Retired

____ Other: Please Specify ______________________________

9. What is your current job title: ___________________________

10. How many years have you been working in this field: ______________________

11. What areas of expertise/services do you provide (e.g., mental health, vocational, educational, independent living, legal, social, medical, community integration, financial)

Please specify: ____

12. Do you collaborate with other agencies?

If yes, please specify: ____

13. What disability populations do you serve?

____

14. What target clients do you serve? (e.g., individual with ASD, families, advocates, guardians, legislators) ____

Others: Please specify: ____

15. What age range of clients do you serve?

____

16. What is the socio-economic status background of clients served by you?

____

APPENDIX D: INTERVIEW PROTOCOL

Interview Protocol

Introduction

The *Transitioning Together*® program (Smith, Greenberg, & Mailick, 2012) involves an eight weekly education and support group sessions for parents/caregivers as well as eight weekly social skill group sessions for teens to:

a) Provide education and support for parents;
b) Provide opportunities for social interaction and learning for adolescents; and
c) Emphasize positivity and problem solving

The *Transitioning Together*® program has two stages of intervention; 1) two individual family joining sessions, and 2) eight multifamily group sessions (Smith et al., 2012). The joining sessions allow the family to meet with the intervention staff before the group meetings to develop rapport and clarify family goals. In addition, the joining sessions also allow the staff to obtain a general idea about any major developmental milestones for both the child with autism and the family as a unit, as well as the resources that the caregiver has. Group sessions involve education on a variety of topics relevant to autism and guided practice with problem-solving for individual family problems. The parent group sessions cover transition planning topics including autism in adulthood, college planning, employment planning, family issues, legal issues, risk to adult independence, community integration and health and well-being. Presentations are given, and handouts are provided for families to take home in each session. Adolescent group sessions are available that involves a variety of games and activities to target skills such as engaging in conversation, recognizing social cues, and using problem solving strategies. An important part of the parent sessions is the problem-solving process.

The aim of the intervention is to provide education and support to the parents/caregivers of adolescents with autism with specific objectives:

- To reduce the stress for families
- To improve family coping strategies and problem-solving
- To support social engagement and self-direction of transition age individuals

I am planning on adapting this program for parents that is culturally appropriate in Ghana and would like to hear about your intervention ideas so that we can make the intervention more meaningful, applicable and doable. I will appreciate feedback in terms of the topics and the logistics, as well as anything else you think can improve this intervention.

This meeting should last about 90 mins, and you will be provided with a GHC 50.00 note at end of the meeting to thank you for your time today.

Guiding Questions

1) What are your thoughts on each of the 8 topics covered in this intervention? Do you think they are appropriate and useful? Why or why not?
    a. Autism in adulthood

   b. College planning
   c. Employment planning
   d. Family issues
   e. Legal issues
   f. Risk to adult’s independence
   g. Community integration
   h. Health and wellbeing

2) In looking at the Ghanaian setting, are there any other topics, you think can help improve this intervention?

3) What are your thoughts about the format of the intervention?
   a. Individual family joining sessions
      - Two individual meetings
        1. Each individual meeting lasts for 60 minutes
      - Appropriate days, times and location (e.g., school, community, home)
      - Establish short and long-term transition goals, assign task responsibilities, appropriate language
   b. Group sessions
      - Group of 8-10 families in a group session
      - Eight group sessions that provide specific information on the topics mentioned above (90 minutes each)
      - Order of topics
      - Appropriate days, times and location
      - Appropriate language
      - Appropriate people who should run these groups
   c. Adolescent group sessions
      - Is it important to have it? If yes, why. If no, why not?
      - Adolescent groups are meant to help them interact with each other. In addition to this, are there any other aspects, besides increase in social interaction, should be addressed?
      - Appropriate skill building activities
      - Appropriate days, times and location
      - Appropriate language
      - Appropriate people who should run these groups

4) In addition to using PowerPoints for presentations, are there other things (prompts: handouts, list of resources) you would like to obtain by attending this intervention?

5) Are there other inputs and aspects you think can help improve this intervention?

6) What are your thoughts of potential benefits of this intervention?
   a. For the family as unit
   b. For individuals with autism
   c. For practitioners

    d. For caregivers

7) What are your thoughts of potential challenges of this intervention?
    a. For the family as unit
    b. For individuals with autism
    c. For practitioners
    d. For caregivers

APPENDIX E: EVALUATION CHECKLIST

Transitioning Together® GH caregiver program pre-implementation Evaluation Checklist

Completed by …………………………… Date…………………………………………
Profession ……………………………… Number of years in Service …………………

Outcomes	
Caregiver Outcome	Comment
1. Do you think this program will lead to an increase in caregiver knowledge	Yes No
2. Do you think this program will enhance the beliefs and attitudes of caregivers	Yes No
3. Do you think that this program will support emotional wellbeing of the caregiver including stress reduction, hope, managing grief where applicable	Yes No
4. Do you think this program will increase caregiver skills that are practical and can be applied in the context of the home	Yes No
5. Do you think this program will lead to increased caregiver empowerment and positive advocacy	Yes No
Child Outcome	Comment
6. Do you think this program will lead to an improvement in the child's quality of life and well being	Yes No
7. Do you think this program will lead to changes autism related deficits (e.g. communication and social interactions)	Yes No
Family Outcome	Comment
8. Do you think this program will lead to improvement in family quality of life (including siblings)	Yes No
9. Do you think this program improves the family's access to getting and mobilization of support	Yes No
10. Do you think this program will reduce family isolation	Yes No
Community Outcome	Comment
11. Do you think this program will have a positive impact on the community (e.g. Awareness, knowledge, stigma)	

Overall Evaluation of outcomes

Processes and Procedures	
Accessibility	Comment
12. Do you think the language of the program manual is accessible to the target population	Yes No
13. Do you think the cost of organizing and accessing the program will be doable	Yes No
14. Do you think the program will require literacy which will impact its accessibility	Yes No
Acceptability	Comment
15. Do you think this program is culturally appropriate to the target population	Yes No
16. Do you think the program material will be acceptable to caregivers	Yes No
17. Do you think this program has a range of teaching modalities that will be beneficial for everyone (e.g. group discussion, experiential learning, feedback, videos)	Yes No
18. Do you think the time frame of the program will be acceptable for caregivers	Yes No
Psychological Process	Comment
19. Do you think this program informs and prepares caregivers of next steps and support after completion of the program	Yes No
20. Do you think the program structure actively facilitates caregiver to caregiver support	Yes No
Overall Evaluation of Processes and Procedure	

Implementation Landscape	
Sustainability	
21. Do you think this program will be sustainable in its intended context	Yes No
22. Do you think this program can be replicated in different centers across the nation	Yes No
Overall evaluation for Implementation Landscape	

Overall Evaluation of the program

APPENDIX F: PROGRAM MANUAL

Program Manual
1. Transitioning Together® GH Program Overview
2. Tips for Facilitators
3. Problem-Solving
4. Templates for Weekly Materials
5. Parent Group Sessions 1–4

PREFACE

Transitioning Together ® GH is an education and support program for families of adolescents with autism spectrum disorders (ASDs). This program was culturally adapted from the Transition Together ® (Smith, Greenberg, & Mailick, 2012) with permission. This manual is designed to guide the facilitation of the Transitioning Together ® GH parent group sessions. The Parent Group Facilitator Guide provides facilitators with a description of the structure and goals of group sessions, and a framework for providing families with education and support. This manual is designed for the sole use of trained Transitioning Together facilitators and their team members. Any other use or distribution of materials is not supported by the authors.

GOALS

Transitioning Together aims to provide education and support to parents of adolescents with autism. The specific objectives are:

1. To reduce distress for families of individuals with autism.
2. To improve family coping strategies and problem solving.
3. To support social engagement and self-direction of transition age adolescents with autism.

PARENT GROUP SESSIONS

The parent group meets for 4 weekly sessions. Each session involves education on a topic relevant to autism and the transition to adulthood as well as guided practice with problem solving for individual family challenges. Parent group sessions last approximately 2 hours. Sessions begin with 15 minutes of socializing followed by 45 minutes of education and 60 minutes of discussion and problem solving. For each problem-solving activity, the group chooses one problem a family is facing. The group works together to select strategies that the family can implement to address that problem. Families are invited to share updates on strategy implementation with the group during subsequent sessions. This process provides an opportunity to gain from the vast experiences of the multiple families present and to focus on addressing problems in a constructive, non-critical way.

The group will maintain a WhatsApp group through which parents and facilitators can communicate.

Session	Goals
Session 1: Transitioning with Autism	• Meet other families • Learn about developmental course of autism
Session 2: Growing Up	• Learn about employment services and strategies • Finding community activities and social • opportunities • Discuss safety concerns for adults with autism
Session 3: Behavior Management	• Learn strategies for behavior management • during adolescence and early adulthood
Session 4: Family Issues and Wellbeing	• Learn about impact of autism on family and • the environment on individuals with autism • Learn about risks to parental health and well-being • Learn coping skills and self-care strategies

TIPS FOR ORGANIZING GROUPS

OVERVIEW

During each session, program staff should act as educators, arbitrators, and family advocates. Despite the increasing prevalence of autism, considerable controversy exists regarding ways to assess, diagnose, and treat individuals with autism. Unclear etiology has lead scientists and parents to develop their own theories regarding the nature of autism and the mechanisms that improve and/or worsen symptoms in children. It's important that program staff understand these current issues in autism from multiple perspectives to best support families. Families receive conflicting messages from varying outlets (the media, social networking groups), and it is important that facilitators are aware of these messages and talk to parents openly about them. Above all, facilitators must be sensitive to the concerns of parents and show respect for parents' opinions, while also upholding their responsibility to provide families with valid recommendations.

It is important to send messages on WhatsApp group page in between group sessions to

1. Remind the families of topics shared and strategies discussed during the sessions
2. Problem solve difficulties families might be having at home
3. Share individualized resources/referrals as needed

Group facilitators should also contact participants individually where necessary.

This level of accessibility builds rapport and reinforces to participants that the facilitator is joining with them in working to achieve their family goals; past studies have found that participants rarely misuse this privilege (McFarlane, 2002).

GENERAL STRATEGIES FOR SKILLFUL FACILITATION

Model a positive, solution-focused approach at all times. The importance of maintaining positivity and looking for workable solutions cannot be emphasized enough.

The research is very clear: when parents can maintain positivity (and avoid criticism) in the face of challenging circumstances, it is better not only for their own health and well-being but also for their children. Children's autism symptoms improve when parents increase their positivity.

Model the problem-solving method and positive coping strategies whenever possible.

Note that the goal isn't "fake" positivity (the challenges for adolescents and young adults with autism are very real and should not be diminished or minimized). The goal is to look for strengths, to positively reframe situations, and to find workable solutions, even if they are small steps. Demonstrate positive regard for the parents and the unique challenges they face. Parents should know that you "see" them and that you care about them.

Indicate care for the parents as individuals and not just in relationship to their children. Encourage parents to share about their jobs, their hobbies, their own goals instead of limiting discussions to only the difficulties of their children (this also makes it easier to reduce negativity in the group). Remember that the family unit is the focus of the program.

E.g

“This group is focused on YOU and your child. You care for your child by taking care of yourself.” Maintain a strengths-based attitude and vision of adolescents and their parents. Remember that individuals on the spectrum have a lot to offer and give back to the community.

Note that thinking creatively about how to apply a teen’s strengths can lead to very satisfying solutions (e.g., research is growing in support of microenterprises for adults on the spectrum; some companies are now specifically targeting hiring individuals with autism).

Parents of children with autism have accomplished GREAT things for their children, advocating for major changes in policies and laws (e.g., parental advocacy led to the funding of the study that showed that 1 in 68 children have autism). “OK. It sounds like there are a lot of layers to this problem. We can’t discuss all those points, but we can take a small chunk and discuss it during our problem solving. Just looking around the room, it seems like others can relate and I bet we can come up with some good ideas.” “From talking with each of you, I know how hard you have been working on building skills and strengths with your children. We are going to talk about how to make the process.

SAMPLE PARENT AGENDA

Session ___

Session Title ______________________

Agenda

1. Welcome and Announcements
2. Update from Families
3. New Topic: ____________________

(Title of new topic)

4. Problem Solving
5. Questions and Closing
6. Survey

CAREGIVER GROUP SURVEY

Session ……………………………. Date…………………………….

Please answer the following questions

1. How satisfied are you with the session today

1	2	3	4	5
Very dissatisfied	Dissatisfied	Neutral	Satisfied	Very Satisfied

2. Overall how useful was this session

1	2	3	4	5
Very dissatisfied	Dissatisfied	Neutral	Satisfied	Very Satisfied

3. Overall how satisfied are you with the program so far

1	2	3	4	5
Very dissatisfied	Dissatisfied	Neutral	Satisfied	Very Satisfied

4. Any additional thoughts and concerns?

MEETING SCHEDULE

Date ______________ Transitioning with autism
Date ______________ Growing up
Date ______________ Behavior Management
Date ______________ Family Issues and Wellbeing
All sessions will take place from ______ to ______ at _____.
Please contact us at any time:
Name
Phone
Email

SESSION 1: TRANSITIONING WITH AUTISM

GOALS Welcome members Introduce facilitators and group members; Learn about the developmental course of autism

WELCOME: Welcome all group members. While waiting for all members to arrive, take time for casual chit chat. Begin the group with a time of introductions.

Snacks: Have snacks available for group participants. Depending upon the configuration of the room, snacks could be available on a table nearby or in the center of the table where all group members gather. Alternatively, a meal could be provided.

Agenda for session: Review the agenda (provide a copy of the agenda on the WhatsApp group page). Review what you will do during the session and answer any questions group members may have.

Session PowerPoints: See PDF

INTRODUCE PROBLEM SOLVING

"Given that everyone here has diverse backgrounds and experiences, problem solving in a group can help discover new ideas and solutions. This model for problem solving is based on a business model and has been adapted and found to be successful in groups like this with parents of children with ADHD, conduct disorder, and schizophrenia. Going through the problem-solving steps helps to provide proactive suggestions instead of venting frustrations. When we go through this process, all suggestions are equally valid and valuable, and ideas do not have to be earth-shattering. It's also important to remember that suggestions will not necessarily be the final solution or answer to a complex problem. The goal is to break down a large problem into smaller parts and generate multiple, diverse ideas that could be a next step towards a workable solution."

Step 1: Define Problem

- The clearer the definition, the more useful will be the solutions.
- The more focused planning steps, the more successful the outcome.

Step 2: List All Possible Solutions

- Get ideas of how the problem might be solved or how the goal might be achieved.
- The more possible solutions, the more likely there will be one that addresses the problem or goal well.
- Families come up with the most creative solutions and the ones most likely to work

Step 3: Consider Pros and Cons

- Think about each solution.
- What are the main advantages?
- Where are the disadvantages?
- All suggestions will be discussed in turn—best solutions often come up last!

Step 4: Choose the Best Solution

- Each family can decide which solution (or combination) fits them best. Practice problem solving as a group.

Typically for a problem-solving session, families participate in a “check-in” or “go-around” time to share what has been happening in the past week. Each family gets a turn to briefly share an update. Encourage families to share both positive and negative things. The check-in time provides the facilitators with insights for which problem could be used for the problem-solving session. This week, given that the process is new, and time is limited, the facilitator may want to use a preselected topic that is known to be an issue for multiple families. Be sure to check with families that the topic is agreeable for problem solving before beginning. Remember that it is important to select a more straightforward problem for this initial problem-solving practice. Also, especially for this first week of problem solving the facilitators will need to be particularly mindful of time management.

SURVEYS

Before the session is over, ask participants to complete the Satisfaction for the session. Have group members put the completed surveys, without names, in an envelope.

Let group members know that they will receive this survey after each group and that the confidential feedback helps make the program better for everyone.

END OF SESSION

Say “goodbye” to all group members and remind them of what you will do next week and when you will meet next. Thank them for their active participation.

SESSION 2: GROWING UP

GOALS Learn about employment services and strategies; Finding community activities and social opportunities; Discuss safety concerns for adults with autism.

WELCOME: Welcome all group members. While waiting for all members to arrive, take time for casual chit chat. Begin the group with a time of introductions.

Snacks: Have snacks available for group participants. Depending upon the configuration of the room, snacks could be available on a table nearby or in the center of the table where all group members gather. Alternatively, a meal could be provided

Agenda for session: Review the agenda (provide a copy of the agenda on the WhatsApp group page). Review what you will do during the session and answer any questions group members may have.

Announcements and follow-up: Share announcements about current events. Pass out any resources as a follow-up to past discussions or questions, including problem solving-summaries.

Session PowerPoints: See PDF

PROBLEM SOLVING

Practice problem solving as a group. Review the problem-solving steps and guidelines presented. Complete the problem-solving steps with the selected problem.

A reminder for facilitators: during social time you should ignore, reframe, or deflect criticisms/negativity. Problems are to be discussed in go-around time.

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END OF SESSION

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SESSION 3: BEHAVIOR MANAGEMENT

GOALS: Learn strategies for behavior management during adolescence and early adulthood

WELCOME: Welcome all group members. While waiting for all members to arrive, take time for casual chit chat. Begin the group with a time of introductions.

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Agenda for session: Review the agenda (provide a copy of the agenda on the WhatsApp group page). Review what you will do during the session and answer any questions group members may have.

Announcements and follow-up: Share announcements about current events. Pass out any resources as a follow-up to past discussions or questions, including problem solving-summaries

Session PowerPoints: See PDF

PROBLEM SOLVING

Practice problem solving as a group. Review the problem-solving steps and guidelines presented. Complete the problem-solving steps with the selected problem.

Alternative Activities

Alternative Activity: An alternative activity that can work very well during this week (instead of problem solving a specific family concern) is to create a list of areas that might be risks to independence for their specific children followed by a list of ways to address those risks.

A reminder for facilitators: during social time you should ignore, reframe, or deflect criticisms/negativity. Problems are to be discussed in go-around time.

SURVEYS

Before the session is over, ask participants to complete the Satisfaction for the session. Have group members put the completed surveys, without names, in an envelope.

Let group members know that they will receive this survey after each group and that the confidential feedback helps make the program better for everyone.

END OF SESSION

Say “goodbye” to all group members and remind them of what you will do next week and when you will meet next. Thank them for their active participation.

SESSION 4: FAMILY HEALTH AND WELLBEING

GOALS: Learn about the impact of autism on the family and the environment on individuals with autism.

WELCOME: Welcome all group members. While waiting for all members to arrive, take time for casual chit chat. Begin the group with a time of introductions.

Snacks: Have snacks available for group participants. Depending upon the configuration of the room, snacks could be available on a table nearby or in the center of the table where all group members gather. Alternatively, a meal could be provided

Agenda for session: Review the agenda (provide a copy of the agenda on the WhatsApp group page). Review what you will do during the session and answer any questions group members may have.

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Session PowerPoints: See PDF

PROBLEM SOLVING

Practice problem solving as a group. Review the problem-solving steps and guidelines presented. Complete the problem-solving steps with the selected problem.

A reminder for facilitators: during social time you should ignore, reframe, or deflect criticisms/negativity. Problems are to be discussed in go-around time.

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END OF SESSION

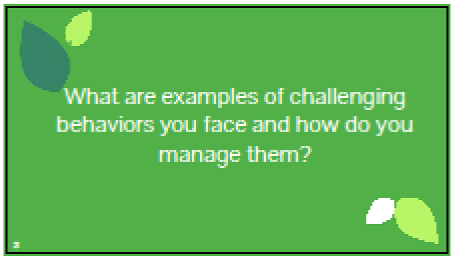
Say “goodbye” to all group members and remind them of what you will do next week and when you will meet next. Thank them for their active participation.

APPENDIX G: SAMPLE OF PROGRAM MODULES

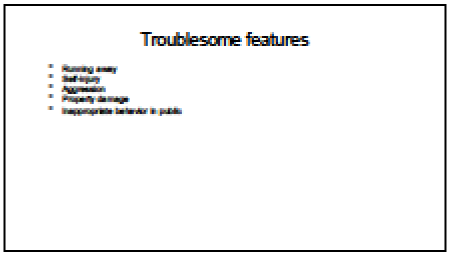
Behavior Management

Agenda

1. Challenging Behaviors
2. Strategies to manage challenging behaviors
3. Problem solving

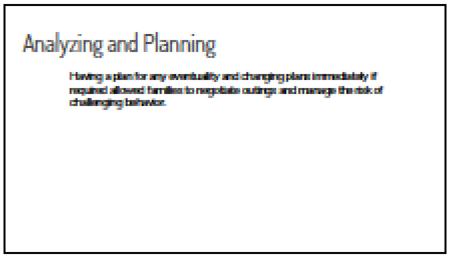


What are examples of challenging behaviors you face and how do you manage them?



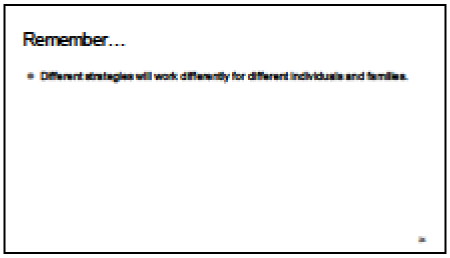
Troublesome features

- Running away
- Self-injury
- Aggression
- Property damage
- Inappropriate behavior in public



Analyzing and Planning

Having a plan for any eventuality and changing plans immediately if required allowed families to negotiate outings and manage the risk of challenging behavior.



Remember…

- Different strategies will work differently for different individuals and families.

Transitioning with Autism

Agenda

1. Working Towards Transition
2. Positive Trends
3. Introduction to Problem Solving

What is Autism?

What are the key area of difficulties with autism?
What are the differences between toddlers and adolescents?
Does autism in adolescence require more attention in relation to toddlers?

Let's review some concepts

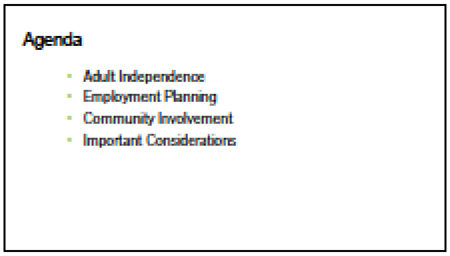
- Education
- Employment
- Communication
- Transportation
- Residential
- Travel
- Relationships
- Community perception
- Supports

Introduction to Problem Solving

Next Week

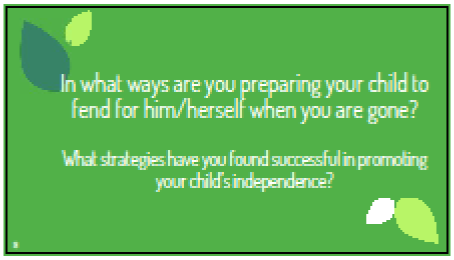
1. Adult Independence
2. Employment Planning
3. Community Involvement
4. Important Considerations

Growing Up



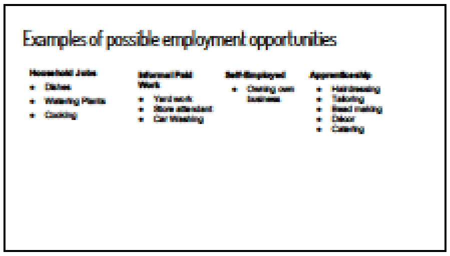
Agenda

- Adult Independence
- Employment Planning
- Community Involvement
- Important Considerations



In what ways are you preparing your child to fend for him/herself when you are gone?

What strategies have you found successful in promoting your child's independence?



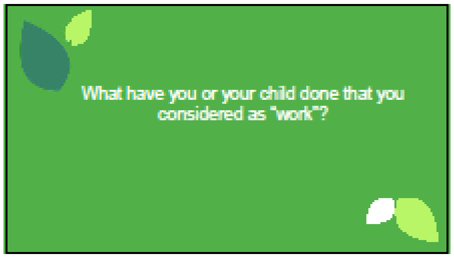
Examples of possible employment opportunities

Household Jobs
- Dishes
- Watering Plants
- Cooking

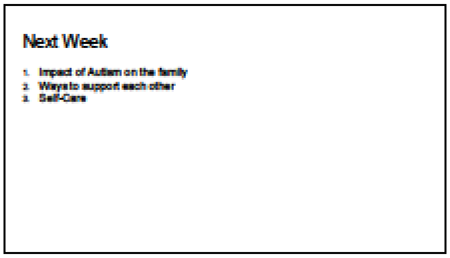
Informal Paid Work
- Yard work
- Store attendant
- Car Washing

Self-Employed
- Owning own business

Apprenticeship
- Hairdressing
- Tailoring
- Bead making
- Décor
- Catering



What have you or your child done that you considered as "work"?



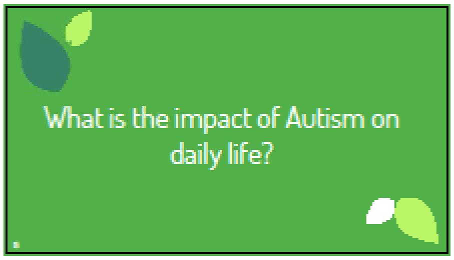
Next Week

1. Impact of Autism on the family
2. Ways to support each other
3. Self-Care

Autism and the family

Agenda

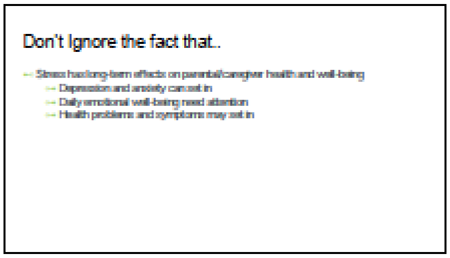
1. Impact of Autism on family/ Debunking Myths
2. Ways of supporting each other
3. Self-Care/Coping strategies



What is the impact of Autism on daily life?

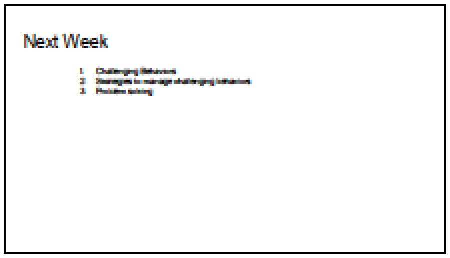
Myth

- All Marriages End in Divorce
  - Although the risk of divorce is higher for couples with a child on the spectrum, most stay together.



Don't Ignore the fact that..

- Stress has long-term effects on parental/caregiver health and well-being
  - Depression and anxiety can set in
  - Daily emotional well-being need attention
  - Health problems and symptoms may set in



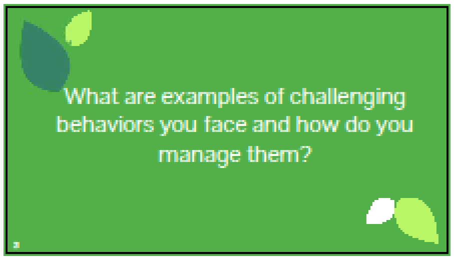
Next Week

1. Challenging Behaviors
2. Strategies to manage challenging behaviors
3. Problem solving

Behavior Management

Agenda

1. Challenging Behaviors
2. Strategies to manage challenging behaviors
3. Problem solving



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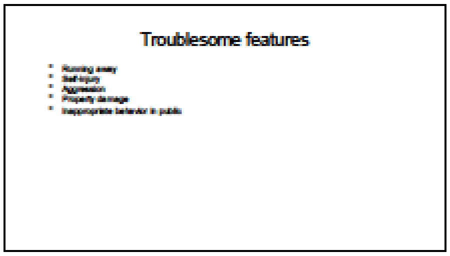
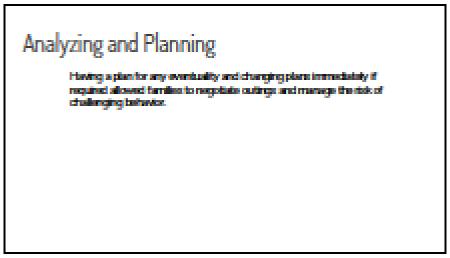


Troublesome features

- Running away
- Self-injury
- Aggression
- Property damage
- Inappropriate behavior in public



Analyzing and Planning

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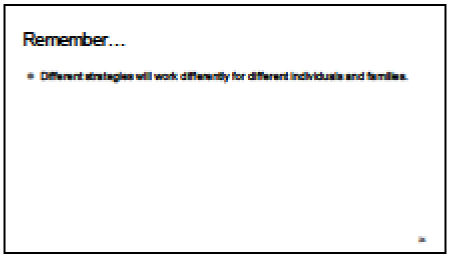

Remember…

- Different strategies will work differently for different individuals and families.

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