ADAPTATION AMONG FAMILIES OF ADOLESCENTS WITH DEVELOPMENTAL DISABILITIES UTILIZING AUGMENTATIVE AND ALTERNATIVE COMMUNICATION TECHNOLOGIES

By

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ABSTRACT

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Family involvement and support is critical for adolescents with developmental disabilities (DD) who often have complex communication needs, such as autism and/or Down syndrome. Adolescents with DD benefit from augmentative and alternative communication (AAC) technology to support communication. Although family involvement is vital to successful AAC utilization, limited research has examined family factors associated with adaptation. The purpose of this dissertation was to examine factors associated with family adaptation to AAC among families of adolescents with autism and/or DS. Dissertation aims: (1) evaluate the state of the science on family adaptation among children/adolescents with DD utilizing an AAC device for communication; (2) examine associations between parental/adolescent characteristics and family functioning based on the frequency of AAC device use by the adolescent; and (3) qualitatively explore parent-reported contributing factors of family adaptation among adolescents' using AAC. This dissertation used a three-manuscript format. Manuscript one is an integrative review to assess the state of the science on family adaptation of children with DD utilizing AAC devices for communication. Five online databases were searched, and 33 articles met eligibility. Findings demonstrated that to enhance the science underpinning family adaptation to AAC use, future research should be grounded conceptually and address important components of the Resiliency Model. Manuscripts two and three report data from a cross-sectional mixed-methods study. Families (n=227) of adolescents aged 13–18 years diagnosed with autism and/or DS participated.

A family was defined as at least one parent and an adolescent with a DD. Manuscript two examines quantitative findings. Associations between reported parental/adolescent characteristics and family functioning across three distinct groups of families based on frequency (high, mid, low) of their adolescents' AAC device use were evaluated. Descriptive, correlations, and multiple linear regression analyses revealed parental/adolescent characteristics associated with family adaptation were: parental employment and education, younger parents, better adolescent communication function, and type of AAC device. However, after controlling for relevant covariates, adolescent communication function emerged as the only significant predictor of family adaptation. The unadjusted mean family adaptation score for the high-usage group was significantly higher than both the low and mid-usage groups. Findings provide insights into identification of at-risk families and the need for family interventions. Manuscript three examines qualitative data from semi-structured interviews conducted with a sub-sample of eight parents to explore parent-reported factors contributing to family adaptation among adolescents using AAC. Recorded interviews were transcribed, and two independent reviewers coded the data. Five major themes emerged: *Contextual Strains and Influences, Continuum of Person-First Approach, Opening Doors, Facilitators of Support,* and *Planning is Key*. Findings revealed not only the challenges parents face in supporting an adolescent with a DD using an AAC device but also attributes, resources, perceptions, and strategies that either contributed or hindered family adaptation. In summary, this mixed methods dissertation guided by an established family nursing framework contributed to the state of the science by examining important but often neglected concepts relative to how families adapt to adolescent AAC use. Findings will contribute to the development of tailored interventions to assist families of adolescents with DD adapt to new communication technologies.

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KEY TO ABBREVIATIONS

AAC	Augmentative and Alternative Communication
ASD	Autism Spectrum Disorder
DD	Developmental Disabilities
CFCS	Communication Function Classification System
CCN	Complex Communication Needs
CP	Cerebral Palsy
DS	Down Syndrome
FIATS	Family Impact of Assistive Technology Scale
ID	Intellectual Disability
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analysis
SLP	Speech-Language Pathologist

CHAPTER ONE: INTRODUCTION

Families' experience ongoing challenges when there is an adolescent member with developmental disabilities (DD), such as autism spectrum disorder (ASD) and/or Down syndrome (DS). Adolescents with DD may have difficulties with speech, language, and hearing, resulting in communication and social-emotional deficits. Augmentative and alternative communication (AAC) technology systems can help overcome complex communication needs (CCN) by enhancing capacities for communication exchange and socialization. Family adaptation, which is an ongoing dynamic process, requires adjustment to the demands of raising an adolescent with CCN, especially when AAC is involved.

The National Institutes of Child Health and Human Development (NICHD) and the National Institutes of Deafness and Other Communication Disorders (NIDCD) emphasize the important role of technology in improving health outcomes for adolescents with lifelong communication needs (2021). Technology in the form of AAC devices supports everyday communicative interactions. However, an adolescent's successful integration of technology into daily life is dependent on familial engagement in the process (McNaughton et al., 2008). Despite recognized benefits to using AAC, families-especially parents- experience challenges when supporting the adolescent in the use of this technology (Angelo, 2000; Bailey et al., 2006; Brady et al., 2006; Marshall & Goldbart, 2008). Recent advances in technology, such as apps, mobile i-devices, and numerous social media platforms, have increased the complexity involved with integrating AAC devices (Light et al. 2019; McNaughton & Light, 2013; Meder & Wegner, 2015). However, little is known about the familial experience as families adapt to challenges associated with adjusting to what is required to help their adolescent be successful with the advancing AAC technology. The purpose of this study was to examine factors associated with family adaptation to AAC among families of adolescents with autism and/or Down syndrome.

Dissertation Aims:

1. Evaluate the state of the science on family adaptation among children and adolescents with DD utilizing an AAC device for communication.

   The research questions for this aim:

   - What is the state of the science regarding family adaptation when there is a child in the family with DD who utilizes AAC devices to support communication?
   - How common is the use of a family conceptual model to guide a review of the literature on family adaptation to AAC technology?

2. Examine the associations between parental characteristics, adolescent characteristics, and family functioning based on the frequency of use of their adolescents' current AAC device.

   The research questions for this aim:

   - What is the relationship between parental characteristics (age, sex, education, marital status, SES, geographical area) and family functioning (total FIATS-AAC score for adaptation) for three distinct groups (families) by frequency of AAC device use by the adolescent (i.e., low usage, mid-usage, high-usage groups)?
   - What is the relationship between adolescent characteristics (disability diagnosis, age, sex, race, communicative function, current device category) and family functioning (total FIATS-AAC score for adaptation) for three

distinct groups of (families) by frequency of AAC device use by the adolescent (i.e., low usage, mid-usage, high-usage groups)?

  - What are the differences in family functioning (total FIATS-AAC score for adaptation) for three distinct groups (families) based on frequency of AAC device use by the adolescent (i.e., low usage, mid-usage, high-usage groups)?

3. Through interviews, qualitatively explore parent-reported contributing factors of family adaptation among adolescents' AAC use employing the Resiliency Model during the critical developmental stage of adolescence.

   The research questions for this aim:

   - What are parents' perceptions of demands, type, appraisal, resources, and problem-solving/coping associated with family adaptation when an AAC device is used by an adolescent with DD in the family?

This dissertation used the three-manuscript format. Specific research questions are introduced with each manuscript in Chapters 2-4.

Background and Significance

Recent estimates in the United States reveal that one in six children aged 3 to 17 years (about 15%) have one or more DD (Center for Disease Control [CDC], 2019). A developmental disability refers to a childhood mental or physical impairment or combination of impairments that result in substantial functional limitations in major life activities (Accardo et al., 2003). Developmental disabilities may include ASD, DS, intellectual disability, learning disorders, vision impairment, and speech/language delays (CDC, 2019). Data from the CDC identified a 17% (1997–2008) increase in parent reports of children with DD, secondary to improved screening, diagnostics, and enhanced survival of preterm infants (CDC, 2019). The most common developmental disabilities are associated with language impairments and individuals with ASD and DS commonly receive speech and language services (Martin et al., 2018). Thus, the proposed dissertation research study will focus on two DD groups, autism, and Down syndrome.

Developmental disabilities, such as autism are growing in the United States, and lifelong costs for an individual with DD can exceed $3.2 million (Gantz, 2007). Estimates indicate that in the next decade 50,000 teenagers with autism will enter adulthood (Roux et al., 2013). Down syndrome is the most common abnormal chromosomal condition diagnosed in the United States (CDC, 2018), that carries a spectrum of unique lifelong concerns for health, development, and education for affected individuals. Autism and/or Down syndrome affects all ethnic and socioeconomic groups and many of these individuals are likely to have limited speech intelligibility (de Graaf et al., 2015; Durkin et al., 2010). About one million children in the United States have CCN, in which a child is unable to use speech for everyday communication (Binger & Light, 2006; Moorcroft et al., 2019a). The disability may be due to physical, psychological, and/or cognitive impairments. With the growing number of adolescents with DD moving into adulthood, impairments in speech and/or communication are a critical area of development that can be challenging individuals with DD (Holyfield et al., 2017). Subsequently, communication impairments are the most frequently reported reason for needing early childhood and adolescent interventions (Hebbeler et al., 2007). When communication functioning is compromised, adolescents face barriers to successful participation in school, workplace, community, and home; limiting many aspects of independence in their emotional, educational, social and vocational life (Allen & Babin, 2013; Lewis et al., 2004; Moriatry & Gillon, 2006). The implementation of AAC technology devices allows communication access for adolescent children with DD to express thoughts, ideas, and feelings to support social participation and interactions (Holyfield et al., 2017).

Dissertation Aim 1 (DA1)

- *Evaluate the state of the science on family adaptation among children and adolescents with DD utilizing an AAC device for communication.*

Research primarily identifies parent/caregiver challenges, demands, and stressors associated with AAC device use in children, but successful family adaptation to technology integration outcomes has not been explored. Additionally, a range of DD, ages, and genetic conditions have been examined, but findings have been mixed and more studies are needed. Much of the current research has focused on young children, with less research focused on adolescents. Emerging evidence suggests that family adaptation outcomes grounded in a theoretical framework to understand key concepts may lead to better understanding of the multifactorial phenomenon. There are key concepts associated with the state of the science on family adaptation. Each will be addressed and related to the state of the science. Further, Chapter 2 (manuscript 1) provides a review of the literature on this topic.

Family adaptation. Seligman and Darling (2007) demonstrated the importance of family adaptation to optimize management of a child’s disability. While some families experience poor adaptation, such as the development of depression, altered self-concept, marital problems, and social isolation in their members, other families identify the process more positively and experience personal growth, psychological well-being, and family quality of life (Schlebusch et al., 2017; Van Riper, 2007). Family members of children with DD are at higher risk for mental health problems than families with non-developmentally disabled children, secondary to sustained challenges in their adaptation to the child’s chronic conditions and related impairments

(Accardo et al., 2003; Wilson & Peterson, 2017). Such families face greater caregiving demands than those of children without DD (King et al., 2002). Often children with DD interact with a wide range of service providers to manage care needs. Such demands increase perceived stress and subsequent emotional distress often contributing to parental mental health issues (King et al., 2002). It is documented that highly stressed family members, are less able to provide adequate support and care for their children with DD, a situation associated with poor outcomes for both the child and parent such as increased utilization of services, economic costs and diminished quality of life (Dykens et al., 2014; Lindo et al., 2016).

Families, the most significant partners for adolescents who use AAC, can positively or negatively influence utilization outcomes, but their support role is often underestimated (Baxter et al., 2012; Saito & Turnbull, 2007; Parette & Angelo, 1996). AAC interventions that are focused solely on the adolescent may contribute to family stress, non-compliance, and device abandonment, thus increasing potential for poor developmental outcomes, and/or reduced family quality of life (Baxter et al., 2012; Meder & Wegner, 2015; Parette & Angelo, 1996; Rackensperger, 2012; Saito & Turnbull, 2007). In cases of AAC abandonment, resources, including device costs, time invested in training, and non-anticipated transportation expenses for families and professionals, are wasted (Baxter et al., 2012; Parette & Angelo, 1996; Van Niekerk et al., 2017).

Parents and caregivers acknowledged multiple fluctuating roles including caregiver, teacher, playmate, therapist, technical support, and advocate (Brady et al., 2006; McNaughton, et al., 2008). Across studies, parents perceived competing demands, resources, and services as increasing stress for the family and possibly diminishing the overall effectiveness of the intervention (Clarke et al., 2011; Jones, et al., 1998). Despite the above-mentioned issues, little research has examined factors influencing family adaptation to AAC. Additionally, research that focuses on the effects of technology on family adaptation has often lacked theoretical grounding in an established family theory.

Adolescents with developmental disability. Children with physical disabilities, communication difficulties, and/or developmental delays have shifting health, social, educational, and community needs as they become adolescents (King et al., 2002). Adolescence is a complicated developmental period when major physical (hormonal), cognitive, social, linguistic, and emotional changes occur (Smith, 2015). The changes that occur in adolescence across multiple domains place heavy impact on communication needs and skills particularly for individuals with DD (Holyfield et al., 2017; Smith, 2015). Adolescents with DD face new complex challenges that are uniquely different from experiences of younger children.

Physically, with the rapid growth of the skeletal structure in adolescence, general motor abilities are altered and may lead to changes in speech intelligibility while adolescents are simultaneously experiencing increasing educational demands (Smith, 2015). Classroom expectations in middle and high school are more intense compared to pre-school and elementary classes since adolescents begin to prepare for post-secondary learning and employment opportunities (Holyfield et al., 2017). In adolescence, the rate, quantity, and pace of communication exchange, as well as group interactions, increases within various settings (Smith, 2017). Additionally, social communication that occurs in intimate relationships and for peer acceptance assumes a higher level of importance for adolescents than earlier childhood (Holyfield et al., 2017; Smith, 2015). Societal attitudes and familiarity with AAC influence peers' attitudes about adolescents that use AAC, ultimately impacting social inclusiveness and presenting possible barriers for adolescent engagement (Beck et al., 2010). Emotionally, adolescence is a vulnerable time period for development of self-esteem, assertiveness, and autonomy (Hockenberry et al., 2019). A chronic condition, such as CCN, adds a risk factor for poor adolescent psychological health (Wisk & Weitzman, 2017). To meet developmental milestones, adolescents with DD who use AAC require increased opportunities for social interactions to prepare them for employment and independent participation in community activities (Holyfield et al., 2017; Sievers et al., 2018). Studies have demonstrated successful AAC device use positively influences interactions with peers, family members, educators, and other service professionals across educational, social, vocational, and civic contexts (Holyfield et al. 2017; Kent-Walsh et al., 2015). During adolescence, families of children with DD are adjusting to developmental transitions, and AAC technology changes may support but also challenge this process.

Use of AAC device. Communication is the exchange of information between people in which the responsibility for the interpersonal process is shared between communication partners (Hidecker et al., 2011). People express thoughts, ideas, needs, and feelings through speech and language. Functional communication skills are required to initiate and maintain daily interactions within the natural environment (Light, 1989). The functionality of communication skills largely depends on the demands of environment, in addition to the individual's personal and communication partner characteristics (Hidecker et al., 2011; Light, 1989). As individuals develop and change over time in relation to the demands and support in their environments, modifications in their functional communication skills must occur likewise (Light, 1989).

Adolescent children with DD who have CCN can have a wide range of communication disorders and functional communication abilities (Light & McNaughton, 2014). Communication disorders are described from several perspectives including descriptions of the affected anatomical structure and function, engagement in activities, social participation, physical environments, and personal levels (Hidecker et al., 2011). While discussion of communication disorders has traditionally been on the anatomical body and structure, in which the components of how a child produces speech sounds and uses grammar are assessed and treated (Hidecker et al., 2011), a shift has occurred recently to focus on children's ability to communicate in activities and their participation level in real-life situations (Hidecker et al., 2011). Validated assessment tools, such as the Communication Function Classification System (CFCS), can be applied to determine communication function within a range of speech/language disorders among children of varying ages, including adolescence (Hidecker et al., 2017). The CFCS allows for stratification of communication ability in children with DD based on functional ability. The utilization of this validated tool in this dissertation permits an understanding of the communication skills of adolescents with autism and/or DS from a parental perspective within daily-living communicative exchanges between family members and other communication partners.

Augmentative and alternative communication. Individuals with DD who have CCN benefit from the utilization of AAC systems to enhance communication (American Speech Language Hearing Association [ASHA], 2019). Augmentative and alternative communication includes picture symbols, computers/iPads with communication apps, and speech generating devices (SGD) to support communication exchanges. Typically, AAC is differentiated into two broad groups: unaided and aided AAC (ASHA, 2019). Unaided AAC consists of natural communication modes, such as gestures, facial expressions, and sign language. Aided AAC, on the other hand, includes the use of an external tool, and is further broken down into three categories: low-technology (i.e., AAC with no battery or computer component), mid-technology (i.e., AAC with battery component only), and high-technology AAC (i.e., AAC with computer component) (Baxter et al., 2012; Holyfield, 2017; Moorcroft et al., 2019a).

The AAC field has seen changing trends in the demographics of the population utilizing AAC, a shift in the scope of communication needs, and a proliferation in mobile technology and communication software apps (Light et al., 2019; Light & McNaughton, 2012; McNaughton & Light, 2013). Such trends have impacted healthcare and nursing practice, especially because nurses work in a variety of settings, and care for a broad spectrum of individuals with DD utilizing diverse AAC technology (Finke et al., 2008; Hemsley et al., 2011; Wilson & Peterson, 2017). Such shifts also reflect the increasing incidence of autism, the longer average life span for individuals with DS (National Down Syndrome Society [NDSS], 2019), the heightened focus on early intervention, increased societal acceptance and awareness of DD (McNaughton & Light, 2013), and improved survival rates for children born with DD in general (CDC, 2019; Light et al., 2019). Additionally, given advancing technology, accessibility of AAC has become widely available with mobile technologies, expanded communication interactions (e.g., face-to-face, written) and media platforms (e.g., Facebook, Twitter, etc.; Light et al., 2019; McNaughton & Light, 2013). Such trends pose challenges surrounding the effective translation of evidence-based AAC intervention into the daily lives of families of children with CCN (Light et al., 2019; Moorcroft et al., 2019b). For example, Johnson et al., 2006 reported that only 39.35% of AAC systems introduced by speech-language pathologists (SLPs) across pediatric and adult settings, were utilized by individuals for more than a year prior to abandonment. Researchers indicate that interventions involving AAC should extend beyond the child who has CCN to address the needs and skills of family members other communication partners, such as teachers, school team, peers, healthcare professionals, and employers (Andzik, et al., 2018; Henderson et al., 2008; Kent-Walsh et al., 2015; Moorcroft et al., 2019a; Moorcroft et al., 2019b).

This dissertation aim focused on updating the state of the science by assessing the conceptual theories utilized in quantitative and qualitative research on family adaptation when the family includes an adolescent with DD who utilizes AAC devices to support communication. Additionally, this aim addressed the viability of utilizing a family conceptual model for guiding the review of literature on family adaptation to AAC technology. Therefore, based on the current literature, an understanding of the theory that guides AAC research and the applicability of theoretical frameworks utilized in this research is needed. This dissertation aim filled a scientific gap by identifying an appropriate theoretical model and potentially important key concepts applicable to the population of interest.

Dissertation Aim 2 (DA2)

- *Examine associations between parental characteristics, adolescent characteristics, and family functioning based on the frequency of use of their adolescents' current AAC device.*

Based on the review of the literature for DA1, a specific lack of knowledge concerning the effect of AAC technology on family adaptation was evident. Additionally, the range of children's DD, ages, developmental stages, communicative function, AAC device use, and parental/caregiver participant characteristics across studies exposes the complexity of symptoms and challenges making comparisons about family adaptation across groups of families difficult. Subsequently, a lack of the utilization of measurement instruments with reported psychometric properties to empirically assess the dimensions of adolescent and family functioning influenced by AAC technology use was limited in the literature.

Parental characteristics. In previous research, diversity is lacking among family samples in terms of age, sex, socioeconomic status, marital status, family size, and education level (Allaire et al., 1991; Anderson et al., 2015; Anderson et al., 2014; Batorowicz et al., 2014; Blosser 1994; Borg et al., 2015; Bourke-Taylor et al., 2013; Goldbart & Marshall, 2004; McNaughton et al., 2008; Meder & Wegner, 2015; Mei et al., 2015; Serpentine, et al., 2011; Singh et al., 2017; Thunberg et al., 2016). Research has shown that culture, language, socioeconomic status, and technology literacy of families may impact AAC use (Moorcroft et al., 2019a). Additionally, research has revealed that household size and income influences language development (Donohue et al., 2015; Schlebusch et al., 2017). Another study revealed that perceptions of mothers and fathers regarding AAC interests, needs, and resources vary; therefore, recording and understanding respondent information is an important next step in research to understand family functioning (Jones et al., 1998). Most studies looked at basic parental characteristics to assess the needs, priorities, and preferences of families of adolescents, but studies did not examine the characteristics in correlation with an outcome variable (Schlebusch et al., 2017; West et al., 2020). Thus, variation in parental personal factors, such as age, sex, race, education, income, language, parental technology literacy, and access to AAC services needs to be further examined to better understand their potential personal factors influencing family outcomes (Andzik et al., 2018; Delarosa, et al., 2012; Kron et al., 2018; Light et al., 2019; Ryan et al., 2018).

Adolescent characteristics. Unfortunately, there is a lack of knowledge concerning the intricacy of an adolescent's communication function and DD challenges influencing family functioning. Each adolescent with DD has different individual needs that requires support specific to AAC usage (Meder & Wegner, 2015). Research has identified that the severity of the

DD is much more than the diagnosis; the health and functional impacts on adolescents appear to have a more notable impact on family functioning (Lollar et al., 2012; Schieve et al., 2011; Skelton et al., 2021). Previous research identifies a wide variety of study populations within and across studies containing a range of ages of children, diverse DD, communicative functions, and assistive devices utilized (West et al., 2020). This variability in research makes comparability between studies inconclusive. Furthermore, much of the current research has focused on families of younger children and not adolescent families (Light & McNaughton, 2012). Studies that have focused on adolescents have captured some adolescent characteristics, but studies have not examined the characteristics in correlation with an outcome variable (Skelton et al., 2021; West et al., 2020). Overall, it seems that capturing the complex characteristics of adolescents with communication disabilities presents challenges for research.

Family functioning. Family functioning, which is also referred to as family adaptation, is the outcome of a family's response and efforts to bring a new level of balance to the demands of a stressful situation (McCubbin et al., 1996; Van Riper, 2007). Families are integral to the assessment, implementation, and integration of AAC. By enhancing communication, AAC promotes an adolescent's independence, facilitates social relationships, improves educational opportunities, and enhances positive health outcomes (Hebbeler et al., 2007; Rackensperger, 2012). When successfully utilized, parents of adolescents across a wide range of DD have reported positive gains for adolescents with AAC including improved communication, quality of life, independence, and enhanced future opportunities in adulthood (Angelo, 2000; Angelo et al., 1996; Bailey et al., 2006; Batorowicz et al., 2014; Light & McNaughton, 2012; Millar et al., 2006; Rackensperger, 2012; Van Niekert et al., 2017). Additionally, research indicates that AAC interventions contribute to decreasing challenging behavioral problems, while also increasing compliance and on-task behaviors for adolescents with DD (Bopp et al., 2004). Hence, adolescent use of AAC has many benefits, but its successful integration requires a robust commitment and continuous support from families (Delarosa et al., 2012; Ryan et al., 2018). Previous studies have identified a lack of consistency in usage of instruments with satisfactory psychometric properties to measure child and family functioning in domains that may be influenced by AAC use (Kron et al., 2018). Thus, the effects of AAC interventions on family outcomes maybe underreported with both poor quality and limited empirical evidence regarding the perspectives of families and associated factors related to their functioning (Delarosa et al., 2012).

Adolescent frequency of use of AAC device. The frequency of AAC technology use, as well as well as the type of AAC technology device (e.g., low, mid-level, or high tech) implemented for an adolescent with DD, has an impact on the primary caregivers (e.g., parents; Ryan et al., 2018). The unexpected social isolation, public attitudes about the child's communication disability, efforts to seek peer socialization activities, and opportunities to integrate the device into the community/society creates additional strain for parents (Batorowicz et al., 2014; McNaughton et al., 2008). Additionally, technology portability and AAC device limitation issues create perceptions of increased parent/caregiver strain (McNaughton et al., 2008). Ultimately, the training, implementation, and maintenance of the AAC system is largely dependent on the family. Research indicates that AAC use at home is related to positive child communication outcomes in language development (Sievers, et al., 2018). Additionally, previous AAC research involving families inconsistently reported children's AAC device use by groups (e.g., frequency of use, type) and included numerous developmental disability diagnoses within and across studies (Anderson et al., 2015; Blosser, 1994; Donohue et al., 2015; Meder &

Wegner, 2015; Parette et al., 2000; Schlebusch et al., 2017; Schlebusch et al., 2016; Serpentine et al., 2011; Sievers et al., 2018). Such inconsistencies in sampling methods makes it difficult to compare AAC use in families related to severity of communication symptoms. Thus, future studies should include an evaluation of the frequency of use of the AAC system as well as an understanding the type of AAC system utilized.

Describing the association between family and adolescent personal factors, such as sex, race, education, and income will enhance the literature by focusing on the diversity among sample characteristics and their potential relationships to family functioning assessed with a recognized psychometric measure specific to families using AAC devices. Additionally, this dissertation aim examined groups of families based the frequency of AAC device use by the adolescent and type of device as well as severity of the adolescent's communication symptoms. Typically, adolescent families were examined within a standardized group without acknowledgements of the impact of these characteristics on family functioning. Thus, this dissertation aim contributed to filling the gap by examining parent and adolescent characteristics and patterns of family adaptation, defined as family functioning, across families grouped by frequency of AAC device use among a sample of adolescents with autism and/or Down syndrome.

Dissertation Aim 3 (DA3)

- *Through interviews, qualitatively explore parent-reported contributing factors of family adaptation among adolescents' AAC use employing the Resiliency Model during the critical developmental stage of adolescence.*

Although research suggests a family systems lens could be useful to understand AAC utilization within families, the Resiliency Model of Family Stress, Adjustment, and Adaptation

(1996) has yet to be explored within this population. The key intermediate contributors associated with family adaptation in the context of adolescent AAC use are family: demands, type, appraisal, resources, problem-solving and coping. Each area will be addressed qualitatively to assist with expanding the application of an established framework to enhance the understanding and operationalization of intermediate contributors that help and support families of adolescents with DD utilizing AAC devices.

Family adaptation and AAC device use during adolescence. Families of adolescents with DD face unique obstacles. Typically, adolescence is marked by behavioral changes that stem from increasing independence, puberty, and encroaching adulthood (Erikson, 1963). These normative changes may create more difficulties for families of an adolescent with a disability (McGinley & Alexander, 2018). For example, adolescents with a DD who have CCN may manifest frustration, anxiety or depression, disruptions in eating patterns, and sleep hygiene issues that interfere with functioning and health (AACP, 2013). While families may view their role as an advocate and protector, adolescents' may rebel if they perceive their parents' as controlling as they strive for increasing independence (Holyfield, et al., 2017; Smith, 2015). Additionally, during this time families adapt and transition from pediatric to adult services while evaluating resources and navigating complex service systems (Burke, 2017; Lindo et al., 2016). Importantly, families of adolescents with DD utilizing AAC have ongoing expectations for the teenager's lifelong engagement in society across a range of environments including continuing education, home life, healthcare system interactions, and community involvement (Holyfield et al., 2017; Light et al., 2019). Thus, understanding family perceptions of AAC use is essential during this critical developmental time period (Holyfield et al., 2017).

Family demands specific to AAC use. Family challenges are associated with supporting adolescent children who use AAC. Reported challenges include not only emotional and physical demands stemming from the disability, but also device/technology challenges and limitations, insufficient time to learn AAC, and lack of multidisciplinary services and teamwork (Bailey, et al., 2006; Crisp et al., 2014; Hemsley et al., 2013; Jones et al., 1998; Schlebusch, et al., 2017; Thunberg et al., 2015). Additionally, research reports that some families have inadequate financial support, lack knowledge surrounding the AAC device, and have insufficient support from professionals (Bourke-Taylor et al., 2013; Goldbart & Marshall, 2004; Marshall & Goldbart, 2008; McCord & Soto, 2004; McNaughton, et al., 2008; Singh, et al., 2017). While AAC devices can improve communication capabilities for adolescents with DD, they also add layers of complexity related to training requirements, programming assistance, financial accessibility, and integration into daily living situations and family functioning (Ryan et al., 2018).

Family type. A family's basic set of attributes and traits have been shown to influence the family processes of adaptation (McCubbin et al., 1996). For example, patterns of family life which can consist of family rules and norms as well as family goals and values play an important role in explaining family outcomes in the face of critical life events (McCubbin et al., 1996). Despite the known benefits of recognizing attributes to better understand family patterns of functioning, there is a lack of research that explicates family attributes among families of adolescents with DD utilizing AAC devices.

Family appraisal. Understanding the family's perceptions of their ability to manage the critical event, such as adolescent AAC use, is family appraisal. For example, families may experience positive and negative emotions that stem from their perceptions of their adolescent's

AAC use. Some studies have found that AAC use is appraised as a positive tool for enhancing adolescents' quality of life, advancement of communication competence and language development as well as for increasing independence (Angelo, 2000; Bailey et al., 2006; Batorowicz et al., 2014; Borg et al., 2015; Singh et al., 2017). Yet, other families experience negative emotions secondary to their appraisal of the lack of information and knowledge about AAC use, negative societal attitudes, and gaps in services over time (Brady et al., 2006; Marshall & Goldbart, 2008; Moorcraft et al., 2019a; Parette et al., 2000; Romski et al., 2011; Serpentine et al., 2011). Hence, further research that evaluates both positive and negative appraisals of the critical event, proposed as the need for AAC adoption within families, will assist in gaining knowledge about family adaptation and functioning in this specific context.

Family resources. Family unit level resources, include specific strengths and capabilities available to assist with ongoing challenges associated in raising a child with DD. Families with adequate resources are shown to better manage critical events, such as adolescent AAC use, than families with limited resources (Angelo, 2000; Hetzroni, 2002; Jones, et al., 1998; Marshall & Goldbart, 2008; McCubbin et al., 1996; Mei, et al., 2015; Schlebusch, et al., 2017). Family resources could include supportive relationships, parental education level, income, as well as communication effectiveness. Thus, a comprehensive evaluation of resources that potentially impact family adjustment to adolescent AAC use carries potential to advance understanding of modifiable factors that can be changed to support adaptation.

Family problem-solving and coping. Adaptation to the pressures associated with raising a child with a DD depend on coping processes and strategies utilized by the family unit and/or individual members to resolve problems and issues. Families are recognized to utilize a range of diverse problem-solving and coping strategies. For example, some families primarily utilize active approaches to coping by modifying external factors, whereas others use passive approaches by regulating emotional responses. Limited research has evaluated problem-solving and coping strategies utilized by families of adolescents with DD who use AAC (Anderson et al., 2015; Anderson et al., 2014; Hemsley et al., 2013; McNaughton et al., 2008).

Successful integration of AAC technology into an adolescent's life includes the family unit. There are challenges, stressors, and demands faced by families. Yet, some families adapt successfully, and others do not. A holistic understanding of family adaptation is limited in research. Unfortunately, past research does not operationalize the intermediate contributors of the Resiliency Model within the perspective of families with adolescents utilizing AAC devices. Thus, this exploration updated the state of the science to move towards more generalizable research from the themes derived by interviews with families.

Although family involvement is important to successful AAC device utilization, little is known about how families of adolescents adapt to technology integration. This dissertation adds to the state of the science by: (1) assessing and updating the literature, (2) identifying a family theoretical model and key concepts applicable to the population of interest, (3) examining adolescent and family characteristics and their association with family functioning based on frequency of AAC use, and (4) providing families' perspectives of their experiences with AAC surrounding their adolescent. This dissertation serves as the foundation for the future development of a program of research by evaluating modifiable model components associated with family outcomes.

Conceptual Framework

McCubbin & McCubbin's (1993) Resiliency Model of Family Stress, Adjustment, and Adaptation is utilized to conceptualize family adaptation, the key concept for this dissertation work (see Figure 1.1). The model examines families of children with chronic conditions/disabilities and the methods that can be used to adapt, adjust, and minimize the intrusiveness of the disability on family life (Knafl & Gilliss, 2002; McCubbin et al., 1996). The model helps to "explain why some families adapt and become stronger in the face of stressful circumstances; whereas others remain vulnerable, and some deteriorate" (Van Riper, 2000, p. 269). The Resiliency Model has been utilized in studies of families of children with various chronic conditions and has been empirically tested in diverse family member makeups and ethnic groups from many different countries (Choi, 2015; McCubbin et al., 1996; Van Riper, 2007; 2000). Utilizing a systems approach while combining both family stress and resiliency theories, the model highlights the complex role that the family system plays in the variability of outcomes and the well-being of individual members (McCubbin et al., 1996). Family systems theory, including the Resiliency Model, continue to guide contemporary family research from a variety of disciplines (White et al., 2015).

First, a detailed discussion of the Resiliency Model will be provided, and the model depicted. Secondly, the adapted conceptual model, followed by the operational model for this dissertation will be comprehensively described.

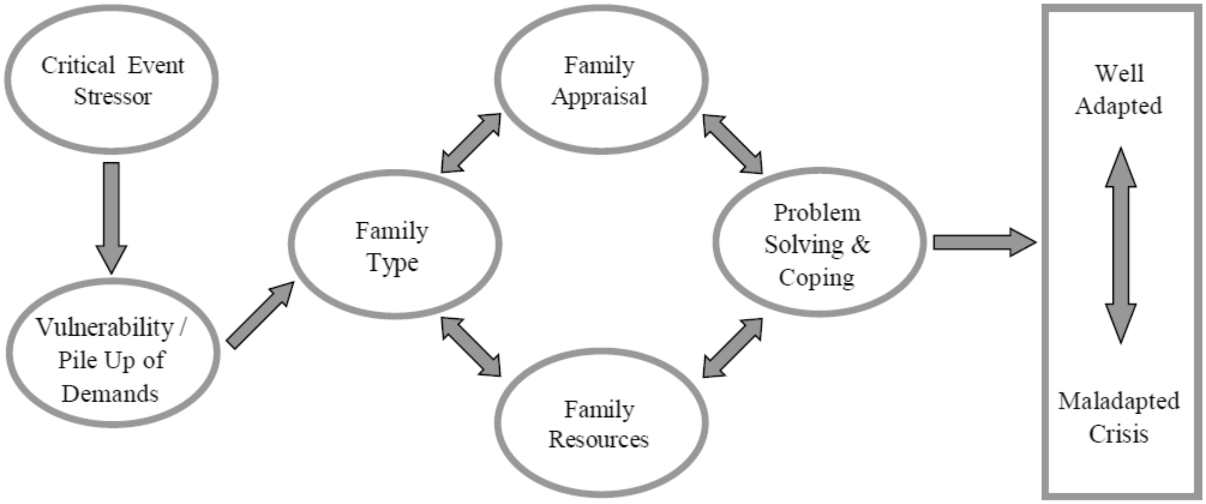
Conceptual Model

According to the Resiliency Model, a series of interacting components shape family processes and outcomes of adaptation. The model components are: critical event/stressor, family demands, family type, family appraisal, family resources, and family problem-solving/coping. Each component of the Resiliency Model evaluates behaviors and interactions within the family system and interactions within the community, extended family, friends, neighbors, community programs and services to explain the variability in outcomes of family functioning/adaptation

(McCubbin et al., 1996). The model serves as a guiding framework for understanding factors that support and/or hinder family adaptation to a child's chronic condition, such as caring for an adolescent with DD utilizing AAC (Van Riper, 2000). The Resiliency Model depicts parents as units that impact the family system in bidirectional ways with intervening factors that shape the course of adaptation (Boss & Mulligan, 2003). While theory is important to guide research, only two published reports have proposed family systems theories to guide studies related to families caring for a child who uses AAC (Mandak et al., 2017; Schlebusch et al., 2017; Schlebusch et al., 2016).

The Resiliency Model begins with the critical event followed by factors (demands, type, appraisal, resources, problem-solving/coping) that shape positive or negative outcomes of family adaptation. Each factor will be briefly described in addition to the model relationships.

Figure 1.1: Resiliency Model of Family Stress, Adjustment, and Adaptation



Adapted from McCubbin, M. A., Thompson, A., & McCubbin, H.I., (1996). *Family assessment: Resiliency, coping and adaptation [Figure]*. Madison, WI: University of Wisconsin-Madison.

Critical event/stressor. The critical event or stressor is defined as a life event that produces or has the potential to produce changes in the family system (McCubbin et al., 1996; Van Riper, 2000).

Vulnerability/pile up of family demands. The demands are the strains, stress, challenges, and problematic transitions faced by the family unit (McCubbin et al., 1996).

Family type. Family type refers to a basic set of attributes that characterize and/or explain how a family typically operates or behaves, often referred as family typologies (McCubbin et al., 1996). Four types/typologies (e.g., regenerative, versatile, rhythmic, traditionalistic) represent a method to understand family traits/strengths and to classify families into unique groups that characterize their behaviors in the face of stressful events and transitions (McCubbin et al., 1996). Regenerative families reflect the dimensions of hardiness and coherence, whereas versatile families are characterized by flexibility and bonding. Rhythmic families are based on dimensions valuing the importance of family time and routines, whereas traditionalistic families emphasize rituals, celebrations, and customs (McCubbin et al., 1996).

Family appraisal. Family appraisal is the family's evaluation of the critical events or stressors and their perceived ability to manage the related demands (McCubbin et al., 1996).

Family resources. Family resources are the positive strengths and capabilities of individual family members, the family unit, and their associated community (McCubbin et al., 1996). These resources include social and financial support, as well as intangible resources including self-esteem, knowledge, and cultural heritage and customs.

Problem-solving and coping. Problem-solving and coping are specific actions taken by individual members or the family unit to manage challenges, as well as processes and skills to acquire, allocate, and use resources that reduce strains and modify negative family appraisals (McCubbin et al., 1996).

Adaptation. Adaptation is the outcomes of family efforts to bring a new level of stability and functioning to a vulnerable, stressful or crisis situation (McCubbin et al., 1996; Van Riper, 2000). Efforts may include modifying the environment and relationships internally and/or externally such as with the community.

Model relationships. The Resiliency Model proposes that family system components are interconnected and require holistic examination (White et al., 2015). For example, by modifying resources and/or problem-solving and coping, family adaptation can be improved. Components in the model are modifiable and important foci for intervention development for families. In the model (see Figure 1.1), the critical event directly influences the vulnerability/pile up of demands. The model acknowledges that the adaptation continuum outcome variable has the potential to be mediated by the interacting bi-directional model components of family type, appraisal, resources, and problem-solving and coping.

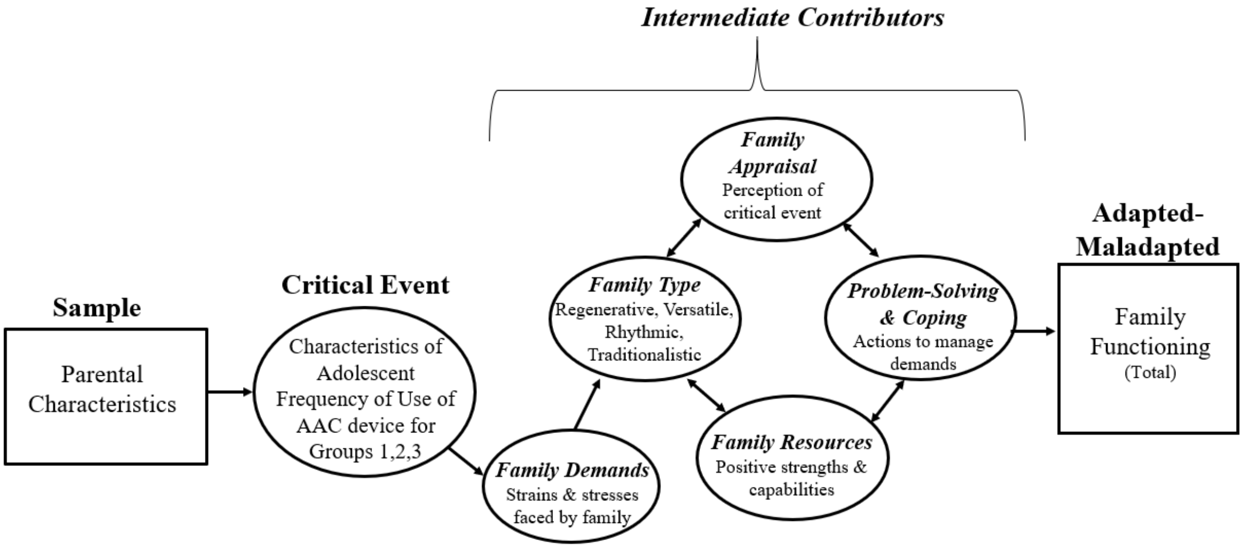
Limitations. The Resiliency Model has limitations. First, some critics contend that a systems theory may be too abstract and global to be useful (White et al., 2015). However, applying a conceptual model with specific concepts from general ideas across diverse contexts helps to see connections in the natural and social world to understand the similarity of processes (White et al., 2015). A second criticism is the application of the differentiation between familial perspectives and individual family member perspectives of adaptation (Boss & Mulligan, 2003). Family research has relied on accounts of individual family members (Boss & Mulligan, 2003). For example, in this dissertation study, each parent serves as a proxy for the family unit perspective, and the family is not analyzed from the individual member level perspective (e.g., mother, father, sibling).

Strengths. The Resiliency Model has several strengths. It incorporates various levels of analysis, including the individual, family, and society (White et al., 2015). Additionally, the model depicts relationships among multiple underlying factors, such as family resources, demands, type, appraisal, and problem-solving/coping (Boss & Mulligan, 2003). The model has been empirically tested in families from different countries, varying ethnic groups, and diverse member makeup (e.g., single parent, two-parent) with satisfactory outcomes (McCubbin et al., 1996). Lastly, the model has been tested in families with children with various chronic conditions, such as diabetes, cancer, cerebral palsy, DS, and other disorders (Choi 2015; McCubbin et al., 1996; Van Riper, 2007; 2000).

Adapted Resiliency Model of Family Stress, Adjustment, and Adaptation

The original McCubbins' model was adapted for this dissertation work (see Figure 1.2). This adapted version of the Resiliency Model will be used to examine family adaptation as family functioning quantitatively in the context of adolescent use of AAC as a stressor/critical event (Yeh & Bull, 2011). The adapted model depicts the state of the science and areas that need to be examined in the specific population of families under investigation for this dissertation. For example, the model shows that parental characteristics will be addressed. Additionally, the model illustrates two of the main elements from the Resiliency Model to address the previously noted gaps in research: 1) critical event- for this dissertation, critical event/stressor is defined as stressors associated with the characteristics of the adolescent with DD and the type and frequency of use of an AAC device; and 2) adaptation-maladaptation continuum- adaptation and maladaptation are represented by family functioning. The other Resiliency Model components (e.g., family demands, type, appraisal, resources, and problem-solving/coping) were explored qualitatively to understand the family functioning when raising an adolescent utilizing an AAC device.

Figure 1.2: Adapted Resiliency Model



Adapted from McCubbin et al., 1996

Parental characteristics. To examine the families under investigation, the following parental characteristics are included: age, sex, race, education, marital status, family size, annual income, respondent relationship to the adolescent, environmental/neighborhood geography (e.g., urban, suburban, rural) of family home, and primary language(s) spoken in the home. Parents and family members are vital partners to adolescents with DD utilizing AAC (Holyfield et al., 2017).

Components from the Original Model

While the original model components are defined previously with the conceptual model, the intermediate contributors to family adaptation in terms of this study are explained in this section.

Critical event/stressor. For this dissertation, the critical event is defined as the characteristics of the adolescent with DD and the frequency of use of an AAC device.

Family demands. Family demands are the perceived strains on families of adolescents with DD who use AAC devices, which are most often expressed by the parents. Such strains may include previously identified factors such as multiple roles, increased time demands, inadequate financial supports, inaccessibility of multidisciplinary professional services, lack of professional interdisciplinary teamwork, lack of AAC device training (e.g. programming, use, repair), device limitations- including the lack of customizations to culture and non-English language programming, physical and emotional demands of the child's disability, and social isolation from public perceptions of the child's communication disability (Allaire et al., 1991; Anderson et al., 2014; Angelo, 2000; Bailey, et al., 2006; Batorowicz, et al., 2014; Borg et al., 2015; Bourke-Taylor, et al., 2013; Brady, et al., 2006; Clarke, et al., 2011; Hemsley, et al., 2013; Marshall & Goldbart, 2008; McNaughton, et al., 2008; Mei, et al., 2015).

Family type. Family type refers to typologies or classifications that help to describe different or similar clusters of families and their responsiveness to critical events, such as adolescent AAC device use (see above Conceptual Model description).

Family appraisal. Family appraisal refers to the positive or negative perceptions of the AAC device utilization. Positive and negative appraisals can co-occur, and families who are able to balance this dialectic may optimize their functioning. Positive appraisals potentially include that AAC is perceived as a positive tool, for instance, improving an adolescent's quality of life, supporting language and literacy development, increasing communication competence, and increasing independence for opportunities for the future (Angelo, 2000; Bailey et al., 2006; Batorowicz et al., 2014; Borg et al., 2015; Singh et al., 2017). Negative appraisals potentially include the lack of information and knowledge, stigma and frustrations related to not understanding the adolescent (Brady et al., 2006; Marshall & Goldbart, 2008; Parette et al., 2000; Romski et al., 2011; Serpentine et al., 2011).

Family resources. Family resources are the strengths and capabilities of family members, the family unit, and the community (McCubbin, et al., 1996). Individual level resources that play a role in family functioning/adaptation include spousal support and the ability to understand the child (Jones, et al., 1998; Marshall & Goldbart, 2008). Familial routine, smaller household size, income, cultural practices, and respect for professionals were reported in studies as family unit assets that enhance adaptation to AAC use (Angelo, 2000; Hetzroni, 2002; Marshall & Goldbart, 2008; Mei, et al., 2015; Schlebusch, et al., 2017). Additionally, families reported better adaptation if they possessed informational support from AAC resources, access to community disability resources, and professional collaboration/partnerships with schools, day care, other family members, and peers (Anderson, et al., 2014; Angelo, 2000; Bailey, et al., 2006; Crisp, et al., 2014; Huer, et al., 2001; McCord & Soto, 2004; Meder & Wegner, 2015; Mei, et al., 2015; Parette, et al., 2000; Romski, et al., 2011; Schlebusch, et al.., 2017; Serpentine, et al., 2011; Singh, et al., 2017; Stuart & Parette, 2002).

Family problem-solving and coping. Families utilize diverse problem-solving and coping processes and strategies. Some families become advocates for their child to protect them, while others actively educate themselves about AAC resources (Angelo, 2000; Goldbart & Marshall, 2004; Hemsley et al., 2013; Marshall & Goldbart, 2008; McNaughton et al., 2008; Thunberg et al., 2016). Some families seek involvement and collaborative approaches to manage AAC technology, yet others embrace AAC as a mechanism for communication enhancement finding their own ways to adjust to the technology (Allaire et al., 1991; Anderson et al., 2015; Anderson et al., 2014; Bailey et al., 2006; Blosser et al., 1994; Huer et al., 2001; Serpentine et al., 2011). For families, “coping and problem-solving may be directed at the reduction or elimination of demands, the acquisition of additional resources, the ongoing management of family systems tension, and shaping the appraisal" (McCubbin et al., 1996, p. 50).

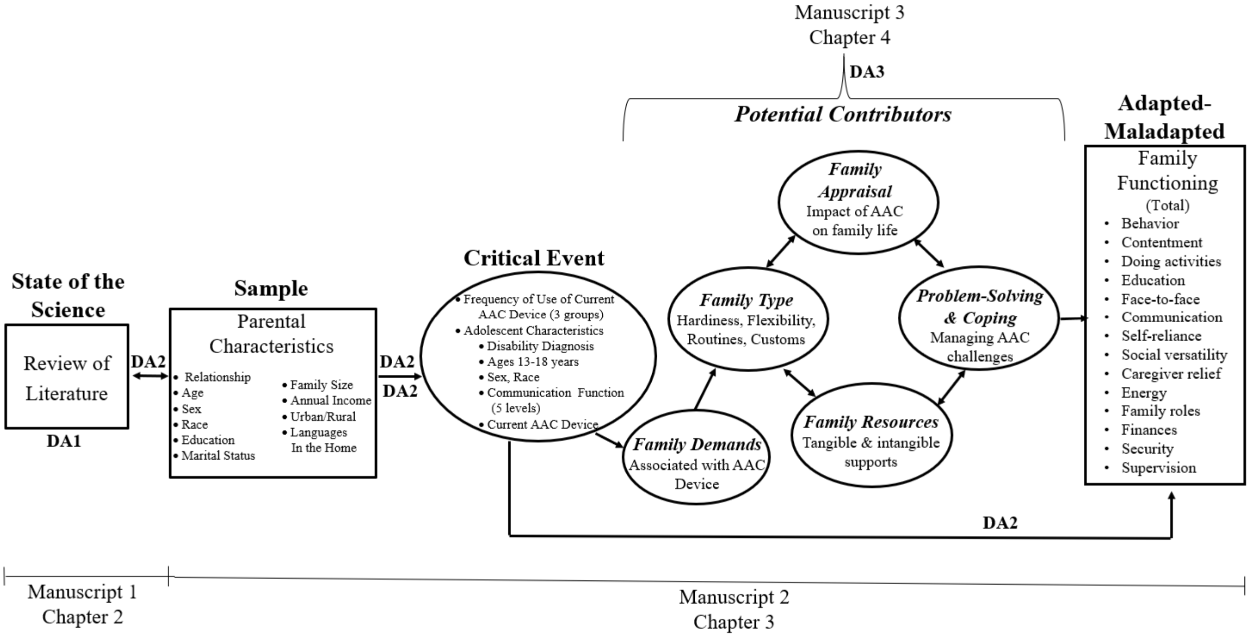
Adaptation-maladaptation. Adaptation-maladaptation is a process in which families engage to create a balance between the needs of the adolescent with DD, the individual family members, and the family unit (McCubbin et al., 1996; Choi & Van Riper, 2017). Family adaptation, described as family functioning in this dissertation, refers to the outcome or impact of AAC use by an adolescent with a DD within the lives of families (Delarosa et al., 2012; Ryan et al., 2018). *Maladaptation* is a state of imbalance between the demands and the capabilities whereas the demands outpace the capacity of the family network to function effectively.

Model relationships. The adapted model depicts a directional relationship between parental characteristics and the critical event. Next, from the critical event to family function/adaptation there are possibly five intermediate conceptual contributors that may have an influence on family adaptation. This study qualitatively examined these five intermediate contributors for opportunities to strengthen the model.

Operational Resiliency Model

The operational model (see Figure 1.3) now describes the previous concepts as variables with their measurement parameters to be tested.

Figure 1.3: Operational Resiliency Model



Note. Dissertation Aim = DA.
The three groups are: low-usage, mid-usage, high-usage.
The five levels are: Level I (best function), Level II, Level III, Level IV, Level V (most difficulty).

State of the science. A complete literature review was conducted examining both quantitative and qualitative research of family adaptation in families of children with DD who use AAC. Next, the model components for this study will be described moving from left to right in Figure 1.3.

Sample (Parents).

Parental characteristics. Self-reported parental characteristics were included to characterize the sample under investigation. These characteristics included: age, sex, race, education, marital status, family size, annual income, employment status, respondent relationship to the adolescent, environmental/neighborhood geography of family home, and primary language(s) spoken in the home. These personal factors are important to understand and acknowledge to accommodate for the additional barriers that these factors may present for families (Moorcroft et al., 2019a). Age was measured as a continuous variable reported in years, and sex was a dichotomous categorical variable as male or female. Designated racial group was a categorical variable (e.g., American Indian/Alaska Native, Asian, Black/African American, Pacific Islander, White/Caucasian, Other). Educational status was categorized by the highest level of school completed (e.g., no college; some college; bachelor's degree, bachelor's degree plus). Marital status consisted of three categories (e.g., married or in a partnership, not married, prefer not to disclose), and family size was defined as the number of individuals related to the adolescent by blood, marriage, adoption, or foster care living in the same household. Annual income was measured in three monetary categories, ranging from less than $50,000 to more than $90,000. Employment status consisted of three categories (e.g., employed full time, employed part time, not currently working). Respondent relationship consisted of five categories (e.g., biological parent, adoptive parent, stepparent, foster parent, other). Parents selected one classification describing the geographical area of their home (e.g., urban, suburban, rural), and primary language was measured in one of three categories; English, Spanish, or other.

Critical event. Adolescent use of AAC device refers to the critical event or life event impacting the family of the adolescent. The first component is the frequency of use of the AAC device. Given the limitations of a cross-sectional study, the information gathered from responses about the frequency of the device use categorizes potential familiarity and understanding of AAC responses (e.g., three groups based on how often the adolescent has utilized the identified primary AAC device). The three distinct groups are: low-usage, mid-usage, high-usage. Previous research has indicated that increased frequency of AAC exposure and use at home mediates AAC intervention success, facilitates language development, and influences family functioning (Sievers et al., 2018). The second component of the critical event involves the specific characteristics of the adolescent as described by the parent (proxy for family). These characteristics include disability diagnosis, age, sex, race, type of current AAC device, and communicative function. These adolescent factors are important to understand and acknowledge to accommodate for the additional barriers and supports that these factors may present (Moorcroft et al., 2019a). The type of aided AAC device has three categories: low-technology (i.e., AAC with no battery or computer component), mid-technology (i.e., AAC with battery component only), and high-technology AAC (i.e., AAC with computer component) (Baxter et al., 2012; Holyfield, 2017; Moorcroft et al., 2019a). The Communication Function Classification System (CFCS) was used to assess communicative functioning of the adolescent (Hidecker et al., 2017; Hidecker et al., 2011). The CFCS is a validated tool that allows parents, clinicians, and researchers to categorize children's communication skills into five exclusive levels based on how they interact in everyday situations requiring communication (Hidecker et al., 2017; Hidecker et al., 2011). The levels vary by familiarity of communication partner, the adolescent's pace of communication interactions, and the adolescent's success of sending and receiving messages. In Level I, adolescents function best; and those in Level V have the most difficulty (Hidecker et al., 2017; Hidecker et al., 2011).

Adaptation. Adaptation was operationalized by evaluation of family functioning. Family functioning is influenced by the dynamic interaction of seven adolescent and six family components. The seven adolescent components include: 1) appropriate behavior (*behavior*), 2) content (*contentment*), 3) control of his/her own actions (*doing activities*), 4) educational success (*education*), 5) communicative function (*communication*), 6) degree of activity independence (*self-reliance*), and 7) ability to interact with others (*social versatility*) (Delarosa et al., 2012; Kron et al., 2018; Ryan et al., 2018; Ryan et al., 2007). The six family components include: 1) management of caregiving responsibilities (*caregiver relief*), 2) energy needed to assist the adolescent (*energy*), 3) family member involvement in caregiving (*family roles*), 4) financial stress (*finances*), 5) worry of adolescent's safety (*security*), and 6) attention needed from family members (*supervision*) (Delarosa et al., 2012; Kron et al., 2018; Ryan et al., 2018; Ryan et al., 2007). While the six family components are not a direct measure of the intermediate contributors of the Resiliency Model (e.g., demands, type, appraisal, resources, problem-solving and coping), however all but family type are indirectly measured (see Table 1.1). Due to this circumstance, the intermediate contributors of the model were further evaluated through qualitative interviews. This direct and indirect measure of the intermediate contributors was necessary due to the novel application of the model which is not examined with individual measures in this phenomenon.

The Family Impact of Assistive Technology Scale for Augmentative and Alternative Communication (FIATS-AAC) will provide data about family functioning (Delarosa, et al., 2012). FIATS-AAC is an 89-item family-report (by parents as family proxy) questionnaire that measures family functioning related to AAC interventions for children aged 3 to 18 years and their families. FIATS-AAC measures family adaptation (termed functioning) according to six dimensions (*caregiver relief, energy, family roles, finances, security, supervision*) and adolescent functioning according to seven dimensions (*behavior, communication, contentment, doing activities, education, self-reliance, social versatility*) (Delarosa, et al., 2012). The items are scored on a 7-point Likert scale. The scale ranges from 7 (strongly agree) to 1 (strongly disagree). Item responses within each dimension are summed and divided by the number of valid responses to create a mean dimension, ranging from 1 (lowest level) to 7 (highest level). Higher scores suggest higher positive functional levels within a specific dimension. Summing the mean domain scores for all 13 dimensions calculates the total FIATS-AAC score. The FIATS-AAC sum scores range from 13–91, with higher scores indicating higher levels of functioning. The overall alpha of the FIATS-AAC scale is 0.91, with the parent/family related subscale alpha's ranging from .68 to .99 and the child related subscale alpha's ranging from .66 to .90 (Delarosa, et al., 2012).

Intermediate contributors. Family demands, type, appraisal, resources, problem-solving and coping as depicted in the adapted and operational models was examined via semi-structured recorded Zoom© (2020) interviews with parents (parents as family proxy) (see Appendix for guide). Transcripts of the interview summaries were analyzed and coded with development of content themes. Qualitative evaluation of the aforementioned components provided an opportunity to explore important aspects associated with family functioning where members include adolescents with DD who utilize AAC.

Model relationships. Since this was the first study in AAC literature guided by the Resiliency Model, specific variables were examined quantitatively and qualitatively. It is acknowledged that in future work these will need to be merged. The operational model depicts a bidirectional relationship between the state of the science and the sample characteristics examined in this study (DA1). The sample characteristics and critical event are supported by the literature to influence each other (Angelo, 2000; Hetzroni, 2002; Jones, et al., 1998; Marshall & Goldbart, 2008; McCubbin et al., 1996; Mei, et al., 2015; Schlebusch, et al., 2017), and can directly influence family functioning (DA2) (Angelo, 2000; Bailey et al. 2006; Delarosa et al., 2012; Rackensperger, 2012). The critical event is hypothesized to directly influence the five intermediate contributors of family (demands, type, appraisal, resources, problem-solving/coping) of the Resiliency model that are explored qualitatively (DA3) influencing family functioning (McCubbin et al., 1996; West et al., 2020). Even though there is less literature to support the hypothesis, this gap in research directs the qualitative work that was completed through this dissertation.

Purpose

The purpose of this study was to examine factors associated with family adaptation to AAC among families of adolescents with autism and/or Down syndrome. Thus, the aims of the study were: (1) evaluate the state of the science on family adaptation among children and adolescents with DD utilizing an AAC device for communication; (2) examine the associations between parental characteristics, adolescent characteristics, and family functioning based on the frequency of AAC device use by their adolescent; and (3) qualitatively explore parent-reported contributing factors of family adaptation among adolescents' AAC use employing the Resiliency Model. Although the challenges faced by families of adolescents with DD are recognized, little is known how families adapt to the integration and use of AAC technology during this critical life stage.

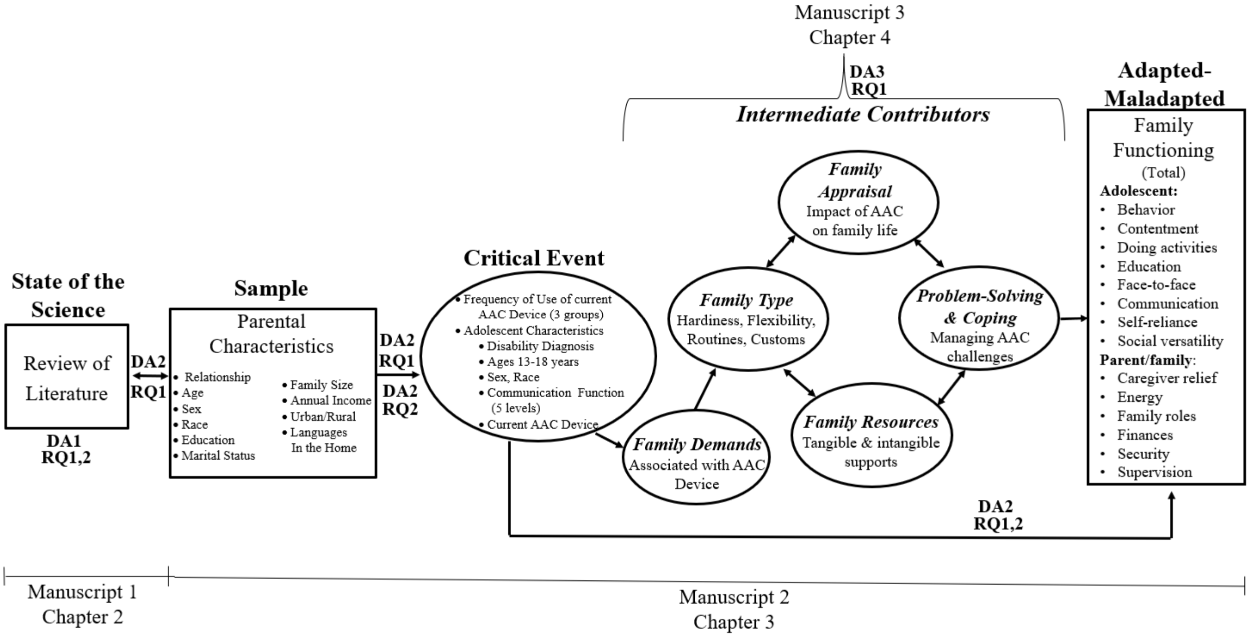
Previous research has focused on younger children and the range of DD within and across studies making comparisons across different group characteristics of families difficult to interpret and generalize (McNaughton & Light, 2015). Additionally, studies have lacked theoretical grounding and have had inconsistent use of measurement instruments with psychometric properties to understand factors specific to AAC use for families (Delarosa et al., 2012; Ryan et al., 2007). This dissertation aimed to produce knowledge to fill these gaps. Findings provided a foundation for understanding perceived factors that impact familial adaptation to AAC devices for adolescents with DD. Ultimately this dissertation set the stage for the development of a program of research to identify factors associated with vulnerability in families of adolescents with DD. Subsequently, this dissertation built evidence for development of tailored interventions to support at risk families and optimize family outcomes.

Given previous studies have not used instruments specific to the AAC population (Jones, et al., 1998; Clarke, et al., 2011; Schlebusch, et al., 2017), this study utilized a valid and reliable instrument, the FIATS-AAC. The FIATS-AAC measures the functional and contextual factors of AAC use that impact everyday lives (Delarosa et al., 2012; Ryan et al., 2007; Stein, & Jessop, 2003) and examined family adaptation during adolescence (McNaughton & Light, 2015). Second, previous research has been largely atheoretical (Mei et al., 2015; Schlebusch, et al., 2017), whereas this study included the use of an established family model applicable to the target population, encompassing a holistic examination of family concepts, leading to an increased understanding of the factors that play a critical role in how a family adapts to adolescent AAC device use. The quantitative portion of this mixed methods study evaluated relationships between the critical event and the outcome (adaptation). The qualitative portion of the dissertation work extended findings with an exploration of the other model components within the context of the phenomenon. Thus, this study elicited detailed descriptions of family experiences of supporting adolescent AAC use and provided qualitative data to extend and corroborate quantitative findings (Creswell, 2009). This dissertation offered a novel approach because previous studies have solely used either qualitative or quantitative methods. Lastly, the study outcomes had the potential to improve knowledge and provide a better understanding of families with diverse racial, socioeconomic, and educational backgrounds utilizing AAC.

Dissertation Format

The multiple manuscript format was utilized to produce three stand-alone manuscripts from Chapters 2, 3, and 4 that will be submitted for publication. Each manuscript addressed the research questions within the three aims of this dissertation relative to familial adaptation to AAC interventions for adolescents with DD who have CCN (see Figure 1.4). For ease of following Chapters 2, 3 and 4, dissertation aims and research questions (RQ) addressed in each chapter were added to the operational model. Additionally, each manuscript was identified clearly with solid linear lines at the top and bottom of the model.

Figure 1.4: Operational Resiliency Model with Research Questions



Note. DA represents dissertation aim; RQ represents research question.
The three groups are: low-usage, mid-usage, high-usage.
The five levels are: Level I (best function), Level II, Level III, Level IV, Level V (most difficulty).

Chapter 2 (Manuscript 1)

Chapter 2 was an integrative review guided by Whittmore & Knafl's (2005) methodology. This paper examined both quantitative and qualitative research concerning family adaptation in families of children who use AAC. The research questions for the review are:

1. What is the state of the science regarding family adaptation when there is a child in the family with DD who utilizes AAC devices to support communication?

2. How common is the use of a family conceptual model to guide a review of the literature on family adaptation to AAC technology?

Additionally, the review framed the literature with an assessment of the conceptual foundations of family adaptation utilizing the Resiliency Model (1993). The paper utilized the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) and the Mixed Methods Appraisal Tool (MMAT). The manuscript was formatted for submission and was published in the Journal of Family Nursing.

Chapter 3 (Manuscript 2)

Chapter 3 includes an examination of the: 1) relationship between parental characteristics (age, sex, race, education, marital status, socio-economic status, geographical area) and family functioning (adaptation) for three distinct groups (families) based on frequency of AAC device use of an adolescent, 2) relationship between adolescent characteristics (disability diagnosis, age, sex, race, communicative function, current device category) and frequency of AAC device use by an adolescent, and 3) differences in family functioning (adaptation) for three distinct groups (families) based on frequency of AAC device use.

The research questions for Chapter 3 were:

1) What is the relationship between parental characteristics (age, sex, education, marital status, SES, geographical area) and family functioning (total FIATS-AAC score for adaptation) for three distinct groups (families) by frequency of AAC device use by the adolescent (i.e., low usage, mid-usage, high-usage groups)?
2) What is the relationship between adolescent characteristics (disability diagnosis, age, sex, race, communicative function, current device category) and family functioning (total FIATS-AAC score for adaptation) for three distinct groups of (families) by

frequency of AAC device use by the adolescent (i.e., low usage, mid-usage, high-usage groups)?

3) What are the differences in family functioning (total FIATS-AAC score for adaptation) for three distinct groups (families) related to the frequency of AAC device use (i.e., low usage, mid-usage, high-usage groups)?

A cross-sectional quantitative design was used. Survey data were collected from a parent/caregiver of an adolescent aged 13–18 years with autism and/or Down syndrome using AAC, who understood both written and spoken English, and had access to the internet. Families were recruited via the internet as a convenience sample from the following registries, support groups, and a social networking site (Facebook): ResearchMatch, DS-Connect Registry, Autism Society of Michigan, and Apraxia Kids. Based on the "frequency of use" responses, percentiles were used to formulate groups for analysis. Data analysis included descriptive statistics and relationships between parental/adolescent characteristics and family functioning was analyzed according to the type of variables. The manuscript was formatted for submission to the Augmentative and Alternative Communication journal for publication consideration.

Chapter 4 (Manuscript 3)

Chapter 4 utilized the Resiliency Model of Family Stress, Adjustment, and Adaptation (1996) framework to examine the perceptions of families of adolescents utilizing AAC. The research question for this manuscript was:

1) What are parents' perceptions of demands, type, appraisal, resources, and problem-solving/coping associated with family adaptation when an AAC device is used by an adolescent with DD in the family?

This chapter utilized a qualitative design. A qualitative approach with semi-structured interviews explored families' experiences, using parents as the family proxy. Key interacting family components (e.g., demands, type, appraisal, resources, and problem-solving/coping) explored in DA3 to enhance the understanding of outcomes associated with family adaptation. A subsample of families from the online survey and quantitative analysis in Chapter 3 participated in the semi-structured interviews. This design provided a diverse exploration of family adaptation when the adolescent with DD uses AAC. Qualitative data analysis was performed. Interviews were transcribed by a professional transcriptionist verbatim, and two independent reviewers coded the data to develop thematic summaries of each family's interview (Creswell & Creswell, 2018). Comparisons across the subset of interviewed families' (parents as proxy) thematic summaries were examined for patterns among the sample of families supporting adolescent AAC use. The manuscript was formatted for submission to the Journal of Pediatric Nursing for publication consideration.

Chapter 5

Chapter 5 summarizes dissertation findings and synthesizes conclusions for future implications as they contribute to nursing research, practice, education, and policy.

APPENDICES

Appendix A: Interview Guide

Interview Guide

Interview Format	Family Component	Questions
Opening/ice breaker question		• Tell me how you first learned about this study. • During this interview, we want to know what resources exist and the potential needs for families and parents with teenager's who use AAC.
Transition questions		• How would you describe your family? o Tell me about your family. • How would you describe your teenager who uses AAC? • When did he/she begin using an augmentative and alternative communication (AAC) device? o Tell me about your decision to use AAC. • What type of AAC device does he/she use? • Describe the benefits associated with your teenager's use of an AAC device? o What comes to mind? o Please give me example(s) of positive experiences in using the AAC device.
Key questions	Demands	• Describe the challenges associated with your teenager's use of an AAC device? o What comes to mind? o Please tell me more and give me some example(s).
	Type	• How do you manage or handle those challenges or stressors associated with your teenager's use of the AAC device? o What comes to mind? o Please tell me more and give me some examples. • Describe strengths or characteristics/qualities of your family assisting with the management of these challenges or stressors associated with your teenager's use of the AAC device? o Tell me about key moments or events that

Interview Guide (cont'd)

		have affected your family while your adolescent has been utilizing AAC. o Describe how your family plans for trying new activities which involve your teenager's use of AAC. o Discuss how your family works together to help each other encourage the use of your adolescent's AAC during family events and/or outings.
	Appraisal	• Describe the impact of your teenager's use of AAC on family/parent life? o Can you give an example? o What experiences have you had that made you bring that/those examples up?
	Resources	• What resources are available to support you, as your teenager progresses towards young adulthood (if not mentioned: ask about school, community resources, friends, other family members, professionals)? o Please describe some examples. o Is there anything else?
	Problem-solving & coping	• Tell me how your family is planning for potential future challenges with AAC device use. o Please describe an example(s)? • Tell me why the AAC device has been effective? o Please help me understand why you feel this way.
Ending questions		• Before we end this interview, is there anything else about AAC we should have talked about but didn't? Is there any area where you want to add more information?
Closing		• Thank you so much for participating in our project. Your participation is integral in helping us understanding families' needs and supports for teenagers with CCN who utilize AAC systems. We hope you have felt heard and benefited from our discussions too.

Appendix B: FIATS

-AAC Subscales and Intermediate Contributors

Table 1.1

FIATS-AAC Subscales and Family Adaptation Model Intermediate Contributors

Subscale	Cronbach's α	Number of items	Family Model Intermediate Contributors
Adolescent Components			
Behavior	0.85	6	
Contentment	0.66	7	
Doing activities	0.71	5	
Education	0.85	7	
Face-face communication	0.90	8	
Self-reliance	0.74	7	
Social versatility	0.78	7	
Family Components			
Caregiver relief	0.99	9	Problem-solving & coping
Energy	0.77	7	Demands
Family roles	0.68	7	Resources
Finances	0.88	5	Resources
Security	0.80	7	Appraisal
Supervision	0.77	7	Demands
Total FIATS-ACC score (sum)		89	

Note. AAC= Augmentative and Alternative Communication; FIATS-AAC= Family Impact of Assistive Technology Scale for Augmentative and Alternative Communication.

REFERENCES

REFERENCES

Accardo, P.J., Whitman, B.Y, Behr, S.K., Farrell, A., Magenis, E., & Morrow-Gorton, J. (2003). *Dictionary of Developmental Disabilities Terminology*. 2nd ed. Baltimore, MD: Paul H. Brookes Publishing Co.

Allaire, J.H., Gressard, R.P., Blackman, J.A., & Hostler, S.L. (1991). Children with server speech impairments: Caregiver survey of AAC use. *Augmentative and Alternative Communication*, *7*(4), 248–255.

Allen, L. F. & Babin, E. A. (2013). Associations between caregiving, social support, and well-being among parents of children with childhood apraxia of speech. *Health Communication*, *28*, 586–576.

American Speech-Language-Hearing Association. (ASHA). (2019). *Augmentative and alternative communication*. Retrieved from https://www.asha.org/PRPSpecificTopic.aspx?folderid=8589942773&section=Key_Issue

Anderson, K. L., Balandin, S., & Stancliffe, R. J. (2015). Alternative service delivery models for families with a new speech generating device: Perspectives of parents and therapists. *International Journal of Speech-Language Pathology*, *17*(2), 185–195. https://doi.org/10.3109/17549507.2014.979876

Anderson, K. L., Balandin, S., & Stancliffe, R. J. (2014). Australian parents' experience of speech generating device (SGD) service delivery. *Developmental Neurorehabilitation, 17*(2), 75–83. doi: 10.3109/17518423.2013.857735

Andzik, N.R., Schaefer, J.M., Nichols, R.T., & Chung, Y. (2018). National survey describing and quantifying student with communication needs. *Developmental Neurorehabilitation*, 21(1), 40-47. doi: 10.1080/17518423.2017.1339133

Angelo, D. H. (2000). Impact of augmentative and alternative communication devices on families. *Augmentative and Alternative Communication*, *16*(1), 37–47.

Angelo, D. H., Kokoska, S., & Jones, S. (1996). Family perspective on augmentative and alternative communication: Families of adolescents and young adults. *Augmentative and Alternative Communication*, *12*(1), 13–22.

Bailey, R. L., Parette, H. P., Stoner, J. B., Angell, M. E., & Carroll, K. (2006). Family members' perceptions of augmentative and alternative communication device use. *Language, Speech, and Hearing Services in Schools*, *37*, 50–60.

Batorowicz, B., Campbell, F., VonTetzchner, S., King, G., & Missiuna, C. (2014). Social participation of school-aged children who use communication aids: The views of children and parents. *Augmentative and Alternative Communication, 30*(3): 237–251. doi: 10.3109/07434618.2014.940464

Baxter, S., Enderby, P., Evans, P., & Judge, S. (2012). Barriers and facilitators to the use of high-technology augmentative and alternative communication devices: A systematic review and qualitative synthesis. *International Journal of Language & Communication Disorders*, *47*(2), 115–129. doi: 10.1111/j.1460-6984.2011.00090.x

Beak, A. R., Kosuwan, K., & Prochnow, J. M. (2010). The development and utilization of a scale to measure adolescents' attitudes toward peers who use augmentative and alternative communication (AAC) devices. *Journal of Speech, Language, and Hearing Research*, *53*, 572–578. doi: 0.1044/1092-4388(2009/07-0140)

Binger, C. & Light, J. (2006). Demographics of preschoolers who require AAC. *Language, Speech, and Hearing Service in Schools*, 37, 200-208. doi: 10.1044/0161-1461(2006/022)

Blosser, J. L. (1994). Recommendations for clinicians based on parents' experiences. *Clinics in Communication Disorders*, *4*(4), 246–253.

Bopp, K. D., Brown, K. E., & Mirenda, P. (2004). Speech-language pathologists' roles in delivery of positive behavior support for individuals with developmental disabilities. *American Journal of Speech-Language Pathology*, *13*, 5–19.

Borg, S., Agius, M., & Agius, L. (2015). A user and their family's perspective of the use of a low-tech vs a high-tech AAC system. *Studies in Health Technology and Informatics, 217,* 811–818. doi: 10.3233/978-1-61499-566-1-811

Boss, P. & Mulligan, C. (2003). *Family stress: Classic and contemporary readings*. Thousand Oaks, CA: Sage.

Bourke-Taylor, H., Cotter, C., & Stephan, R. (2013). Young children with cerebral palsy: Families self-reported equipment needs and out-of-pocket expenditure. *Child: Care, Health, and Development*, *40*(5), 654–662. doi: 10.1111/cch.12098

Brady, N., Skinner, D., Roberts, J., & Hennon, E. (2006). Communication in young children with Fragile X Syndrome: A qualitative study of mothers' perspectives. *American Journal of Speech Language Pathology*, *15*(4), 353–364.

Burke, S.M. (2017). The use of technology by adolescents with intellectual and developmental disabilities. *Journal of Pediatric Nursing*, 37, 134-135. http://dx.doi.org/10.1016/j.pedn.2017.06.019

Center for Disease Control and Prevention. (2019). Developmental disabilities. Retrieved from https://www.cdc.gov/ncbddd/developmentaldisabilities/features/birthdefects-dd-keyfindings.html

Center for Disease Control and Prevention. (2018). Facts about Down syndrome. Retrieved from https://www.cdc.gov/ncbddd/birthdefects/downsyndrome.html

Choi, H. (2015). Adaptation in families of children with down syndrome: A mixed-methods design. *Journal of Korean Academy of Nursing*, 45(4), 501-512.

Clarke, M. T., Newton, C., Griffiths, T., Price, K., Lysley, A., & Petrides, K. V. (2011). Factors associated with the participation of children with complex communication needs. *Research in Developmental Disabilities*, *32*, 772–780. doi: 10.1016/j.ridd.2010.11.002

Creswell, J.W. & Creswell, J.D. (2018). *Research design: Qualitative, quantitative, and mixed methods approaches*. (5th ed.). Los Angeles, CA: Sage.

Crisp, C., Burke Draucher, C., & Cirgin Ellett, M. L. (2014). Barriers and facilitators to children's use of speech-generating devices: A descriptive qualitative study of mothers' perspectives. *Journal for Specialists in Pediatric Nursing*, *19*, 229–237.

de Graaf, G., Buckley, F., Skotko, B.G. (2015). Estimates of the live births, natural losses and elective terminations with Down syndrome in the United States. *American Journal of Medical Genetics Part A*, 167A, 756–767.

Delarosa, L., Horner, S., Eisenberg, C., Ball, L., Renoni, A., & Ryan, S. E. (2012). Family impact of assistive technology scale: Development of a measurement scale for parents of children with complex communication needs. *Augmentative and Alternative Communication*, *28*(3), 171–180. doi: 10.3109/07434618.2012.704525

Donohue, D.K., Bornman, J., & Granlund, M. (2015). Household size is associate with unintelligible speech in children who have intellectual disabilities: A South African study. *Developmental Neurorehabilitation*, *18*(6), 402–406. doi: 10.3109/17518423.2014.890256

Durkin, M.S., Maenner, M.J., Meaney, F.J., Levy, S.E., DiGuiseppi, C., Nicholas, J.S., et al. (2010). Socioeconomic inequality in the prevalence of autism spectrum disorder: Evidence from a U.S. Cross-Sectional Study. *PLoS ONE* 5(7), e11551. https://doi.org/10.1371/journal.pone.0011551

Dykens, E. M., Fisher, M. H., Lounds Taylor, J., Lambert, W., & Miodrag, N. (2014). Reducing distress in mothers of children with autism and other disabilities: A randomized trial. *Pediatrics*, *134*(2), e454–e454. doi: 10.1542/peds.2013-3164

Erikson, E.H. (1963). *Childhood and society* (2nd ed.). New York: Norton.

Ganz, M. L. (2007). The lifetime distribution of the incremental societal costs of autism. *Archives of Pediatrics & Adolescent Medicine*, 161(4), 343–349. https://doi.org/10.1001/archpedi.161.4.343

Goldbart, J. & Marshall, J. (2004). "Pushes and pulls" on the parents of children who use AAC.

Augmentative and Alternative Communication, 20(4), 194–208. doi: 10.1080/07434610400010960

Hebbeler, K., Spiker, E., Bailey, D., Scarborough, A., Malik, S., Simensson, R., Singer, M., & Nelson, L. (2007). Early intervention for infants and toddlers with disabilities and their families: Participants, services, and outcomes. Final report of the National Early Intervention Longitudinal study (NEILS). Retrieved from https://pdfs.semanticscholar.org/28be/acda70854a34982fae5693e29c67d17675b3.pdf

Hemsley, B., Kuek, M., Bastock, K., Scarinci, N., & Davidson, B. (2013). Parents and children with cerebral palsy discuss communication needs in hospital. *Developmental Neurorehabilitation*, *16*(6), 363–374. doi: 10.3109/17518423.2012.758187

Henderson, S., Skelton, H., & Rosenbaum, P. (2008). Assistive devices for children with functional impairments: Impact on child and caregiver function. *Developmental Medicine and Child Neurology*, 50(2), 89-98. doi: 10.1111/j.1469-8749.2007.02021.x

Hetzroni, O. (2002). Augmentative and alternative communication in Israel: Results from a family survey. *Augmentative and Alternative Communication*, *18*(4), 255–266. https://doi.org/10.1080/07434610212331281341

Hidecker, M.J., Cunningham, B.J., Thomas-Stonell, N., Oddson, B., & Rosenbaum, P. (2017). Validity of the Communication Function Classification System for use with preschool children with communication disorders. *Developmental Medicine & Child Neurology*, 59, 526-530. doi: 10.1111/dmcn.13373

Hidecker, M.J., Paneth, N., Rosenbaum, P., Kent, R., Lillie, J., Eulenberg, J.B., Chester, K., Johnson, B., Michalsen, L., Evatt, M., Taylor, K. (2011). Developing and validating the Communication Function Classification System for individuals with cerebral palsy. *Developmental Medicine & Child Neurology*, 53, 704-710. doi: 10.1111/j.1469-8749.2011.03996.x

Hockenberry, M.J., Wilson, D., & Rodgers, C.C. (2019). *Wong's Nursing Care of Infants and Children*. (11 ed.). St. Louis, MO: Elsevier.

Holyfield, C., Drager, K. D. R, Kremkow, J. M. D., & Light, J. (2017) Systematic review of AAC intervention research for adolescents and adults with autism spectrum disorder. *Augmentative and Alternative Communication*, *33*(4), 201–212. doi: 10.1080/07434618.2017.1370495

Huer, M. B., Parette, H. P., & Saenz, T. I. (2001). Conversations with Mexican Americans regarding children with disabilities and augmentative and alternative communication. *Communication Disorders Quarterly*, *22*(4), 197–206. https://journals.sagepub.com/doi/abs/10.1177/152574010102200405

Johnson, J.M., Inglebret, E., Jones, C., & Ray, J. (2006). Perspectives of speech language pathologists regarding success versus abandonment of AAC. *Augmentative and Alternative Communication*, 22, 85-99. doi: 10.1080/07434610500483588

Jones, S. D., Angelo, D. H., & Kokoska, S. M. (1998). Stressors and family supports: Families with children using augmentative & alternative communication technology. *Journal of Children's Communication Development*, *20*(2), 37–44.

Kent-Walsh, J., Murza, K. A., Malani, M., & Binger, C. (2015). Effects of communication partner instruction on the communication of individuals using AAC: A meta-analysis. *Augmentative and Alternative Communication*, *31*(4), 271–284. doi: 10.3109/07434618.2015.1052153

King, G., Tucker, M. A., Baldwin, P., LaPorta, J., & Martens, L. (2002). A life needs model of pediatric service delivery: Services to support community participation and quality of life for children and youth with disabilities. *Physical & Occupational Therapy in Pediatrics*, *22*(2), 53–77.

Knafl, K. & Gilliss, C. (2002). Families and chronic illness: A synthesis of current research. *Journal of Family Nursing*, *8*(3), 178–198.

Kron, A.T., Kingsnorth, S., F. Wright, F.V., & Ryan, S.E. (2018). Construct validity of the family impact of assistive technology scale for augmentative and alternative communication. *Augmentative and Alternative Communication*, 34(4), 171-180. doi:10.1080/07434618.2018.1518993

Lewis, B. A., Freebairn, L. A., Hanse, A., Taylor, H., Lyengar, S., & Shriberg, L. D. (2004). Family pedigrees of children with suspected childhood apraxia of speech. *Journal of Communication Disorders*, *37*, 157–175. doi: 10.1016/j.jcomdis.2003.08.003

Light, J. (1989). Toward a definition of communicative competence for individuals using augmentative and alternative communication systems. *Augmentative and Alternative Communication*, 5(2), 137-144, doi: 10.1080/07434618912331275126

Light, J., McNaughton, D., Beukelman,D., Koch Fager, S., Fried-Oken, M., Jakobs, T., & Jakobs, E. (2019): Challenges and opportunities in augmentative and alternative communication: Research and technology development to enhance communication and participation for individuals with complex communication needs. *Augmentative and Alternative Communication,* 35(1). doi: 10.1080/07434618.2018.1556732

Light, J. & McNaughton, D. (2014). Communicative competence for individuals who require augmentative and alternative communication: A new definition for a new era of communication? *Augmentative and Alternative Communication*, 30(1), 1-18. doi: 10.3109/07434618.2014.885080

Light, J. & McNaughton, D. (2012). Supporting the communication, language, and literacy development of children with complex communication needs: State of the science and future research priorities. *Assistive Technology*, *24*, 34–44. doi: 10.1080/10400435.2011.648717

Lindo, E. J., Kliemann, Combes, B. H., & Frank, J. (2016). Managing stress levels of parents of children with developmental disabilities: A meta-analytic review of interventions. *Family Relations*, 65, 207–224. doi: 10.1111/fare.12185

Lollar, D.J., Hartzell, M.S., & Evans, M.A. (2012). Functional difficulties and health conditions among children with special health care needs. *Pediatrics, 129*(3), e714-e722. doi: https://doi.org/10.1542/peds.2011-0780

Mandak, K., O'Neill, T., Light, J., & Fosco, G. (2017). Bridging the gap from values to actions: A family systems framework for family-centered AAC services. *Augmentative and Alternative Communication, 33*(1), 32–41. doi: 10.1080/07434618.2016.1271453

Marshall, J. & Goldbart, J. (2008). 'Communication is everything I think.' Parenting a child who needs augmentative and alternative communication (AAC). *International Journal of Language & communication Disorders*, 43(1), 77–98. doi: 10.1080/13682820701267444

Martin, G.E., Bush, L., Klusek, J., Patel, S., & Losh, M. (2018). A multimethod analysis of pragmatic skills in children and adolescents with Fragile X syndrome, autism spectrum disorder, and Down syndrome. *Journal of Speech, Language, and Hearing Research*, 61(12), 3023-3037. doi: 10.1044/2018_JSLHR-L-18-0008

McCord, M. S. & Soto, G. (2004). Perceptions of AAC: An ethnographic investigation of Mexican-American families. *Augmentative and Alternative Communication*, *20*(4), 209–227. doi: 10.1080/07434610400005648

McCubbin, H.I., Thompson, A.I., & McCubbin, M.A. (1996). *Family assessment: Resiliency, coping and adaptation: Inventories for Research and Practice*. Madison, WI: University of Wisconsin-Madison.

McCubbin, M.A. & McCubbin, H.I. (1993). Families coping with illness: The Resiliency Model of Family Stress, Adjustment, and Adaptation. In C. Danielson, B. Hamell-Bissell, P. Winstead-Fry, (Eds.) *Families, health & illness: Perspectives on coping and intervention* (pp. 21-63). St. Louis: Mosby.

McGinley, V. A. & Alexander, M. (2018). *Parents and families of students with special needs: Collaborating across the age span*. Thousand Oaks, CA: Sage.

McNaughton, D. & Light, J. (2015). What we write about when we write about AAC: The past 30 years of research and future directions. *Augmentative and Alternative Communication*, *31*(4), 261–270. doi: 10.3109/07434618.2015.1099736

McNaughton, D. & Light, J. (2013). The iPad and mobile iechnology revolution: Benefits and challenges for individuals who require augmentative and alternative communication. *Augmentative and Alternative Communication*, 29(2), 107-116. doi: 10.3103/07434618.2013.784930

McNaughton, D., Rackensperger, T., Benedek-Wood, E., Krezman, C., Williams, M. B., & Light, J. (2008). “A child needs to be given a chance to succeed”: Parents of individuals who use AAC describe the benefits and challenges of learning AAC technologies. *Augmentative and Alternative Communication*, *24*(1), 43–55. doi: 10.1080/07434610701421007

Meder, A. M. & Wegner, J. R. (2015). iPads, mobile technologies, and communication applications: A survey of family wants, needs, and preferences. *Augmentative and Alternative Communication*, *31*(1), 27–36. doi: 10.3109/07434618.2014.995223

Mei, C., Reilly, S., Reddihough, D., Mensah, F., Green, J., Pennington, L., & Morgan, A. T. (2015). Activities and participation of children with cerebral palsy: Parent perspectives. *Disability and Rehabilitation*, *37*(23), 2164–2173. doi:10.3109/09638288.2014.999164

Millar, D. C., Light, J. C., & Schlosser, R. W. (2006). The impact of augmentative and alternative communication intervention on the speech production of individuals with developmental disabilities: A research review. *Journal of speech, Language, and Hearing Research*, *49*, 248–266.

Moorcroft, A., Scarinci, N., & Meyer, C. (2019a). A systematic review of the barriers and facilitators to the provision and use of low-tech and unaided AAC systems for people with complex communication needs and their families. *Disability and Rehabilitation: Assistive Technology*, 14(7), 710-731. doi: 10.1080/17483107.2018.1499135

Moorcroft, A., Scarinci, N., & Meyer, C. (2019b). Speech pathologist perspectives on the acceptance versus rejection or abandonment of AAC systems for children with complex communication needs. *Augmentative and Alternative Communication*, 35(3), 193-201. doi: 10.1080/17434618.2019.1609577

Moriarty, B., & Gillon, G. (2006). Phonological awareness intervention for children with childhood apraxia of speech. *International Journal of Language & Communication Disorders*, *41*, 713–734.

National Institute on Deafness and Other Communication Disorders [NIDCD] (2017). *NIDCD Strategic Plan 2017–2021*. Retrieved from https://www.nidcd.nih.gov/sites/default/files/Documents/NIDCD-StrategicPlan2017-508.pdf

National Institute on Deafness and Other Communication Disorders. [NIDCD]. (2014). *NIDCD fact sheet: Speech and language developmental milestones*. Retrieved from http://www.nidcd.nih.gov/health/voice/pages/speechandlanguage.aspx

National Down Syndrome Society. [NDSS]. (2019). *Down syndrome fact sheet*. Retrieved from http://www.ndss.org/wp-content/uploads/2017/08/NDSS-Fact-Sheet-Language-Guide-2015.pdf

Parette, H. P., Brotherson, M. J., & Blake Huer, M. (2000). Giving families a voice in augmentative an alternative communication decision-making. *Education and Training in Mental Retardation and Developmental Disabilities*, *35*(2), 177–190.

Parette, H. P. & Angelo, D. H. (1996). Augmentative and alternative communication impact on families: Trends and future directions. *The Journal of Special Education*, *30*(1), 77–98.

Rackensperger, T. (2012). Family influences and academic success: The perceptions of individuals using AAC. *Augmentative and Alternative Communication*, *28*(2), 106–116. doi: 10.3109/07434618.2012.677957

Romski, M., Sevcik, R. A., Adamson, L. B., Smith, A., Cheslock, M., & Bakeman, R. (2011). Parent perceptions of the language development of toddlers with developmental delays before and after participation in parent-coached language interventions. *American Journal of Speech-Language Pathology*, *20*, 111–118. doi: 10.1044/1058-0360(2011/090087)

Roux, A.M., Shattuck, P.T., Cooper, B.P., Anderson, K.A., Wagner, M., & Narendorf, S.C. (2013). Postsecondary employment experiences among young adults with an autism spectrum disorder. *Journal of American Academy of Child & Adolescent Psychiatry*, 52(9), 931-9.

Ryan, S.E., Shepherd, T.A., Renzoni, A.M., Servais, M., Kingsnorth, S., Laskey, C., Ward, K., & Bradley, K. (2018). Responsiveness of a parent-reported outcome measure to evaluate AAC interventions for children and youth with complex communication needs. *Augmentative and Alternative Communication*, 34(4), 348-358. doi:10.1080/07434618.2018.1520296

Ryan, S. E., Campbell, K. A., & Rigby, P. J. (2007). Reliability of the Family Impact of Assistive Technology Scale for families of young children with cerebral palsy. *Archives of Physical Medicine and Rehabilitation*, *88*, 1436–1440.

Saito, Y. & Turnbull, A. (2007). Augmentative and alternative communication practice in the pursuit of family quality of life: A review of the literature. *Research & Practice for Persons with Severe Disabilities*, *32*(1), 50–65.

Schieve, L.A., Boulet, S.L., Kogan, M.D., Van Naarden-Braun, K., & Boyle, C.A. (2011). A population-based assessment of the health, functional status, and consequent family impact among children with Down syndrome. *Disability and Health Journal, 4*(2), 68-77. https://doi.org/10.1016/j.dhjo.2010.06.001

Schlebusch, L., Dada, S., & Samuels, A. E. (2017). Family quality of life of South African families raising children with Autism Spectrum Disorder. *Journal of Autism Developmental Disorders*, *47*, 1966–1977. doi:10.1007/s10803-017-3102-8

Schlebusch, L., Samuels, A. E., & Dada, S. (2016). South African families raising children with autism spectrum disorders: Relationship between family routines, cognitive appraisal, and family quality of life. *Journal of Intellectual Disability Research*, *60*(5), 412–423. doi: 10.1111/jir.12292

Seligman M. & Benjamin Darling, R. (2007). *Ordinary families, special children: A systems approach to childhood disability*. (3rd ed.). New York, NY: Gilford Press.

Serpentine, E. C., Tarnai, B., Drager, K. D., & Finke, E.H. (2011). Decision making of parents of children with autism spectrum disorder concerning augmentative and alternative communication in Hungry. *Communication Disorders Quarterly*, *32*(4), 221–231. doi: 10.1177/152574019353938

Sievers, S.B., Trembath, D., & Westerveld, M. (2018). A systematic review of predictors, moderators, and mediators of augmentative and alternative communication (AAC) outcomes for children with autism spectrum disorder. *Augmentative and Alternative Communication*, 34(3), 219-229. doi: 10.1080/07434618.2018.1462849

Singh, S. J., Hussein, N. H., Kamal, R. M., & Hassan, F. H. (2017). Reflections of Malaysian parents of children with developmental disabilities on their experiences with AAC. *Augmentative and Alternative Communication*, *33*(2), 110–120. doi: 10.1080/07434618.2017.1309457

Skelton, B., Knafl, K, Van Riper, M., Fleming, L., & Swallow, V. (2021). Care coordination needs of families of children with Down syndrome: A scoping review to inform development of mHealth applications for families. *Children, 8*, 588. https://doi.org/10.3390/children8070558

Smith, M. (2015). Adolescence and AAC: Intervention challenges and possible solutions. *Communication Disorders Quarterly*, *36*(2), 112–118. doi: 10.1177/1525740114539001

Stein, R. E. K. & Jessop, D. J. (2003). The Impact on Family Scale revisited: Further psychometric data. *Journal of Developmental & Behavioral Pediatrics*, *24*(1), 9–16.

Stuart, S. & Parette, H. P. (2002). Native Americans and augmentative and alternative communication issues. *Multiple Voices for Ethnically Diverse Exceptional Learners*, *5*(1), 38–53.

Thunberg, G., Buchholz, M., & Nilsson, S. (2015). Strategies that assist children with communicative disability during hospital stay: Parents' perceptions and ideas. *Journal of Child Health Care*, *20*(2), 224–233. doi: 10.1177/1367493514568298

Van Niekerk, K., Dada, S., Tonsing, K., & Boshoff, K. (2017). Factors perceived by rehabilitation professionals to influence the provision of assistive technology to children: A systematic review. *Physical & Occupational Therapy in Pediatrics*, 1–22. doi: 10.1080/01942638.2017.1337661

Van Riper, M. (2007). Families of children with Down syndrome: Responding to “A change in plans” with Resilience. *Journal of Pediatric Nursing*, *22*(2), 116–128. doi:10.1016/j.pedn.2006.07.004

Van Riper, M. (2000). Family variables associated with well-being in siblings of children with Down syndrome. *Journal of Family Nursing*, *6*(3), 267–286.

West, P., Van Riper, M., Wyatt, G., Lehto, R., Douglas, S.N., & Robbins, L. (2020). Adaptation to technology use in families of children with complex communication needs: An integrative review and family theory application. *Journal of Family Nursing*, 26(2), 153-178. https://doi.org/10.1177/1074840720915536

White, J.M., Klein, D.M., & Martin, T.F. (2015). *Family theories: An introduction* (4th ed.). Los Angeles, CA: Sage.

Whittemore, R., & Knafl, K. (2005). The integrative review: Updated methodology. *Journal of Advanced Nursing*, *52*(5), 546–553. doi: 10.1111/j.1365-2648.2005.03621.x

Wilson, S.A. & Peterson, C.C. (2018). Medical care experiences of children with autism and their parents: A scoping review. *Child: Care, Health and Development*, 44, 807-817. doi: 10.1111/cch.12611

Wisk, L.E. & Weitzman, E.R. (2017). Expectancy and achievement gaps in educational attainment and subsequent adverse health effects among adolescents with and without chronic medical conditions. *Journal of Adolescent Health*, 61(4), 461-470. http://dx.doi.org/10.1016/j.jadohealth.2017.04.006

Yeh, P. & Bull, M. (2011). Use of the resiliency model of family stress, adjustment, and adaptation in the analysis of family caregiver reaction among families of older people with congestive heart failure. *International Journal of Older People Nursing*, *7*, 117–126 doi: 10.1111/j.1748□3743.2011.00275.x

CHAPTER TWO: ADAPTATION TO TECHNOLOGY USE IN FAMILIES OF CHILDREN WITH COMPLEX COMMUNICATION NEEDS: AN INTEGRATIVE REVIEW & FAMILY THEORY APPLICATION

Abstract

Families with children who have developmental disabilities and complex communication needs (CCN) face challenging demands impacting family adaptation. Many children with CCN use augmentative and alternative communication (AAC) devices to support communication, yet little is known about family adaptation to such technology. To fill this gap, an integrative review, guided by the Resiliency Model of Family Stress, Adjustment, and Adaptation was conducted to assess conceptual foundations and the state of the science of family adaptation among children utilizing AAC. Web-based searches were conducted using the Preferred Reporting Items for Systematic Reviews and Meta-Analysis and the Mixed-Methods Appraisal Tool. Thirty-three studies met eligibility. Findings demonstrated that to enhance the science underpinning family adaptation to AAC use, future research should be grounded conceptually and address important components of the Resiliency Model. Work in this emerging area will identify and facilitate nursing efforts to assist families as they adapt to communication technology.

Background

Developmental disabilities (DD), defined as childhood mental or physical impairments resulting in substantial functional limitations in major life activities, place challenging demands on families, particularly parents/caregivers (Accardo et al., 2003). It is estimated that close to one million children have complex communication needs (CCN) in the United States, with speech/communication impairment the most common reason for early intervention services (Binger & Light, 2006; Hebbeler et al., 2007). Families of children with DD must continually adapt to changing health, social, educational, and community needs as the child develops (King et al., 2002). Children with DD are at higher risk for health problems than non-developmentally disabled children because of co-existing chronic conditions compounded by challenges with communication, that may contribute to undiagnosed conditions (Accardo et al., 2003). Thus, families of children with DD face greater care giving demands than those of non-developmentally disabled children, and often interact with a wide range of service providers to manage care needs (McGinley & Alexander, 2018). Research has demonstrated the importance of family adaptation to optimize management of a child's disability (Seligman & Darling, 2007), yet families often experience heightened caregiving burden and increased levels of perceived stress (Dykens et al., 2014).

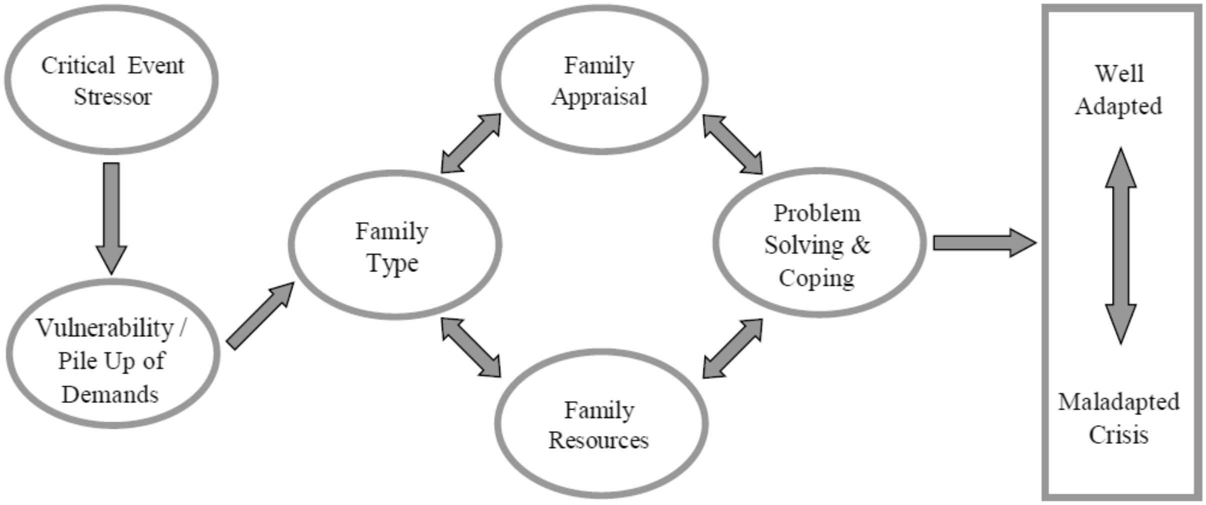
Living with sustained challenges can contribute to unhealthy family behaviors that negatively impact the psychological and physical health of parents/caregivers (Allen & Babin, 2013; Woodman, 2014). Parents must adapt to the changing care demands, evaluate resources, and navigate complex systems of services to support their children while balancing daily family life routines (Lindo et al., 2016). According to McCubbin, Thompson, & McCubbin (1996), family adaptation is the outcome of efforts to bring balance, harmony, coherence, and functioning to the demands and stress of daily life. Parents/caregivers are viewed as the orchestrators or leaders of the family. Researchers have documented that highly stressed parents are less able to implement interventions for their children with disabilities; consequently, their children make less progress (Dykens et al., 2014). Hence, understanding factors that empower and support families to adapt and cope with continual changing demands may lead to the enhancement of parents/caregivers' quality of life (QOL), which is central to achieving optimal child health outcomes (Cachia et al., 2016; Minor et al., 2006).

One emerging area requiring adaptation for families of children with DD who have CCN is the use of technology referred to as augmentative and alternative communication (AAC). Augmentative and alternative communication includes picture symbols, computers/iPads with communication apps, and speech-generating devices (SGD) to support communication exchanges. Children with CCN utilize AAC technology to enhance communication and social interactions (American Speech-Language-Hearing Association [ASHA], 2017). The AAC field has seen an increase in the number of children who require AAC for communication, which maybe a result of a rise in Autism Spectrum Disorder (ASD) and improved survival rates for children born with DD (CDC, 2015; Light et al., 2019). Additionally, there is increased accessibility of AAC with the wide availability of mobile technologies, as well as an increased acceptance and awareness of DD (McNaughton & Light, 2013). Unfortunately, such devices come with inherent challenges. The rapid technology proliferation has changed the scope of communication interactions significantly in society (Allen & Shane, 2014; Light et al., 2019; Light & McNaughton, 2012; McNaughton & Light, 2013; Meder & Wegner, 2015). Children communicate through a wide range of interactions (e.g. face-to-face, written) as well as through expanded communication platforms (e.g. Facebook, Twitter, etc.; Light et al., 2019; McNaughton & Light, 2013). While AAC devices can improve communication capabilities for children with CCN, they also add layers of complexity related to training, programming, financial accessibility, and integration of the device into daily living. Families of children with CCN utilizing AAC have expectations for their child's engagement in society across a range of environments including education, family, healthcare, and community (Holyfield et al., 2017; Light et al., 2019). Such expectations and layers of complexity may have a negative impact on family adaptation.

To enhance understanding of factors that may facilitate adaptation in families of children with CCN utilizing AAC technology, the studies in this review were categorized according to the key concepts of the Resiliency Model of Family Stress, Adjustment, and Adaptation (Figure 1; McCubbin et al., 1996). Grounding this review in an established framework provides a structured conceptual approach for evaluating key interacting family components (e.g., demands, type, appraisal, resources, and problem solving/coping) that shape processes and outcomes associated with family adaptation (Figure 2.1). Utilizing both family stress and resiliency theory, the model emphasizes the complex role the family system plays in the variability of outcomes and the well-being of individual family members, including parents/caregivers (McCubbin et al., 1996). Additionally, the Resiliency Model has been extensively tested in families of children with chronic conditions such as diabetes, cancer, as well as DD, including cerebral palsy and Down syndrome (McCubbin et al., 1996). Research suggests a family systems lens could be useful to improve an understanding of families of children with CCN utilizing AAC to inform practice (Mandak et al., 2017). Little work, however, has been conducted within the theoretical bases of AAC research and utilizing an established framework in this area carries potential to advance the science through a more structured lens. Studies could then be compared and contrasted, and common variables utilized to understand possible modifiable factors for targeting future nursing interventions to assist families of children with CCN utilizing AAC.

Guiding Framework

Figure 2.1: Resiliency Model of Family Stress, Adjustment, and Adaptation



Conceptual model. Adapted from McCubbin, M. A., Thompson, A., & McCubbin, H.I., (1996). *Family assessment: Resiliency, coping and adaptation*. Madison, WI: University of Wisconsin-Madison.

In Figure 2.1, the selected model components are presented, followed by adaptation versus maladaptation outcomes. The model begins with the critical event, in this case the use of an AAC device by a child with CCN. *Demands* are defined as the stressors, strains, hardships, and transitions faced by the family unit raising a child with CCN (McCubbin et al., 1996). *Type* is a set of basic attributes about the family system which characterize and explain how a family typically behaves (McCubbin et al., 1996). *Appraisal* is the family's meaning or perception of the critical events or stressors and their ability to manage the related demands (McCubbin et al., 1996). *Resources* are the strengths and capabilities of individual members, the family unit, and the community (McCubbin et al., 1996). *Problem-solving and coping* are specific actions taken by individual members or the family unit to manage challenges and demands, as well as acquire, allocate, and use resources that reduce strains and modify family appraisal (McCubbin et al., 1996). Lastly, *adaptation* occurs when the family balances the (1) demands of the child with

CCN, (2) family's perceptions of those demands, (3) utilization of their resources/strengths, and (4) family's ability to organize and manage the demands. In cases where the family is not able to achieve balance, and adaptation is not successful, maladaptation occurs. *Maladaptation* is a state of imbalance in the family system, creating a condition and opportunity for the family to modify above-mentioned model components. For the present review, adaption versus maladaptation is focused on family adaptation to ACC use by a child with CCN.

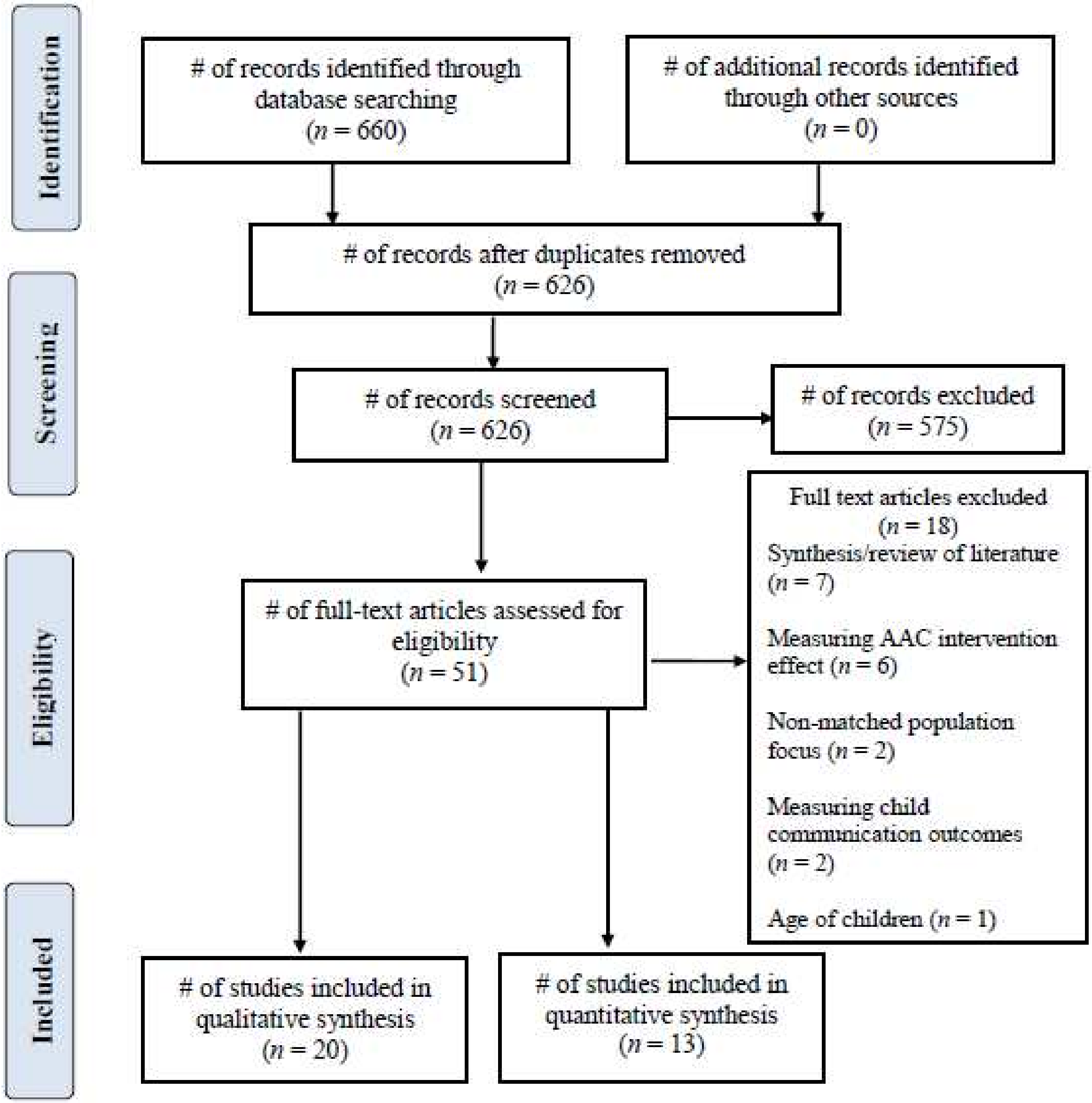
Aims of the Integrative Review

The purpose of this integrative review is to examine both quantitative and qualitative research concerning family adaptation in families of children with CCN who use AAC. Specifically, the primary aim of the review was to assess the conceptual foundations of family adaptation utilizing the Resiliency Model while: (1) synthesizing the related literature within the theoretical model; (2) assessing measurement tools utilized in studies with families of children with CCN to identify factors impacting adaptation; and (3) discussing implications for nursing practice and directions for further research within a family systems framework.

Methods

The Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) (Figure 2.2; Liberati et al., 2009) was used to report the process of obtaining and including literature for the review. In addition, the integrative review methodology framework of Whittemore and Knafl (2005) was utilized to direct the rigor of the review. This method allows for the inclusion of diverse methodologies (for example, experimental and non-experimental research) in a single assessment of the literature to better understand a phenomenon (Whittemore & Knafl, 2005). Other reviews, such as systematic reviews, meta-analyses, and meta-syntheses methods are aimed at exclusively synthesizing quantitative or qualitative studies. An integrative review is an innovative and novel approach in the field of AAC research concerning families of children with CCN. No integrative reviews in this area of research have been currently found. Given the varied methodological approaches incorporated in this review, the Mixed Methods Appraisal Tool (MMAT) was utilized for quality appraisal of the studies (Pace et al., 2011).

Figure 2.2: PRISMA Diagram



Flow diagram of the retrieval and screening process (AAC: Augmentative and Alternative Communication).

Eligibility Criteria

Studies were included if they met the following inclusion criteria: 1) focused on families with children younger than age 26 with CCN (regardless of developmental disability diagnosis) using AAC; 2) published in English; 3) peer reviewed; 4) unrestricted publication dates; and 5) original studies regardless of design. Studies were excluded if: 1) the main objective was to measure AAC intervention effectiveness in children rather than familial adaptation, 2) did not include children younger than 26 years with CCN, 3) non-matched population focus, or 4) only addressed professionals/practitioners' perspectives of AAC. Systematic reviews, meta-analyses, reviews of literature, unpublished studies/documents, and commentaries were excluded.

Data Sources and Search Strategies

A literature search was conducted to identify literature from various disciplines including nursing. Studies were located using the following key terms: ("complex communication needs" OR CCN) OR (AAC OR augmentative and alternative communication) AND (family OR parents OR mother OR father OR caregiver) AND (adapt OR adaptation OR resilient OR resiliency OR cope OR coping) in multiple online databases (i.e., CINAHL, PUBMED, ERIC, PsychInfo, and Web of Science). Abstracts and full text articles were independently screened by two researchers, utilizing Covidence© (2018), a web-based software platform. F1000 Workspace was used to manage, store, and share selected articles. Mutual consensus between the two investigators was reached for included studies.

Data Extraction and Synthesis

Studies were extracted using an electronic resource tool, F-1000 Workspace, for managing bibliographies, citations, and references. For each of the included studies, the following data were extracted: authors, country, methodology, participants and sample characteristics, instruments/ measures, and key findings. Next, family factors reported in the studies as influencing adaptation were reviewed and grouped according to four key components of the Resiliency Model: demands, appraisal, resources, and problem-solving/coping (see Figure 1). One of the model components, family type, is based on a family's levels of hardiness and cohesiveness, was not measured according to McCubbin et al. (1996) in any of the extracted studies; therefore, was not applicable in this review.

Quality Assessment

According to Whittemore and Knafl (2005), evaluation of quality sources in a review that encompasses different research designs is complex, and there is not a specific standard to adhere to; however, quality should be addressed in a meaningful way. We safeguarded against lower quality by only reviewing peer-reviewed studies. Additionally, the Mixed Methods Appraisal Tool (MMAT), which was designed for the appraisal of literature that includes qualitative, mixed methods, and quantitative studies (i.e., randomized controlled, non-randomized, and descriptive) (Pace et al., 2011). Inter-rater reliability was evaluated following two independent evaluations. The MMAT was also utilized to evaluate the source and type of data, sampling, instrumentation, and data analysis of findings (Pluye et al., 2011). The quality assessment for each study (Tables 2.1 and 2.2) was addressed in the limitations section of the review.

Results

The initial search from the databases yielded 660 records. A review for duplicates was conducted (*n* = 34), and the remaining 626 records were screened at the title and abstract levels. Fifty-one abstracts met screening criteria and were assessed at the full text level for eligibility by the first and second authors independently. Mutual consensus was reached for the exclusion of 18 studies. The search strategy was based on the PRISMA guidelines; Figure 2.2 provides details of the search results along with the rationale for exclusion (Moher et al., 2009). Reference lists of included studies were searched, and no additional records were identified. A total of 33 studies, including both qualitative (*n* = 20) and quantitative (*n* = 13) met the inclusion criteria and for the review.

Synthesis of the Literature

Setting/design/sample size. Key study characteristics are presented in Table 2.3. Studies were conducted in the United States (*n* = 16), Australia (*n* = 5), the United Kingdom (*n* = 3), South Africa (*n* = 3), and one in Canada, Hungry, Israel, Malaysia, Malta, and Sweden, respectively. Twenty studies utilized qualitative methodology, which included focus groups, case studies, semi-structured interviews, and/or observational designs. The remaining 13 studies were quantitative and primarily utilized cross-sectional descriptive designs, with only one study applying an experimental approach incorporating a pretest-posttest design. The 33 studies included a total of 1,580 participants with sample sizes ranging from 1 to 180.

Participants. Mean age and age range of parent/caregiver participants (representing the family) were not consistently reported across studies, and 18 studies did not report parent/caregiver age. Of those studies that did report age, the parental age-range spanned from 20 to 69 years old. Sex was not reported in 13 studies and parental marital status was reported infrequently across studies. Fourteen studies did not report racial or ethnic group identification; five studies reported 100% White/Caucasian participants, two studies reported 100% Hispanic participants, and one study reported 100% Native American participants. Thirteen studies had a mixture of racial/ethnic backgrounds for their participants. Only one study reported religious identification of their participants. Additionally, socio-economic status (SES) and parental/caregiver education levels were not reported in 11 studies and were not consistently reported across 22 studies. For example, SES was reported by annual family income levels, social class, or employment versus unemployment status. Educational levels of parents/caregivers across 22 studies spanned from grade school to post-graduate education. Only five studies reported geographical locations of family residences (i.e., rural, suburban, or metropolitan).

The majority of studies included children with multiple disabilities as depicted in Table 3. However, 12 studies focused on parents of children with specific conditions (i.e., Cerebral Palsy [*n* = 7], Autism Spectrum Disorder [*n* = 3], Fragile X Syndrome [*n* = 1], non-specified ID [*n* = 1]). Child age was not consistently reported in years of age across studies. For example, some studies utilized school or grade level such as primary, junior, or senior high as a proxy for child ages. Three studies did not report information on the type of AAC (i.e., high or low) technology system utilized by child participants but indicated non-specific receipt of disability-related support services for CCN.

Assessment of Measurements and Instruments

A variety of measures and instruments were used within the included studies. Twenty studies (see Table 2.4) utilized survey questionnaires or interview guides specifically developed for the identified study. For example, in one study, authors developed a survey to assess out-of-pocket expenses related to equipment needs of families with a child with Cerebral Palsy who utilized the Assistance to Participate Scale (APS) to measure the level of assistance required for their child to participate in play and recreation activities. Five studies utilized instruments with reported validity and reliability characteristics. For example, two studies examined quality of life using the Beach Family Quality of Life Scale (Schlebusch et al., 2017; Schlebusch et al., 2016). Specifically, the dimensions included family interaction, parenting, emotional well-being, material/physical well-being, and disability-related support (Schlebusch et al., 2017). One study examined parental stress and potential sources of support using the Parenting Stress Index (PSI) and The Family Support Scale (FSS; Jones et al., 1998). Additionally, two studies utilized the Family Impact of Childhood Disability (FICD) to capture the impact of the child's CCN on the family (Clarke et al., 2011; Schlebusch et al., 2016). None of the studies employed a measure specific to the population of interest: families of children utilizing AAC.

Theoretical Underpinnings: Framing the Literature

Most studies discussed the importance of family-centered approaches to AAC intervention, but only two studies reported the use of a theoretical framework/model. The two theoretical frameworks included The International Classification of Functioning, Disability, and Health Children and Youth Version framework (ICF-CY) (Mei et al., 2015) and the Family Quality of Life (FQOL) approach as it relates to the functioning of families raising children with disabilities (Schlebusch et al., 2017; Schlebusch et al., 2016).

Family model components leading to adaptation versus maladaptation. As previously mentioned, the Resiliency Model (see Figure 2.1) begins with a critical event, which, for this review, is family adaptation to AAC use by a child with CCN.

Demands. Many demands (e.g., stressors, challenges, barriers) were identified in families of children with AAC interventions, including: a) the emotional and physical demands of the disability; b) device/technology challenges and limitations; c) insufficient time to learn AAC; d) lack of multidisciplinary services and teamwork; e) inadequate financial supports; f) lack of knowledge and support from professionals surrounding AAC use; and g) limited cultural/societal awareness and support (Bailey et al., 2006; Bourke-Taylor et al., 2013; Crisp, Burke, & Cirgin, 2014; Goldbart & Marshall, 2004; Hemsley et al, 2013; Jones et al., 1998;

Marshall & Goldbart, 2008; McCord & Soto, 2004; McNaughton et al., 2008; Schlebusch et al., 2017; Singh et al., 2017; Thunberg et al., 2016). Additionally, parents and caregivers acknowledged changes in roles and increased time demands in caring for their child with CCN utilizing AAC. The key roles played by parents were: a) caregiver, b) teacher, c) playmate, d) therapist, e) technical support, and f) advocate (Brady et al., 2006; McNaughton, et al., 2008). In particular, parents/caregivers had to spend more time assisting with their child's care and helping their child to communicate when the child was hospitalized. Parents perceived the hospital staffs' lack of knowledge/training with AAC and lack of time given to communicate with the child as increasing their stress (Hemsley et al., 2013; Thunberg et al., 2016).

Other demands reported by parents/caregivers were related to the lack of AAC device training concerning use, repair, and programming (Allaire et al., 1991; Anderson, et al., 2015; Angelo et al., 1995; Borg, Agius, & Agius, 2015; Brady et al., 2006). Additionally, inconsistent service delivery, inaccessibility of professional services, and ineffective interprofessional teams were additional sources of family stress (Anderson et al., 2014; Angelo et al., 1995; Blosser et al., 1994; Crisp et al., 2014; Goldbart & Marshall, 2004; Hetzroni, 2002; Marshall & Goldbart, 2008; McNaughton et al., 2008; Meder & Wegner, 2015; Serpentine et al., 2011; Singh et al., 2017). The need for funding and out-of-pocket expenses for the AAC device, as well as the technology portability and device limitation issues created perceptions of increased parent/caregiver strain (Allaire et al., 1991; Angelo, 2000; Angelo et al., 1995; Bailey et al., 2006; Borg et al., 2015; Bourke et al., 2013; Crisp et al., 2014; Marshall & Goldbart, 2008; McNaughton et al., 2008; Schlebusch et al., 2017; Serpentine et al., 2011). Further, there were challenges associated with device limitations related to cultural and language preference programming for familial and home interactions. Particularly, a lack of device programming for multiple languages, along with symbols reflecting English structure and North American references instead of customizations for multi-lingual/multicultural families, were problematic (Hetzroni, 2002; Huer, Parette, & Saenz, 2001; McCord & Soto, 2004; Singh et al., 2017; Stuart & Parette, 2002).

Many families reported that the physical communication demands of the child's disability created stress (Donohue et al., 2015; Goldbart & Marshall, 2004; Jones et al., 1998; Schlebusch et al., 2016). The unexpected social isolation, public attitudes about the child's communication disability, efforts to seek peer socialization activities, and opportunities to integrate the device into the community/society created additional strain (Angelo et al., 1996; Batorowicz et al., 2014; Goldbart & Marshall, 2004; McNaughton et al., 2008; Mei et al., 2015; Parette et al., 2000; Singh et al., 2017). Findings from a number of the studies indicated that competing demands, resources, and services may increase family stress and possibly reduce the overall effectiveness of the intervention for the child to interact and function within society (Allaire et al., 1991; Anderson et al., 2014; Angelo, 2000; Bailey et al., 2006; Batorowicz et al., 2014; Borg et al., 2015; Bourke-Taylor et al., 2013; Brady et al., 2006; Clarke et al., 2011; Hemsley et al., 2013; Hetzroni, 2002; Jones et al., 1998).

Another source of stress for parents was the match between their perceived difficulties of the child's disability and the child's "acceptability," or how close the child is to meeting parental expectations of the idealized/hoped for child (Jones et al., 1998). Additionally, fathers perceived that a child's moodiness was a greater source of stress compared with mothers (Jones et al., 1998). For mothers, a greater source of stress was derived from the relationship with the spouse. Consequently, parent-related stressors were found to be greater sources of stress for mothers than fathers (Jones et al., 1998). Such demands (e.g., stressors, challenges, barriers) coincide with the "pile up" component of the underlying conceptual model used in this review.

Appraisal. In many studies, the AAC device was viewed as a positive tool for the child by parents/caregivers. Specific studies indicate the device improved the child's quality of life, supported language and literacy development, communication competence, increased independence, and opportunities for the future (Angelo, 2000; Bailey et al., 2006; Batorowicz et al., 2014; Borg et al., 2015; Singh et al., 2017). However, negative perceptions related to AAC use were also present. These negative views generally centered around lack of information and knowledge, stigma, and frustrations related to not understanding the child (Brady et al., 2006; Marshall & Goldbart, 2008; Parette et al., 2000; Romski et al., 2011; Serpentine et al., 2011).

Findings from studies in South Africa (Schlebusch et al., 2017; Schlebusch et al., 2016), revealed that FQOL is associated with family income, family type (rhythmic), and the severity of Autism Spectrum Disorder (ASD). Additionally, FQOL is strongly associated with regular family routines and positive/negative appraisal of the impact of ASD. The greater the positive appraisal of the impact of ASD on the family, the higher the overall association with FQOL (Schlebusch et al., 2016), indicating the appraisal or meaning given to a stressor, strain, or crises influences the outcomes of the event. Consequently, this implies that positive and negative appraisals co-exist, and families who are able to balance this dialectic may gain a sense of family functioning, as indicated in the McCubbin et al. (1996) conceptual model depicted in this review.

Resources. Individual level resources that played a role in adaptation included spousal support (Jones et al., 1998) and the ability to understand the child (Marshall & Goldbart, 2008). Characteristics such as familial routines, smaller household size, greater income, cultural perspectives, and respect for professionals were reported as resources that enhanced family adaptation to AAC use (Angelo, 2000; Hetzroni, 2002; Donohue et al., 2015; Marshall & Goldbart, 2008; Mei et al., 2015; Schlebusch et al., 2017; Schlebusch et al., 2016). Additionally, informational support to enhance ease of device use was perceived as resources that improved family adaptation (Angelo, 2000; Bailey et al., 2006; Meder & Wegner, 2015; Serpentine et al., 2011; Singh et al., 2017). Furthermore, access to community disability resources, professional collaboration/partnerships, and teaming from schools, day cares, other family members and peers enhanced ongoing adaptation of AAC device implementation and use (Anderson et al., 2014; Angelo, 2000; Bailey et al., 2006; Crisp et al., 2014; Huer et al., 2001; Jones et al., 1998; McCord & Soto, 2004; Meder & Wegner, 2015; Mei et al., 2015; Parette et al., 2000; Romski et al., 2011; Schlebusch et al., 2017; Serpentine et al., 2011; Singh et al., 2017; Stuart & Parette, 2002). Therefore, the described family resources reflected a valued component in the conceptual model.

Problem-solving and coping. Families utilized problem-focused coping strategies by advocating for their child and taking an assertive approach to expressing concerns with professionals in an effort to protect and enhance their child's quality of life (Angelo, 2000; Goldbart & Marshall, 2004; Hemsley et al., 2013; Marshall & Goldbart, 2008; McNaughton et al., 2008; Thunberg et al., 2016). Additionally, self-reliant problem-solving strategies such as becoming an "educated consumer" of AAC with active involvement in device selection, information seeking strategies, and seeking alternative service models with a collaborative family-professional approach were identified (Allaire et al., 1991; Anderson et al., 2015; Anderson et al., 2014; Blosser et al., 1994). Findings indicated that both positive and negative emotional well-being can coexist in families of children with disabilities and mediates the relationship between FQOL (Schlebusch et al., 2017; Schlebusch et al., 2016). Embracing AAC device use as a mechanism for improving children's communicative function rather than curing their disabilities assisted parents with adaptation (Bailey et al., 2006; Huer et al., 2001; Serpentine et al., 2011). Hence, families utilize various problem-solving and coping strategies to assist with the demands of managing a child's AAC device, which is depicted as another component in the McCubbin et al. (1996) model.

Adaptation. Table 2.5 groups key findings by family adaptation components. Families of children with CCN utilizing AAC devices experience not only the demands (e.g., stressors, challenges, barriers) of the technology device, but also the unique demands associated with raising a child with a DD from both within and outside the family unit. Additionally, in the studies reviewed, both positive and negative appraisals co-existed in families and mediated family functioning. Regarding resources, individual level resources (i.e., support from family members, spouses) played an important role in adaptation. Family characteristics (i.e., family income, size, cultural perspectives) and family level resources (i.e., peer support, community resources, interprofessional partnerships) were also associated with adaptation. Lastly, families who utilized various active problem-solving and coping strategies to assist with the demands of managing a child's AAC device facilitated adaptation.

Discussion

Successful integration of an AAC device into a child's life revolves around the family unit. However, it remains evident that limited research exists concerning the effect of the technology on parent/caregiver outcomes or family adaptation. Findings from this review provide insights to guide future implications for family nursing research and practice. The results largely emphasized the reported parental/caregiver challenges, increased demands, and stresses associated with AAC device use in children with CCN. Some families adapt successfully to

AAC technology integration with associated demands, but unfortunately there is limited understanding of the multifactorial phenomenon. Additionally, the range of developmental disabilities within the studies and across studies, such as Autism Spectrum Disorder, Down syndrome, Cerebral Palsy, non-specific intellectual disabilities, and other genetic conditions yields unique severity of symptoms and challenges making comparisons across groups of families difficult. Subsequently, studies included in this review lack consistency in the use of measurement instruments with reported psychometric properties to understand functional and contextual factors specific to AAC use that impact the everyday lives of children and families. This review also highlighted that many studies were not grounded in a theoretical model/framework to explain the interaction of family components that lead to a better understanding of family adaptation to a child's AAC device use.

Implications for Family Nursing Research

Research aimed at understanding and measuring factors that support and help families of children with CCN adapt to the child's communication challenges is needed, especially in the model component areas of family type, appraisal, and problem-solving and coping. The McCubbin et al. (1996) model would be useful in future research to explain why families undergoing similar experiences (i.e., child utilizing AAC) may respond differently depending on interacting components (i.e., family demands, family appraisal, family resources, and family problem-solving communication) that shape the family process and outcomes of adaptation (Van Riper, 2000). Understanding the experiences of families will assist in developing future interventions, and possibly exploring family type/typologies to assist with explaining predictions of family risks or patterns of functioning given certain situations. Additionally, longitudinal studies and the development and testing of interventions to enhance family adaptation to new technology may prove supportive to both the child and family. Future research studies that address the limitations identified in this review would advance the generalizability of findings. Subsequently, new studies with parents of diverse racial, ethnic, socioeconomic, and educational backgrounds would contribute wider influence and perspective.

Implications for Family Nursing Practice

Nurses practice in a variety of settings (e.g., schools, hospitals, clinics) and are a key resource to parents learning to adapt to their child's disability needs and use of AAC. Children with DD are more vulnerable to health problems, often leading to interactions with a wide range of healthcare and service professionals (McNaughton et al., 2010). Since effective communication is essential to enhance coping and positive experiences with health services for both families and children with CCN, nurses should have competence in the use of adaptative communication technologies (Hemsley et al., 2013). Nurses are pivotal to assessing family and parental needs to support successful outcomes of AAC device use and assisting parents with identifying appropriate community resources (Crisp et al., 2014).

Nurses understand that family well-being and quality of life are essential for achieving optimal child outcomes. Therefore, nurses are well positioned to assess the risk of demands/stressors in these families' lives and implement strategies or resources to assist with decreasing demands, encouraging problem-solving communication, and expanding families' range of coping strategies. The lack of empirical evidence regarding the perspectives of families who have children with diverse DD utilizing AAC devices leaves a gap in understanding family adaptation. This demonstrates the need for a clearer picture of the phenomenon to guide nursing practice and aligns with the International Family Nursing Association (IFNA)'s position statements on nursing practice and education. The IFNA Position Statement advocates for the "use of family science, family nursing, and theoretical frameworks to guide discipline-specific and interdisciplinary dialogue regarding family-focused practice and outcomes" (IFNA, 2018).

Limitations

It is important to acknowledge the conceptual and methodological limitations of the studies evaluated in this review. Only two studies identified a conceptual framework to guide the research and neither specifically included a definition of adaptation (Mei et al., 2015; Schlebusch et al., 2017). In the included papers, the most commonly addressed components of the McCubbins' model were family demands, referred to as "pile up"—second in frequency was family resources—whereas only a few studies addressed the appraisal component. Further, many of the studies were inconsistent in documenting the primary source of data and whom it was collected from (i.e., mother, father, caregiver, other family member (Anderson et al., 2015; Anderson et al., 2014; Clarke et al., 2011; Hemsley et al., 2013; Meder & Wegner, 2015; Parette et al., 2000; Schlebusch et al., 2017; Serpentine et al., 2011). Family type was mentioned in only one study; consequently, this model component was omitted from the review. Further, diversity of the samples in terms of size, age, gender, socioeconomic status, marital status, family household members, and education was inconsistently reported across studies. Sample sizes varied widely across studies, with no study justifying their selected sample size.

Only five studies used measures which reported psychometric properties (Bourke-Taylor et al., 2013; Clarke et al., 2011; Jones et al., 1998; Schlebusch et al., 2017; Schlebusch et al., 2016), while the remaining studies utilized questionnaires developed by the authors. Most studies incorporated descriptive cross-sectional designs and participant self-report, therefore limiting the generalizability of findings. In addition, the lack of longitudinal studies reduces the ability to recognize changes in family adaptation to AAC over time. Only one study combined interviews with observations (McCord & Soto, 2004). Finally, only 33 studies were included in this review, and it is possible that some studies were omitted and not reached within the grey literature utilizing the key search terms.

Conclusion

Although research has explored the effectiveness of AAC interventions for children with CCN, it remains evident that limited research exists concerning family adaptation. The innovation of new knowledge in the area of improving family adaptation for children with CCN using AAC devices lies in a multi-pronged approach. This approach must involve a clear conceptualization of the issues through an appropriate model and the discovery of key components that impact family adaptation. Nurse scientists can offer this expertise while engaging diverse professionals, such as speech-language pathologists, healthcare providers, family experts, educators, and technology engineers. Since nursing is a discipline that perceives the individual in relation to the larger environment and community, nurse scientists can lead the discovery of knowledge to impact outcomes for children and their families. Thus, this review provides evidence that nurse researchers need to further evaluate factors that enhance family adaptation to maximize outcomes for families of children with CCN.

APPENDICES

Appendix A: Quality Assessment of Quantitative Studies

Table 2.1

Quality Assessment of Quantitative Studies (n = 13)

Authors, Year	Is the sampling strategy relevant to address the quantitative research question?	Is the sample representative of the population understudy?	Are measurements appropriate (clear origin, or validity known, or standard instrument)?	Is there an acceptable response rate (60% or above)?
Allaire et al., 1991	Y	N	N	Y
Anderson et al., 2014	Y	Y	Y	Y
Angelo 2000	Y	N	N	N
Angelo et al., 1996	Y	N	N	N
Angelo et al., 1995	Y	N	N	N
Bourke-Taylor et al., 2013	Y	N	?	Y
Clarke et al., 2011	Y	Y	Y	N
Donohue et al., 2015	Y	Y	N	Y
Hetzroni, 2002	Y	?	N	?
Jones et al., 1998	Y	N	Y	N
Meder & Wegner, 2015	N	N	N	N

Table 2.1 (cont'd)

Romski et al., 2011	N	?	Y	Y
Schlebusch et al., 2017	Y	Y	Y	N
Schlebusch et al., 2016	N	N	Y	N

Note. Y: Included; N: Not included; ?: Unclear.

Appendix B: Quality Assessment of Qualitative Studies

Table 2.2

Quality Assessment of Qualitative Studies (n = 20)

Authors, Year	Are the sources of qualitative data (archives, documents, informants, observations) relevant to address the research questions (objective)?	Is the process for analyzing qualitative data relevant to address the research question (objective)?	Is appropriate consideration given to how findings relate to the context, e.g. the setting, in which the data were collected?	Is appropriate consideration given to how findings relate to researchers' influence, e.g. through their interactions with participants?
Anderson et al., 2015	Y	Y	Y	Y
Anderson et al., 2014	Y	Y	Y	Y
Bailey et al., 2006	Y	Y	Y	Y
Batorowicz et al., 2014	Y	Y	Y	Y
Blosser 1994	Y	Y	?	?
Borg et al., 2015	Y	Y	Y	Y
Brady et al., 2006	Y	Y	Y	Y
Crisp et al., 2014	Y	Y	Y	Y
Goldbart & Marshall, 2004	Y	Y	Y	Y
Hemsley et al., 2013	Y	Y	Y	Y

Table 2.2 (cont'd)

Huer et al., 2001	Y	Y	Y	Y
Marshall & Goldbart, 2008	Y	Y	Y	Y
McCord & Soto, 2004	Y	Y	Y	Y
McNaughton et al., 2008	Y	Y	Y	Y
Mei et al., 2015	Y	Y	Y	Y
Parette et al., 2000	Y	Y	Y	Y
Serpentine et al., 2011	N	Y	Y	Y
Stuart & Parette, 2002	Y	Y	Y	Y
Singh et al., 2017	Y	Y	Y	Y
Thunberg et al., 2016	N	Y	Y	?

Note. Y: Included; N: Not included; ?: Unclear.

Appendix C: Study Characteristics and Overview

Table 2.3

Study Characteristics and Overview (N = 33)

Author, Year, Country	Design	Purpose	Sample size/Participant description
Allaire et al., 1991 US	Quant	To obtain information about caregivers and their children's AAC use.	***Parents/caregivers*** (*N* = 110) Father (*n* = 5); Mother (n = 95); grandparents (n = 4), foster parents (n = 3), other (n = 3) Age range: NR; SES: NR Ed: NR; Diversity: NR ***Children***: (*N* = 110) Boys: (*n* = 75), Girls: (*n* = 35) Age range: 2–26 yrs. Mean age: 10.4 (4.7) Condition: CP 76%, ASD 3%, other 21% AAC system: low & high
Anderson et al., 2015 Australia	Qual	To explore the experiences of SLP and families regarding alternative modes of support and training for families with a new SGD.	***Parents/caregivers*** (*N* = 7) Mothers/fathers: NR Age range: NR, SES: NR, Ed: NR; Diversity: NR; Geographical location: rural (*n* = 1), metro (*n* = 6) ***Children***: NR; Age: NR Condition: CP, ASD AAC system: high ***SLP*** (*N* = 13) Experience range: 1–12 yrs.
Anderson et al., 2014 Australia	Quant	To explore perceptions of existing support for families with new SDG.	***Parents/caregivers*** (*N* = 6) Mothers/fathers: NR

Table 2.3 (cont'd)

			Age range: NR, SES: NR, Ed: NR; Diversity: NR; Geographical location: regional ($n = 2$), metro ($n = 4$) ***Children***: ($N = 6$) Age: primary school ($n = 4$), High school ($n = 2$) Condition: CP, ASD, ID, Dyspraxia AAC system: high
Angelo, 2000 US	Quant	To identify the impact of AAC device use on families and parents.	***Parents/caregivers*** ($N = 114$) Father ($n = 10$), Mother ($n = 92$), unspecified ($n = 12$) Age range: 41–62 yrs. SES: <\$10,000 1% \$10-40,000 38.6% \$40-\$80,000 51.5 % >\$80,000 8.9% Ed: Mothers 41% HS, 57.3% college, Fathers 30.6% HS, 64.8% college Diversity: Mothers & fathers 94.8% White Married: 88.1% Geographical location: suburban 54.6%, urban 10.9%, rural 34.5% ***Children***: (N = NR) Age range: 1–21 yrs. Condition: physical disability, ID/DD, ASD, speech impaired, visually impaired AAC system: low & high
Angelo et al., 1996 US	Quant	To identify family needs of parents of children between the ages of 13 to 21 using AAC.	***Parents/caregivers*** ($N = 132$) Father ($n = 47$), Mother ($n = 85$), families ($n = 97$)

Table 2.1 (cont’d)

			Age range: 41–66 yrs. SES: <$10,000 6.9% $10-30,000 39.1% $31-50,000 34.5%, >$50,000 19.5% Ed: Mothers 40.7% HS, 55% college; Fathers 41.9% HS, 55.4% college Diversity: Mothers & fathers 92% White Married: 71% Geographical location: suburban 33.8%, urban 10.9%, rural 47.9% ***<u>Children</u>***: (*N* = NR) Mean age: 15.6 yrs. Condition: physical disability, ID/DD, multihandicap, speech impaired, visually impaired AAC system: low & high
Angelo et al., 1995 US	Quant	To identify family needs of children between the ages of 3 to 12 years using AAC.	***<u>Parents/caregivers</u>*** (*N* = 91) Father (*n* = 35), Mother (*n* = 56), families (*n* = 59) Age range: 27–69 yrs. SES: <$20,000 21.2% $21-30,000 15.4% $31-40,000 21.2%, $40-50,000 9.6% >$50,000 32.6% Ed: Mothers 44.8% HS, 55.2% college; Fathers 34.6% HS, 63.5% college Diversity: Mothers & fathers 100% White Married: 86.2%

Table 2.3 (cont’d)

			Geographical location: NR ***Children***: (*N* = NR) Mean age: 8.69 yrs. Condition: physical disability, ID/DD, multihandicap, speech impaired AAC system: low & high
Bailey et al., 2006 US	Qual	To examine family members ‘perceptions regarding the use of AAC devices. Factors perceived to affect students’ use, family expectations, and benefits of AAC device.	***Parents/caregivers*** (*N* = 6) Father (*n* = 1), Mother (*n* = 5) Age range: 15–60 SES: 100% middle class Ed: Grammar to bachelor Diversity: 100% White Geographical location: NR ***Children***: (*N* = 7) Boys: (*n* = 7), Girls: (*n* = 0) Age range: Jr. high to HS Condition: Non-specified moderate, severe or multiple AAC system: low & high
Batorowicz et al., 2014 Canada	Qual	To examine the views of children who use aided communication and their parents, on social participation, communicative interactions, and relationships.	***Parents/caregivers*** (*N* = 8) Father (*n* = 2), Mother (*n* = 6) Age range: NR, SES: NR Ed: HS to post-graduate; Diversity: NR Geographical location: NR ***Children***: (*N* = 8) Boys: (*n* = 2), Girls: (*n* = 6) Age range: 5–14 yrs.

Table 2.3 (cont'd)

			Mean age: 10.9 (3.5) Condition: CP, non-specified AAC system: low & high
Blosser, 1994 US	Qual	To describe parental experiences with SLP and the intervention process.	***Parents/caregivers*** (*N* = 3) Father (*n* = 0), Mother (*n* = 3) Age range: NR, SES: NR Ed: NR; Diversity: NR Geographical location: rural (*n* = 1), NR (*n* = 2) ***Children***: (*N* = 3) Boys: (*n* = 1), Girls: (*n* = 2) Age range: 4–8.5 yrs. Condition: CP, visual & hearing impairments AAC system: NR
Borg et al., 2015 Malta	Qual	To explore the parental and child perceptions of managing and using two different forms of AAC (low tech and high tech).	***Parents/caregivers*** (*N* = 1) Father (*n* = 0), Mother (*n* = 1) Age range: NR, SES: NR Ed: NR; Diversity: NR Geographical location: NR ***Children***: (*N* = 1) Boys: (*n* = 0), Girls: (*n* = 1) Age: 9 yrs. Condition: right hemimegalencephaly, seizures AAC system: low & high
Bourke-Taylor et al., 2013 Australia	Quant	To investigate estimations of equipment needs of families raising a child with CP and complex needs in early years.	***Parents/caregivers*** (*N* = 29) Mother (*n* = 26); Father (*n* = 3); Couples (*n* = 21); families (*n* = 29)

Table 2.3 (cont'd)

			Age range: NR Median income: $88,000 Ed: NR; Diversity: NR Geographical location: NR ***Children*** (*N* = 29) Boys/girls: NR Age range: 2–12 yrs. Condition: CP AAC system: low & high
Brady et al., 2006 US	Qual	To provide information about communication in young children with Fragile X Syndrome and how families react to and accommodate communication in their children.	***Parents/caregivers*** (*N* = 55) Families (*n* = 55) Father (*n* = 0), Mother (*n* = 55) Age range: 20–41yrs. Ed: range of 8–19 years SES: 27% low income Diversity: 95% White, 4% Black, 1 % Latino Married: 85% Geographical location: NR ***Children*** (*N* = 55) Boys (*n* = 44), Girls (*n* = 11) Age range: 2–3 yrs. Condition: FXS AAC system: low & high
Clarke et al., 2011 UK	Quant	To conduct an analysis of relations between children with CCN and environmental factors and children's participation in everyday informal activities.	***Parents/Caregivers*** (*N* = 97) Mothers/father: NR Age range: NR Ed: NR; SES: NR ***Children*** (*N* = 95) Boys (*n* = 64), Girls (*n* = 31)

Table 2.3 (cont'd)

			Mean age: 10.02 (4.08) Condition: CP 51%, ASD 9%, Dyspraxia 6%, DS 1%, Severe LD 10%, other genetic conditions 16% Diversity: White 84%, Black 3%, Other 12% AAC system: low & high
Crisp et al., 2014 US	Qual	To identify barriers and facilitators to children's use of SDG.	***Parents/Caregivers*** ($N = 14$) Father ($n = 0$), Mother ($n = 14$) Age: NR SES: mid to upper class Ed: all with some college Diversity: 100% White ***Children*** ($N = 14$) Boys/girls = NR Age range: 5–23 yrs. Condition: ASD, CP, DS, other genetic disorders AAC system: low & high
Donohue et al., 2015 South Africa	Quant	To identify whether socioeconomic factors increased the odds of South African children with ID exhibiting co-occurring conditions of motor delay and/or unintelligible speech.	***Parents/Caregivers*** ($N = 145$) Father ($n = 30$), Mother ($n = 96$), other ($n = 19$) Age: 22–67 yrs., Mean age: 39.43 (8.56) SES: < \$7,500 64% > \$7,500 36% Ed: 50% education < 10th grade, 32% HS, 18% after HS Diversity: reported in home languages Household size: 2-13 people Mean household size: 5.08 ***Children*** (N = NR)

Table 2.3 (cont’d)

			Boys/girls = NR Age range: 8–14 yrs. Condition: ID AAC system: NR
Goldbart & Marshall, 2004 UK	Qual	To explore the lived experience of children who use AAC and the impacts on family life.	***Parents/Caregivers*** (*N* = 11) Mother (*n* = 9), Foster parent (*n* = 1), mother/father (*n* = 1) Age: NR; SES: NR Ed: NR; Diversity: NR ***Children*** (*N* = 11) Boys (*n* = 5), Girls (*n* = 6) Age range: 3–8 yrs. Condition: CP 53%, ID 35%, HI 12%, Epilepsy 5% AAC system: low & high
Hemsley et al., 2013 Australia	Qual	To understand communication needs and experiences of parents and children with CP and CCN in hospital.	***Parents/caregivers*** (*N* = 10) Mother/father: NR Age range: NR Ed: NR; SES: NR Diversity: NR ***Children*** (*N* = 10) Boys (*n* = 1), Girls (*n* = 9) Age range: 2–17 yrs. Condition: CP 100% AAC system: low & high
Hetzroni, 2002 Israel	Quant	To obtain demographic information on families of children who use or had the potential to use AAC, and to examine AAC services in the Israeli society.	***Parents/Caregivers*** (*N* = 69) Father/mother NR Age: NR SES: 31% HS, 69% after HS

Table 2.3 (cont'd)

			Ed: all with some college Diversity: 98% Jewish, 1% Christian, 1% Muslim Geographical location: 77% lived in cities, 16% rural areas ***Children*** (NR) Boys/girls = NR Age range: 3–21 yrs. Condition: CP, ID/DD, ASD, DS, Rett syndrome, other AAC system: low & high
Huer et al., 2001 US	Qual	To describe the perspectives of parents within a Mexican American community regarding AAC services.	***Parents/caregivers*** ($N = 7$) Father ($n = 1$), Mother ($n = 6$) Age range: 29–53 yrs. Ed: ranged from 3rd grade to 1 yr. of college; SES: unemployed ($n = 6$); part-time employed ($n = 1$) Diversity: 100% Mexican American & Spanish speaking ***Children*** ($N = 4$) Boys ($n = 3$), Girls ($n = 1$) Age range: 9–10 yrs. Condition: NR AAC system: low & high
Jones et al., 1998 US	Quant	To identify stressors and family supports of families with young children who use AAC technology and services.	***Families*** ($N = 59$) Mothers ($n = 58$), Fathers ($n = 52$); Married: 86% Age range: 27–69 yrs. Ed: 40% HS, 59% College

Table 2.3 (cont’d)

			SES: 36.5% <\$30,000; 63.5% ≥ \$31,000 Diversity: 100% White ***Children*** (*N* = 46) Boys/girls: NR Age range: 3–12 yrs. Condition: DD 20%, ID 21.8%, Physical 58%, Speech 36%, Multi 43% AAC system: low & high
Marshall & Goldbart, 2008 UK	Qual	To obtain an understanding of the lives and experiences of children who use AAC and the impact on the family life and communication.	***Parents/caregivers*** (*N* = 13) Mother (*n* = 10); Father (*n* = 1); Foster carers (*n* = 2) Single parent families (*n* = 3), Two-parent families (*n* = 8) Age: NR; SES: NR; Ed: NR Diversity: 100% White ***Children*** (*N* = 11) Boys (*n* = 5), Girls (*n* = 6) Age range: 3–10 yrs. Condition: CP, ID, HI, Epilepsy AAC system: low & high
McCord & Soto, 2004 US	Qual	To describe the perceptions of Mexican-American families regarding the communication abilities of children and the impact AAC use has in their lives.	***Parents/caregivers*** (*N* = 4) Families (*n* = 4) Ed: NR; Age range: NR; Mother/fathers: NR SES: low (*n* = 3), mod (*n* = 1) Diversity: 100% Hispanic Language in home: Spanish ***Children:*** (*N* = 4) Boys (*n* = 1), Girls (*n* = 3)

Table 2.3 (cont'd)

			Age range: 7–20 yrs. Condition: CP (*n* = 4) ACC system: low & high
McNaughton et al., 2008 US	Qual	To gain a better understanding of parents' perspectives on the technology learning experiences of children who use AAC.	***Parents/caregivers*** (*N* = 7) Mothers/fathers: NR Age range: NR; SES: NR Ed: College (*n* = 5), NR (*n* = 2) Diversity: NR ***Children*** (*N* = 7) Boys (*n* = 2), Girls (*n* = 5) Age range: 6–30 yrs. Condition: CP (*n* = 7) Diversity: NR AAC system: low & high
Meder & Wegner, 2015 US	Quant	To explore the wants, needs, and preferences of families of children with communication disabilities relative to mobile technologies.	***Parents/Caregivers*** (*N* = 64) Father/mother NR Age range: 18–54 SES: NR; Ed: NR Diversity: NR Geographical location: US, Canada, UK ***Children*** (NR) Boys/girls = NR Age range: NR Condition: CP, ASD, DS, ID, Angelman syndrome, ADHD, CAS, global speech delay, Prader-Willi syndrome, unknown genetic syndrome AAC system: high

Table 2.3 (cont'd)

Mei et al., 2015 Australia	Qual	To explore parental perceptions of the activities and participation of children with CP with range of communication abilities and the personal and environmental factors that influence these.	***Parents/Caregivers*** ($N = 13$) Families ($n = 13$) Father/mother NR Age range: 28–47; SES: NR; Ed: range from secondary to university; Diversity: NR Geographical location: NR ***Children*** ($N = 13$) Boys ($n = 8$), Girls ($n = 5$) Age range: 4.5–9.1 yrs. Condition: CP AAC system: low & high
Parette et al., 2000 US	Qual	To describe the "voices" of families regarding the AAC process.	***Parents/Caregivers*** ($N = 58$) Mothers/fathers: NR Age range: NR; Ed: NR SES: <$20,000 29.3% $21-40,000 12% $40-60,000 9%, >$60,000 12% Diversity: 20.7% Asian, 20.7% Black, 6.8% Native American, 10.3% Hispanic, 25.9% European Geographical locations: across 5 states ***Children*** NR Boys/girls: NR Age range: NR Condition: disabilities AAC system: low & high

Table 2.3 (cont’d)

Romski et al., 2011 US	Quant	To examine parent perception of early communication development before and after participation in a language intervention.	***Parents/Caregivers*** (*N* = 53) Father (*n* = 4), Mother (*n* = 49) Age range: 31–45 yrs. Mean age: 37 (3.6) SES: NR; Ed: 15% HS, 11.3 some college, 41.5% bachelor degree, 32% graduate/professional degree Diversity: 75.5% White, 26.4% Black, 3.8% Asian Geographical location: NR ***Children*** (NR) Boys/girls = NR Age range: 20–40 months Mean age: 30 months Condition: significant risk for speech language delay but upper gross motor skills to touch SGD AAC system: low/high
Schlebusch et al., 2017 South Africa	Quant	To measure and describe the perceived family quality of life of families with a child with ASD.	***Parents/Caregivers*** (NR) Families (*n* = 180) Mothers/fathers: NR Mean age range: 36–40 yrs. Ed: 41% college, 26% HS Diversity: 66% Black SES: 69% employed full-time ***Children*** (*N* = 178) Boys (*n* = 144), Girls (*n* = 34) Age range: 5–9 yrs. Condition: ASD (*n* = 178)

Table 2.3 (cont’d)

			Co-occurring NR conditions (*n* = 177) AAC system: NR
Schlebusch et al., 2016 South Africa	Quant	To investigate the relationship between family routines, cognitive appraisal of the impact of ASD on the family and FQOL in families raising children in South Africa.	***Parents/ Caregivers*** (*N* = 180) Families (*n* = 180) Father (*n* = 28), Mother (*n* = 123), aunt/grandmother (*n* = 4), not specified (*n* = 25) Age range: 36–39 yrs. Ed: 9% less than 11th grade, 17.4% HS, 32% diploma, 14.6% bachelor’s degree, 27% postgraduate degree SES: NR in US currency Diversity: 68% Black ***Children*** (*N* = 178) Boys (*n* = 144), Girls (*n* = 34) Mean age: 5.8 (1.38) Condition: ASD AAC system: NR
Serpentine et al., 2011 Hungry	Qual	To explore the perspectives of Hungarian parents of children with ASD concerning their decision-making processes for communication interventions for their children.	***Parents/ Caregivers*** (*N* = 10) Father/mother: NR Age range: NR; Ed: NR SES: NR; Diversity: NR ***Children*** NR Boys/Girls: NR Age range: at least 4 yrs. Condition: ASD AAC system: NR

Table 2.3 (cont'd)

Stuart & Parette, 2002 US	Qual	To explore the real experience of implementing AAC for Native American students, families, and their educational teams.	***Parents/ Caregivers*** (*N* = 2) Father (*n* = 0), Mother (*n* = 2), Brother (*n* = 1), Aunt (*n* = 1) Age range: NR; Ed: NR; SES: NR Diversity: 100% Navajo ***Children*** (*N* = 2) Boys (*n* = 1); Age: 16 yrs. Girls (*n* = 1); Age: 11 yrs. Condition: CP Diversity: 100% Navajo AAC system: low & high ***Education team***: SLP (*n* = 1), Teacher (*n* = 5), Paraprofessional (*n* = 2)
Singh et al., 2017 Malaysia	Qual	To explore Malaysian parents; perception of AAC and their experience in supporting their children who use AAC.	***Parents/ Caregivers*** (*N* = 12) Father (*n* = 2), Mother (*n* = 10) Age range: 32–47 yrs. Ed: NR; SES: NR Diversity: NR ***Children*** (*N* = 12) Age range: 3–12 yrs. Condition: CP, ASD AAC system: low & high
Thunberg et al., 2016 Sweden	Qual	To investigate parents' experiences of hospital visits with their children with communication disabilities.	***Parents/ Caregivers*** (*N* = 10) Mothers (*n* = 10) Age range: 30–49 yrs. Ed: Secondary (*n* = 3), College (*n* = 7)

Table 2.3 (cont'd)

Diversity: NR; SES: NR
Children (*N* = NR)
Age range: 2–12 yrs.
Condition: communicative disabilities
AAC system: low & high

Note. AAC = Augmentative and alternative communication; ADHD = Attention Deficit Hyperactivity Disorder; ASD = Autism Spectrum Disorder; CAS = Childhood apraxia of speech; CP = Cerebral palsy; DD = Developmental disability; DD = Down syndrome; Ed = Education; FXS = Fragile X syndrome; HI = Hearing impaired; HS = High school; ID = Intellectual disability; LD = Learning disability; NR = Not recorded; Qual = Qualitative study; Quant = Quantitative study; SES = Socioeconomic status; SGD = Speech generating device; SLP = Speech-language pathologist; US = United States; UK = United Kingdom.

Appendix D: Instruments and Key Findings

Table 2.4

Instruments and Key Findings (N = 33)

Author, Year	Instrument/ Measurement	Major Findings
Allaire et al., 1991	Questionnaire developed by authors	Participants reported lack of training, technology issues, funding, and communication with service delivery hinder use of AAC. Participants expressed interest in involvement of AAC selection across their child's development.
Anderson et al., 2015	Semi-structured interviews Focus groups	In person services for families is still a plausible model, but parents and SLP were open to alternative service models. Those include parent-implemented therapy, parent training, peer support, tele-practice with video conferencing, iPhones, and online training packages specific to devices.
Anderson et al., 2014	Semi-structured interviews	Participants discussed perceived barriers to service access, limited therapist expertise in SGD practice, lack of consistency and continuity in services. Participants expressed desire for more collaborative family approaches to empower families as partners in the care of their child with a disability.
Angelo, 2000	Questionnaire developed by author	Participants perceived an increase in family roles, demands, and responsibilities with device use. Participants gained knowledge about devices but expressed needs for evaluative feedback to AAC manufacturers for portable and non-stigmatizing devices. Expression of concern for their child to have social relationships and community interactions. More than half of participants reported positive gains in their child's communication, quality of life, independence, and

Table 2.4 (cont'd)

		opportunities for the future.
Angelo et al., 1996	Questionnaire developed by author	Participants reported priorities for their children during this developmental time frame included: having social opportunities for the adolescent with peers, integrating the device into the community, planning future communication needs, knowledge to maintain, program and repair devices.
Angelo et al., 1995	Questionnaire developed by author	Participants reported priorities for their children during this developmental time frame included: knowledge of AAC, planning for future communication needs, obtaining funding, finding professional services for child, teaching the child about the device, and integrating the device into family life.
Bailey et al., 2006	Semi-structured interviews Questionnaire developed by author	Overall the effect of the use of AAC device was reported as positive for the child but use of technology increased demands for the family with device limitations (portability, dependability), inadequate training, and ineffective teaming with professionals.
Batorowicz et al., 2014	Interviews	Parents and children both described positive and negative experiences related to communication and social participation. Lack of child's interaction with peers who use AAC and lack of meaningful engagement opportunities with typically developing peers. Children who use AAC need extended time for communication interactions to occur with professionals and peers. AAC use may contribute to lack of close peer relationships.
Blosser, 1994	Interviews with mothers and children	Mothers identify themselves as primary case manager for their child's treatment programs. Participants desired more in-depth

Table 2.4 (cont'd)

		information regarding child's communication problems and impact to coordinate services and incorporate therapy into home activities.
Borg et al., 2015	Semi-structured interviews with mother and child	The perceived barriers to the use of high tech AAC were: potential breakage, cost of self-funding of the device, and amount of time needed to teach and learn about the device. The child's perception of the barriers of the low-tech device involved dependence on others to construct, and restricted range of syntax. The perceived benefits of the use of high tech AAC were: easier to access apps, customizable, increased child's independence, and supported comprehensive language and literacy development.
Bourke-Taylor et al., 2013	Mailed questionnaire Questionnaire developed by authors Assistance to Participate Scale (APS)	Many children with complex disability needs require technology and equipment at families' expense. Financial support to help families offset costs is needed to better support.
Brady et al., 2006	Mullen Scales of Early Learning (MSEL) Semi-structured interviews with mothers	Half the children were non-verbal and learning AAC. Mothers identified challenges with helping child to communicate and obtaining SLP services. Mothers have multiple roles, such as caregiver, teacher, therapist, and advocate.
Clarke et al., 2011	Health Utilities Index (HUI) Trait Emotional Intelligence Questionnaire (TEIQUE 360F) Communication aid measures	Caregiver assessment of the impact of the disability on the family may predict intensity of child participation in informal everyday activities (e.g., social, recreational, self-improvement)

Table 2.4 (cont'd)

	Children's Assessment of Participation & Enjoyment Questionnaire (CAPE) Family Impact of Childhood Disability (FICD)	
Crisp et al., 2014	Interviews in person, telephone, or Skype technology Questionnaire developed by author	Barriers to use of SDG were device limitations, lack of help from professionals, negative reactions by others, limited financial supports. Facilitators to user friendly designs, acceptable voice quality, support from professionals, use by others in social settings, ease of financial services
Donohue et al., 2015	Questionnaire developed by authors	Household size was found to be negatively related to whether children had intelligible speech, but only 17% of children in the sample had unintelligible speech.
Goldbart & Marshall, 2004	Individual interviews Questionnaire developed by author	Engagement of families in the AAC process varies with competing demands on caregivers, available external supports and services.
Hemsley et al., 2013	Focus group sessions with parents Interviews with children with a parent present	Children with CCN want to talk with HCP in hospitals. Barriers include: lack of access to AAC system, lack of time of hospital staff, lack of confidence and competence of staff using device. Parents manage competing demands to support their child at the bedside but must fulfill work obligations and familial obligations too.

Table 2.4 (cont'd)

Hetzroni, 2002	Questionnaire developed by authors	Most of the participants in the study lived in the city, highly educated, born in Israel, and came from upper-middle class backgrounds. Most of the families were content with AAC services but reported issues with technology issues and lack of support leading to caregiver frustration. Limited number of participants reported family participation in AAC assessment and decision-making processes.
Huer et al., 2001	Structured interview questions developed by authors	General perspectives from the Mexican American parents revealed that family is the central concept of community for a shared sense of responsibility for the child's therapy and progress. A desire for AAC device outputs, training, and instructions to be in Spanish to be more useful in the home. Participants felt devices are more useful outside of the home, and worried about cost of device. Parents place high emphasis and value on child's non-verbal cues of communication. Participants expressed great respect for professionals working to help child, but not did emphasis active role in decision making process for desire not to "impose".
Jones et al., 1998	Parenting Stress Index (PSI) Family Support Index (FSS)	Participants revealed that a source of stress is the factor of acceptability and physical demandingness of the child's disability. Participants depend on immediate family members and professionals for assistance.
Marshall & Goldbart, 2008	Interview guide developed by author	Factors impacting parent engagement with child's communication development are burden with daily duties in caring for a child with a disability, prioritizing issues, insufficient time, frustration, guilt, financial pressures, and

Table 2.4 (cont'd)

		professional services and therapy coordination.
McCord & Soto, 2004	Semi-structured and informal interviews with parent and other family members Multiple interviews and observations over 6–8-month time period	Participants found AAC device to be impractical and not useful at home because of financial barriers, as well as cultural and language preferences for speed and intimacy during home/family interactions. All participant families valued AAC for educational purposes and environments.
McNaughton et al., 2008	Modified focus group approach using online technology platform called Phorum 3.3.2 Research team developed questions	Parents of children with CCN play the role of caregiver, teacher, playmate, technical support, and advocate. Frustrations with lack of services, training of professionals, and lack of collaborative team approaches.
Meder & Wegner, 2015	Questionnaire developed by authors	Participants valued iDevices and applications that were affordable, easy to use, and could be used for multiple functions. Families valued information from professionals on how a child could use the device to meet their individual needs, and comparisons among devices.
Mei et al., 2015	Interview questions developed by authors	Barriers identified by participants included that their own interactions can impede their child's participation, unfamiliar people and settings, negative attitudes by others, and child's frustration. Facilitators included support from family and school, familiar routine, child's positive disposition, and immersion with other children. Modifying the environment could enhance communication and participation.
Parette et al., 2000	Focus group and interview questions developed by authors	Families identified that professionals should understand the sources of demands are from both within and outside of the

Table 2.4 (cont'd)

		family unit. AAC affects all members of the family, and each child with a disability has unique needs. Professionals need to collaborate with families for communication goals and interventions across home, school, and the community with varying ethnic and cultural backgrounds.
Romski et al., 2011	Parent Perception of Language Development (PPOLD)- developed by author Child outcome measure was the number of augmented and spoken words the children used.	Giving children with significant language difficulties access to SGD not only improves vocabulary for children but may have positive effects for parents too. An alternative modality for a child's communication may decrease the pressure on parents regarding unsuccessful communication attempts with their child. Helping parents find successful ways to communicate with their child can result in positive changes in parent-child interactions.
Schlebusch et al., 2017	Beach Family Quality of Life Scale (FQOL) Demographics survey created by authors	Families were most satisfied with disability services that they were receiving, but emotional well-being should be an area of focus. Family income, family type, and severity of ASD were associated with FQOL.
Schlebusch et al., 2016	Family Routines Inventory (FRI) Family Impact of Childhood Disability (FICD) Beach Center Family Quality of Life Scale (FQOL)	The regularity of family routines provides a direct positive relationship with FQOL. Additionally, positive and negative appraisal can co-exist in families with ASD and mediates the relationship between FQOL.

Table 2.4 (cont'd)

Serpentine et al., 2011	Interviews conducted Authors developed questions	Participants accessed a variety of resources to obtain information about communication interventions but did not include evidence-based sources. Participants perceived interventions as a mechanism for improvement rather than cure. Participants reported willingness to try a communication intervention based on professionals' recommendations, but most wanted to try other options but limited in service center options.
Singh et al., 2017	Interviews conducted Authors developed questions	Participants perceived that AAC use as positive on their children, but they face challenges with the AAC device, collaborative supportive team efforts, lack of services, and limited societal and cultural awareness/support.
Stuart & Parette, 2002	Observation and videotaping of students using AAC Interviews conducted Authors developed questions	Parents and professionals indicated complexity and inadequacy of technology to combine Navajo and English for phonological aspects. Also, lack of understanding and sensitivity to inclusion of Navajo custom messaging. Large workloads of professionals contribute to limited training and programming for cultural inclusivity with AAC.
Thunberg et al., 2016	Focus group interviews	Participants emphasized the importance of enabling direct communication with their children and hospital staff to understand needs, but staff/professionals need time, knowledge, and training with patients with communication disabilities and AAC.

Note. AAC = Augmentative and alternative communication; ASD = Autism Spectrum Disorder; CCN = Complex communication needs; FQOL= Family quality of life; HPC= Healthcare provider; SGD = Speech generating device; SLP = Speech-language pathologist.

Appendix E: Key Findings Grouped by Family Adaptation Components

Table 2.5

Key Findings Grouped by Family Adaptation Components (N = 33)

	Family Factors			
Author, Year	Family Demands	Family Appraisal	Family Resources	Family Problem-solving & Coping
Allaire et al., 1991	Lack of training Technology issues Funding Service delivery			Involvement in AAC selection
Anderson et al., 2015	Service delivery Training			Alternative service models
Anderson et al., 2014	Service access Therapist expertise Service consistency		Partnership with professionals	Collaborative family approaches
Angelo, 2000	Increase in family roles Increased time to use and maintain device Portability of device Lack of evaluative feedback	Increased knowledge about devices Improvement in child's QOL, communication, independence, opportunities for future	Informational supports Funding through statewide system	Expression of concern
Angelo et al., 1996	Lack of informational support Planning for the future Seeking peer socialization Integrating the device into the community Knowledge to maintain, program and repair device			

Table 2.5 (cont'd)

	Service delivery			
Angelo et al., 1995	Increase in family roles Knowledge of AAC Device limitations Planning for future Obtaining funding Finding professional services Funding sources			
Bailey et al., 2006	Device limitations Inadequate training Ineffective teaming with professionals	AAC device was perceived as positive for child	Ease of use of device Professional teaming for training	Family expectations on increasing independence and communicative competence
Batorowicz et al., 2014	Lack of interaction with child's peers Lack of close peer relationships Lack of device use in different environments	AAC device was perceived as positive for child		
Blosser, 1994	Lack of information of child's communication problem Increased role demand for mother Coordination of services			Becoming an "educated consumer" of professional services
Borg et al., 2015	Inadequate training Increased time to use and maintain device Dependence on others to construct range of language syntax Funding sources	Increased child's independence Supported language and literacy development		

Table 2.5 (cont'd)

Bourke-Taylor et al., 2013	Funding sources for equipment Out of pocket expenses Extent of assistance child needs for daily tasks			
Brady et al., 2006	Finding professional services Increased role demand for mother Concern and stress with not understanding child			
Clarke et al., 2011	Impact of childhood disability on family Extent of assistance child needs for daily tasks			
Crisp et al., 2014	Device limitations Ineffective teaming with professionals Limited financial supports		Support from professionals	
Donohue et al., 2015	Household size Impact of childhood disability on family			
Goldbart & Marshall, 2004	Perception of child's communicative abilities Attitudes of public Integrating the device into the community Increased time to use and maintain device Finding professional services			Advocacy role to be assertive and pushy

Table 2.5 (cont’d)

	Ineffective teaming with professionals			
Hemsley et al., 2013	Increased time spent at hospital to assist with child’s communication Hospital staff’s lack of knowledge of AAC Hospital staff’s lack of time to communicate with child			Advocacy role to protect child
Hetzroni, 2002	Device limitations and programming in multiple languages Increased time to use and maintain device Finding professional services		Cultural diversity	
Huer et al., 2001	Device limitations and programming in Spanish Increased time to understand device		Social support from extended family Respect for professionals	Embracing child’s nonverbal cues within culture
Jones et al., 1998	Parental depression Relationship with spouse		Spousal support Professional service support School/day care support	
Marshall & Goldbart, 2008	Increased caregiving burden/time Social isolation Increased role demand for parents Concern and stress with not understanding child		Ability to understand child Family culture and perspectives	Advocacy role to be assertive and pushy

Table 2.5 (cont’d)

	Professional services and therapy coordination Financial pressures			
McCord & Soto, 2004 US	Financial barriers Device limitations with cultural and language preferences reflecting English structure and North American symbol references Lack of device speed and intimacy during home/family interactions Lack of knowledge of AAC	AAC not perceived to enhance home interaction intimacy only school	Professionals and schools Extended family	
McNaughton et al., 2008	Lack of family involvement in AAC device selection Increased role demand for parents Increased time to use and maintain device Difficulty obtaining services Financial issues Attitudes towards technology Developing communication supports within the community			Educating the public Advocating
Meder & Wegner, 2015 US	Funding sources Device ease of use Lack of professional services Device selection		Knowledge from professionals to use mobile technology Professional support and training	
Mei et al., 2015 Australia	Parental interactions child’ participation	Negative attitudes of others	Support from family, school, peers	

Table 2.5 (cont'd)

	Child's frustrations		Child's disposition Familial routine	
Parette et al., 2000	Lack of family involvement in AAC device selection Lack of sensitivity of professionals for family ethnicity Stress of disability on extended family and sibling interactions Lack of knowledge of AAC	Stigma issues	Professional support and training Partnerships with professionals	
Romski et al., 2011	Parent perception of language development		Professional support and training Partnerships with professionals	
Schlebusch et al., 2017	Parenting Physical well-being Severity of ASD Financial pressures		Disability-related support Family interaction Family income	Emotional well-being
Schlebusch et al., 2016	Parenting Physical well-being Severity of ASD	Cognitive appraisal of impact of ASD	Familial routine	Emotional well-being
Serpentine et al., 2011	Burden of AAC intervention decisions Financial resources Limited availability of high-tech AAC devices		Information to AAC resources Professional support and training Partnerships with professionals	AAC device perceived as a mechanism for improvement not cure

Table 2.5 (cont'd)

Singh et al., 2017	Device ease of use Device functional limitations Lack of support from other family members Lack of professional services Device limitations with cultural and language preferences Lack of societal support	AAC device was perceived as positive for child	Professional support and training Information to AAC resources	
Stuart & Parette, 2002	Device limitations with cultural customs and language preferences Time demands Sibling issues Device ease of use		Professional support and training	
Thunberg et al., 2016	Increased time spent at hospital to assist with child's communication Hospital staff's lack of knowledge/training of AAC Hospital staff's lack of time to communicate with child			Advocacy role to protect child

Note. AAC = Augmentative and alternative communication; ASD= Autism spectrum disorder; QOL= Quality of life.

REFERENCES

REFERENCES

Accardo, P. J., Whitman, B. Y, Behr, S. K., Farrell, A., Magenis, E., & Morrow-Gorton, J. (2003). *Dictionary of Developmental Disabilities Terminology*. (2nd ed.). Baltimore, MD: Paul H. Brookes Publishing.

Allen, L. F., & Babin, E. A. (2013). Associations between caregiving, social support, and well-being among parents of children with childhood apraxia of speech. *Health Communication*, 28, 586–576. https://www.tandfonline.com/doi/abs/10.1080/10410236.2012.703120

Allen, A. A., & Shane, H. C. (2014). Autism spectrum disorders in the era of mobile technologies: Impact on caregivers. *Developmental Neurorehabilitation*, *17*(2), 110–114. https://doi.org/10.3109/17518423.2014.882425

Allaire, J. H., Gressard, R. P., Blackman, J. A., & Hostler, S. L. (1991). Children with server speech impairments: Caregiver survey of AAC use. *Augmentative and Alternative Communication*, *7*(4), 248–255. https://www.tandfonline.com/doi/abs/10.1080/07434619112331275983

American Speech-Language-Hearing Association. (ASHA). (2017). *Augmentative and alternative communication*. Retrieved from https://www.asha.org/PRPSpecificTopic.aspx?folderid=8589942773&section=Key_Issue

Anderson, K. L., Balandin, S., & Stancliffe, R. J. (2015). Alternative service delivery models for families with a new speech generating device: Perspectives of parents and therapists. *International Journal of Speech-Language Pathology*, *17*(2), 185–195. https://doi.org/10.3109/17549507.2014.979876

Anderson, K. L., Balandin, S., & Stancliffe, R. J. (2014). Australian parents' experience of speech generating device (SGD) service delivery. *Developmental Neurorehabilitation*, *17*(2), 75–83. doi: 10.3109/17518423.2013.857735

Angelo, D. H. (2000). Impact of augmentative and alternative communication devices on families. *Augmentative and Alternative Communication*, *16*(1), 37–47.

Angelo, D. H., Kokoska, S., & Jones, S. (1996). Family perspective on augmentative and alternative communication: Families of adolescents and young adults. *Augmentative and Alternative Communication*, *12*(1), 13–22. https://www.tandfonline.com/doi/abs/10.1080/07434619612331277438

Angelo, D. H., Jones, S., & Kokoska, S. (1995). Family perspective on augmentative and alternative communication: Families of young children. *Augmentative and Alternative Communication*, *11*(3), 193–202. https://www.tandfonline.com/doi/abs/10.1080/07434619512331277319

Bailey, R. L., Parette, H. P., Stoner, J. B., Angell, M. E., & Carroll, K. (2006). Family members' perceptions of augmentative and alternative communication device use. *Language, Speech, and Hearing Services in Schools*, *37*, 50–60. https://ajslp.pubs.asha.org/doi/full/10.1044/0161-1461%282006/006%29

Batorowicz, B., Campbell, F., VonTetzchner, S., King, G., & Missiuna, C. (2014). Social participation of school-aged children who use communication aids: The views of children and parents. *Augmentative and Alternative Communication*, *30*(3), 237–251. https://doi.org/10.3109/07434618.2014.940464

Binger, C., Ball, L., Dietz, A., Kent-Walsh, J., Lasker, J., Lund, S., … Quac, W. (2012). Personnel roles in the AAC assessment process. *Augmentative and Alternative Communication*, *28*(4), 278–288. https://doi.org/10.3109/07434618.2012.716079

Blosser, J. L. (1994). Recommendations for clinicians based on parents' experiences. *Clinics in Communication Disorders*, *4*(4), 246–253. https://europepmc.org/abstract/med/7874105

Borg, S., Agius, M., & Agius, L. (2015). A user and their family's perspective of the use of a low-tech vs a high-tech AAC system. *Studies in Health Technology and Informatics, 217*, 811–818. doi: 10.3233/978-1-61499-566-1-811

Bourke-Taylor, H., Cotter, C., & Stephan, R. (2013). Young children with cerebral palsy: Families self-reported equipment needs and out-of-pocket expenditure. *Child: Care, Health, and Development*, *40*(5), 654–662. https://doi.org/10.1111/cch.12098

Brady, N., Skinner, D., Roberts, J., & Hennon, E. (2006). Communication in young children with Fragile X Syndrome: A qualitative study of mothers' perspectives. *American Journal of Speech Language Pathology*, *15*(4), 353–364. https://ajslp.pubs.asha.org/doi/full/10.1044/1058-0360%282006/033%29

Cachia, R. L., Anderson, A., & Moore, D. (2016). Mindfulness, stress, well-being in parents of children with Autism Spectrum Disorder: A systematic review. *Journal of Child and Family Studies*, *25*, 1–14. doi: 10.1007/s10826-015-0193-8

Center for Disease Control and Prevention. (2015). Developmental disabilities. Retrieved from https://www.cdc.gov/ncbddd/developmentaldisabilities/features/birthdefects-dd-keyfindings.html

Clarke, M. T., Newton, C., Griffiths, T., Price, K., Lysley, A., & Petrides, K. V. (2011). Factors associated with the participation of children with complex communication needs. *Research in Developmental Disabilities*, *32*, 772–780. https://doi.org/10.1177%2F0031512517708528

Crisp, C., Burke Draucher, C., & Cirgin Ellett, M.L. (2014). Barriers and facilitators to children's use of speech-generating devices: A descriptive qualitative study of mothers' perspectives. *Journal for Specialists in Pediatric Nursing*, 19, 229–237. https://europepmc.org/abstract/med/24636104

Donohue, D.K., Bornman, J., & Granlund, M. (2015). Household size is associate with unintelligible speech in children who have intellectual disabilities: A South African study. *Developmental Neurorehabilitation*, *18*(6), 402–406. doi: 10.3109/17518423.2014.890256

Dykens, E. M., Fisher, M. H., Lounds Taylor, J., Lambert, W., & Miodrag, N. (2014). Reducing distress in mothers of children with autism and other disabilities: A randomized trial. *Pediatrics*, *134*(2), e454–e454. https://doi.org/10.1542/peds.2013-3164

Goldbart, J., & Marshall, J. (2004). "Pushes and pulls" on the parents of children who use AAC. *Augmentative and Alternative Communication*, *20*(4), 194–208. https://doi.org/10.1080/07434610400010960\

Hebbeler, K., Spiker, E., Bailey, D., Scarborough, A., Malik, S., Simensson, R.,… Nelson, L. (2007). Early intervention for infants and toddlers with disabilities and their families: Participants, services, and outcomes. Final report of the National Early Intervention Longitudinal study (NEILS). Retrieved from https://pdfs.semanticscholar.org/28be/acda70854a34982fae5693e29c67d17675b3.pdf

Hemsley, B., Kuek, M., Bastock, K., Scarinci, N., & Davidson, B. (2013). Parents and children with cerebral palsy discuss communication needs in hospital. *Developmental Neurorehabilitation*, *16*(6), 363–374. https://doi.org/10.3109/17518423.2012.758187

Hetzroni, O. (2002). Augmentative and alternative communication in Israel: Results from a family survey. *Augmentative and Alternative Communication*, *18*(4), 255–266. https://doi.org/10.1080/07434610212331281341

Holyfield, C., Drager, K. D. R, Kremkow, J. M. D., & Light, J. (2017) Systematic review of AAC intervention research for adolescents and adults with autism spectrum disorder. *Augmentative and Alternative Communication*, 33(4), 201–212. doi: 10.1080/07434618.2017.1370495

Huer, M. B., Parette, H. P., & Saenz, T. I. (2001). Conversations with Mexican Americans regarding children with disabilities and augmentative and alternative communication. *Communication Disorders Quarterly*, *22*(4), 197–206. https://journals.sagepub.com/doi/abs/10.1177/152574010102200405

International Family Nursing Association (IFNA). (2018). *IFNA Position Statement on Graduate Education*. https://internationalfamilynursing.org/2018/06/28/graduate-family-nursing-education/

Jones, S. D., Angelo, D. H., & Kokoska, S. M. (1998). Stressors and family supports: Families with children using augmentative & alternative communication technology. *Journal of Children's Communication Development*, *20*(2), 37–44. https://journals.sagepub.com/doi/abs/10.1177/152574019902000205

King, G., Tucker, M. A., Baldwin, P., Lowry, K., LaPorta, J., & Martens, L. (2002) A life needs model of pediatric service delivery: Services to support community participation and quality of life for children and youth with disabilities. *Physical & Occupational Therapy in Pediatrics*, *22*(2), 53–77. https://www.tandfonline.com/doi/abs/10.1080/J006v22n02_04

Liberati, A., Altman, D. G., Tetzlaff, J., Mulrow, C., Gotzsche, P. C., Ioannidis, J. P., … Moher, D. (2009). The PRISMA statement for reporting systematic reviews and meta-analyses of studies that evaluate health care interventions: Explanation and elaboration. *PLoS Medicine*, *6*(7), e1000100.

Light, J., McNaughton, D., Beukelman, D., Koch Fager, S., Fried-Oken, M., Jakobs, T., & Jakobs, E. (2019). Challenges and opportunities in augmentative and alternative communication: Research and technology development to enhance communication and participation for individuals with complex communication needs. *Augmentative and Alternative Communication*. 35(1), 1-12. doi: 10.1080/07434618.2018.1556732

Light, J. & McNaughton, D. (2012). Supporting the communication, language, and literacy development of children with complex communication needs: State of the science and future research priorities. *Assistive Technology*, 24, 34–44. doi: 10.1080/10400435.2011.648717

Lindo, E. J., Kliemann, K. R., Combes, B. H., & Frank, J. (2016). Managing stress levels of parents of children with developmental disabilities: A meta-analytic review of interventions. *Family Relations*, 65, 207–224. https://doi.org/10.1111/fare.12185

Mandak, K., O'Neill, T., Light, J., & Fosco, G.M. (2017) Bridging the gap from values to actions: A family systems framework for family-centered AAC services. *Augmentative and Alternative Communication*, 33(1), 32-41. doi: 10.1080/07434618.2016.1271453

Marshall, J., & Goldbart, J. (2008). 'Communication is everything I think.' Parenting a child who needs augmentative and alternative communication (AAC). *International Journal of Language & communication Disorders*, *43*(1), 77–98. doi: 10.1080/13682820701267444

McCord, M. S., & Soto, G. (2004). Perceptions of AAC: An ethnographic investigation of Mexican-American families. *Augmentative and Alternative Communication*, *20*(4), 209–227. doi: 10.1080/07434610400005648

McCubbin, M. A., Thompson, A., & McCubbin, H. I., (1996). *Family assessment: Resiliency, coping and adaptation*. Madison, WI: University of Wisconsin-Madison.

McGinley, V. A. & Alexander, M. (2018). *Parents and families of students with special needs: Collaborating across the age span*. Thousand Oaks, CA: Sage.

McNaughton, D., Balandin, S., Kennedy, P., & Sandmel, T. (2010). Health transitions for youth with complex communication needs: The importance of health literacy and communication strategies. *Journal of Pediatric Rehabilitation Medicine: An Interdisciplinary Approach 3*, 311–318. doi: 10.3233/PRM-2010-0143

McNaughton, D., & Light, J. (2013). The iPad and mobile technology revolution: Benefits and challenges for individuals who require augmentative and alternative communication. *Augmentative and Alternative Communication, 29*(2), 107-116. doi: 10.3109/07434618.784930

McNaughton, D., Rackensperger, T., Benedek-Wood, E., Krezman, C., Williams, M. B., & Light, J. (2008). "A child needs to be given a chance to succeed": Parents of individuals who use AAC describe the benefits and challenges of learning AAC technologies. *Augmentative and Alternative Communication*, *24*(1), 43–55. doi: 10.1080/07434610701421007

Meder, J., & Wegner, J.R. (2105). iPads, mobile technologies, and communication applications: a survey of family wants, needs, and preferences. *Augmentative and Alternative Communication*, 31(1), 27-36. doi: 10.3109/07434618.2014.995223

Mei, C., Reilly, S., Reddihough, D., Mensah, F., Green, J., Pennington, L., & Morgan, A. T. (2015). Activities and participation of children with cerebral palsy: Parent perspectives. *Disability and Rehabilitation*, 37(23), 2164–2173. doi:10.3109/09638288.2014.999164

Minor, H. G., Carlson, L. E., Mackenzie, M. J., Zernicke, K., & Jones, L. (2006). Evaluation of mindfulness-based stress reduction (MBSR) program for caregivers of children with chronic conditions. *Social Work in Health Care*, *43*(1), 91–109. doi: 10.1300/J010v43n01_06

Moher, D., Liberati, A., Tetzlaff, J., Altman, D. G., & The PRISMA Group (2009). Preferred reporting items for systematic reviews and meta-analysis: The PRISMA statement. *PloS Med, 6*(7), e1000097. doi: 10.137/journal.pmed1000097

Pace, R., Pluye, P., Bartlett, G., Macaulay, A., Salsberg, J., Jagosh, J., & Seller, R. (2011). Testing the reliability and efficiency of the pilot Mixed Methods Appraisal Tool (MMAT) for systematic mixed studies review. *International Journal of Nursing Studies, 49*(1), 47–53. doi: 10.1016/j.ijnurstu.2011.07.002

Parette, H. P., Brotherson, M. J., & Blake Huer, M. (2000). Giving families a voice in augmentative an alternative communication decision-making. *Education and Training in Mental Retardation and Developmental Disabilities*, *35*(2), 177–190. https://www.jstor.org/stable/23879942?seq=1#page_scan_tab_contents

Pluye, P., Robert, E., Cargo, M., Bartlett, G., O'Cathain, A., Griffiths, F., … Rousseau, M.C. (2011). *Proposal: A mixed methods appraisal tool for systematic mixed studies reviews.* Retrieved from http://mixedmethodsappraisaltoolpublic.pbworks.com

Romski, M., Sevcik, R. A., Adamson, L. B., Smith, A., Cheslock, M., & Bakeman, R. (2011). Parent perceptions of the language development of toddlers with developmental delays before and after participation in parent-coached language interventions. *American Journal of Speech-Language Pathology*, *20*, 111–118. doi: 10.1044/1058-0360(2011/090087)

Schlebusch, L., Dada, S., & Samuels, A. E. (2017). Family quality of life of South African families raising children with Autism Spectrum Disorder. *Journal of Autism Developmental Disorders*, *47*, 1966–1977. doi: 10.1007/s10803-017-3102-8

Schlebusch, L., Samuels, A. E., & Dada, S. (2016). South African families raising children with autism spectrum disorders: Relationship between family routines, cognitive appraisal, and family quality of life. *Journal of Intellectual Disability Research*, *60*(5), 412–423. doi: 10.1111/jir.12292

Seligman, M., & Benjamin Darling, R. (2007). *Ordinary families, special children: A systems approach to childhood disability*. (3rd ed.). New York, NY: Gilford Press.

Serpentine, E. C., Tarnai, B., Drager, K. D., & Finke, E.H. (2011). Decision making of parents of children with autism spectrum disorder concerning augmentative and alternative communication in Hungry. *Communication Disorders Quarterly*, *32*(4), 221–231. doi: 10.1177/152574019353938

Singh, S. J., Hussein, N. H., Kamal, R. M., & Hassan, F. H. (2017). Reflections of Malaysian parents of children with developmental disabilities on their experiences with AAC. *Augmentative and Alternative Communication*, *33*(2), 110–120. doi: 10.1080/07434618.2017.1309457

Stuart, S., & Parette, H.P. (2002). Native Americans and augmentative and alternative communication issues. *Multiple Voices for Ethnically Diverse Exceptional Learners*, *5*(1), 38–53. https://multiplevoicesjournal.org/doi/abs/10.5555/muvo.5.1.p8006861217m5414

Thunberg, G., Buchholz, M., & Nilsson, S. (2016). Strategies that assist children with communicative disability during hospital stay: Parents' perceptions and ideas. *Journal of Child Health Care*, *20*(2), 224–233. doi: 10.1177/1367493514568298

Van Riper, M. (2000). Family variables associated with well-being in siblings of children with Down syndrome. *Journal of Family Nursing*, *6*(3), 267–286. https://doi.org/10.1177/107484070000600305

Whittemore, R., & Knafl, K. (2005). The integrative review: Updated methodology. *Journal of Advanced Nursing*, *52*(5), 546–553. doi: 10.1111/j.1365-2648.2005.03621.x

Woodman, A. (2014). Trajectories of stress among parents of children with disabilities: A dyadic analysis. *Family Relations, 63*, 39–54. doi:10.1111/fare.12049

CHAPTER THREE: FAMILY ADAPTATION AND COMMUNICATION TECHNOLOGY: DOES VARIATION IN FAMILY GROUP CHARACTERISTICS MATTER AMONG ADOLESCENTS WITH DEVELOPMENTAL DISABLITIES?

Abstract

Family involvement is critical for adolescents who have developmental disabilities and complex communication needs; consequently, many of these adolescents require augmentative and alternative communication (AAC). The aim of this study was to examine the relationship between parental/adolescent characteristics and adaptation across three groups of families based on frequency of adolescents' use of AAC. This cross-sectional study included: families of adolescents aged 13–18 with autism and/or Down syndrome who use AAC. Family was defined as at least one parent and adolescent. Families enrolled through online recruitment registries, support organizations, or social media. In total, 227 families (parent proxy) completed the online survey. The Family Impact Technology Scale for AAC scores across the three usage groups were compared using Kruskal-Wallis Test (Group 1 (low): 0-170 minutes/week; Group 2 (mid): 171-319 minutes/week; Group 3 (high): 320-1740 minutes/week). Parental/adolescent characteristics associated with family adaptation were: parental employment and education, younger parents, better adolescent communication function, and type of AAC device. Within usage groups, communicative function emerged as the predictor of family adaptation. The mean unadjusted family adaptation score for high-usage was significantly higher than both the low and mid-usage groups. Findings provide insights into at-risk families and imply the need for individualized family interventions to optimize outcomes.

Introduction

Data collected from the Centers for Disease Control and Prevention (CDC) between 2009-2017, showed an 18% increase in the prevalence of developmental disabilities (DD) for children aged 12-17 years (CDC, 2019; Zablotsky et al., 2019). Additionally, research indicated increases in the reported prevalence of autism spectrum disorder (ASD) and intellectual disabilities (ID), such as Down syndrome (CDC, 2019; Zablotsky et al., 2019). Better reporting practices and diagnostic criteria, as well as improved survival rates for children born with DD, all contribute to the growing number of adolescents with DD. Family involvement and support are critical for adaptation to disabilities to ensure adequate communication and enhanced quality of life outcomes for individuals with DD and their families.

Adolescence is a complicated developmental period during which major physical, cognitive, social, linguistic, and emotional changes occur (Smith, 2015). The changes that occur in adolescence across multiple domains place a heavy impact on communication needs and skills particularly for individuals with DD (Holyfield et al., 2017; Smith, 2015). Adolescents with DD face new challenges that are uniquely different from their experiences as younger children. During the adolescent developmental period, families need specialized support to integrate communication devices into their lives. Unfortunately, much of the current research has focused on families of younger children and not adolescent families (Sievers et al., 2018; West et al., 2020). For families who have an adolescent with a DD utilizing augmentative and alternative communication (AAC), this vulnerable developmental time requires significant transitional preparation for the future, including post-secondary education, employment, formation of adult relationships, health care, and community living opportunities. "Families provide essential struts of support, and at times may be left holding the bridge in place by themselves" (Smith, 2015, p. 117). Hence, this study explores AAC use during adolescence to extend current research.

Adolescents with lifelong DD, such as autism and/or Down syndrome (DS), often have complex communication needs (CCN). Augmentative and alternative communication systems can be used to assist these individuals in effective communication and social interactions at home, in school, and in the community (Holyfield et al., 2017; McNaughton et al., 2012). AAC systems not only impact the lives of the adolescent with CCN, but also impact parents, caregivers, and other family members (Angelo, 2000; Bailey et al., 2006; Brady et al., 2006; Marshall & Goldbart, 2008). Successful integration of AAC technology into an adolescent's life requires an enormous commitment and continuous support from family members to encourage adolescents' participation in their environment (Delarosa et al., 2012).

To date, much of the AAC research concerning adaptation among families has been directed at the acknowledgement of parents'/caregivers' fluctuating roles, perceived demands of AAC integration, and factors leading to abandonment of the system (Brady et al., 2006; McNaughton et al., 2008; Clarke et al., 2011; Jones et al., 1998). Sparse research exists related to families of adolescents utilizing AAC devices with specification of the AAC type and focused on examining whether adaptation differs based on various family and adolescent sociodemographic characteristics (Moorcroft et al., 2019). Previous research has focused on some socioeconomic and family demographic factors (e.g., income, parent education, age, household size, child age) that have a perceived impact on child communication delays and/or family quality of life among families raising a child with ASD and/or an intellectual disability (Bourke-Taylor et al., 2013; Donohue et al., 2015; Schlebusch et al., 2017; Schlebusch et al., 2016). Hence, a better understanding of what family demographic characteristics may contribute to families adapting and functioning successfully to challenges associated with AAC technology integration is needed. Moreover, several types of AAC devices are available, which can be classified into three categories: low-technology (i.e., AAC with no battery or computer component), mid-technology (i.e., AAC with battery component only), and high-technology (i.e., AAC with computer component) (Baxter et al., 2012; Holyfield, 2017; Moorcroft et al., 2019). Although both the type of AAC technology device and its frequency of use have the potential to impact family functioning, knowledge is lacking whether differences in these AAC technology characteristics influence family adaptation. These notable deficiencies indicate that research is needed to understand these differences because the utilization of AAC technology is largely dependent on the family.

Another area that has not been adequately investigated is the frequency of AAC use by adolescents' and ranges of developmental disability diagnoses within and across research studies (Sievers et al., 2018; West et al., 2020). Although some researchers have reported that frequency of AAC exposure and use at home facilitates AAC utilization and enhances language development (Sievers et al., 2018), other research indicates that families report stress because of the communication demands related to the child's disability (Anderson et al., 2015; Borg et al., 2015; Brady et al., 2006; Donohue et al., 2015; Goldbart & Marshall, 2004; Jones et al., 1998; Schlebusch et al., 2016). More research is needed to fill gaps concerning the exposure and frequency of AAC use. A systematic review of the literature has identified child-related factors associated with AAC intervention outcomes (Sievers et al., 2018). However, the review focused on young children (less than 10 years old) diagnosed primarily with ASD who utilized a range of modalities/types AAC devices, and the review did not provide insights or understanding of measures of the frequency of AAC usage (time considerations) by families (Sievers et al., 2018).

Also, considerable heterogeneity exists in prior research, specifically regarding the samples included and the frequency and types of devices (Henderson et al., 2008; West et al., 2020). This variability in research makes comparisons between studies challenging. The current study focuses on these areas, two DD diagnoses (ASD and DS), communication function levels, types of AAC systems utilized as well as the frequency with which the devices were utilized by adolescents, to enhance understanding of why some families adapt to challenges associated with AAC technology integration and function successfully, while others struggle or abandon the AAC system during this important developmental stage.

Guiding Framework

A theoretical model is helpful for framing the areas that may contribute to family adaptation to AAC device use by adolescents. This study was guided by the Resiliency Model of Family Stress, Adjustment, and Adaptation (McCubbin et al., 1996). Family systems theories, such as the Resiliency Model, are strengths-based models that can provide insights into understanding families' functional responses to the demands of daily life. This model has successfully been adapted for use with families who have a child with a DD (Van Riper, 2007). According to the Resiliency Model, a series of interacting components shape family processes and outcomes of adaptation. The model components are: critical event/stressor, family demands, family type, family appraisal, family resources, and family problem-solving/coping. Each component of the Resiliency Model evaluates behaviors and interactions within the family system and interactions within the community, extended family, friends, neighbors, community programs and services to explain the variability in outcomes of family functioning/adaptation (McCubbin et al., 1996). In this study the critical event/stressor and family adaptation are examined. The model serves as a guiding framework for understanding factors that support and/or hinder family adaptation to a child's chronic condition, such as caring for an adolescent with DD utilizing AAC (Van Riper, 2000).

Purpose

The purpose of this study was to examine parental/adolescent characteristics and adaptation (defined as family functioning) across three groups of families based on the frequency of adolescents' use of AAC. The critical event is viewed as the frequency of AAC device use by an adolescent with autism and/or Down syndrome.

Research questions

The following three research questions were addressed:

1) What is the association between parental characteristics and family functioning among three groups of families that differ in their frequency of AAC device use by the adolescent (i.e., low-usage, mid-usage, high-usage groups)?
2) What is the association between adolescent characteristics and family functioning among three groups of families that differ in their frequency of AAC device use by the adolescent (i.e., low-usage, mid-usage, high-usage groups)?
3) What are the between group (raw unadjusted) differences in family functioning based on frequency of AAC device use by the adolescent (i.e., low usage, mid-usage, high-usage groups)?

Method

A cross-sectional descriptive design was used to examine data collected via on-line registries, support groups, and a social networking site (Facebook) where potential participants who expressed interest in participating in research studies were contacted. All quantitative data were collected through a Qualtrics© (2018) survey link. The study, including the use of online enrollment through ResearchMatch and DS-Connect, was approved by the investigator's university IRB prior to beginning the study.

Participants

A convenience sample of 227 parents (i.e., mothers; fathers; and/or primary caregivers, such as foster parent or legal guardian) of adolescents aged 13–18 years completed the survey. A family was defined as a unit of at least one parent and an adolescent with a DD. Parents were included in the study if their adolescent: 1) was diagnosed with autism and/or Down syndrome; 2) used an AAC device currently; 3) the parent understood written and spoken English; and 4) the parent had Internet access. Families of adolescents with an acquired hearing impairment or communication disability that resulted from an accident, illness, or trauma were excluded to control for variance in the study.

Recruitment and Enrollment

Families were recruited through ResearchMatch and DS-Connect, via the Internet from the Autism Society of Michigan and Apraxia Kids support organizations, and Facebook. ResearchMatch and DS-Connect are online nationwide volunteer health registries supported by the National Institutes of Health and have a large population of volunteers have consented to be contacted by researchers. Potential participants learned of the study from a brief project summary (see Appendix G) online through: 1) the organizations' official website; 2) its social networking page; and/or 3) listserv. Potential participant volunteers accessed the online informed consent and screening questions via a Qualtrics© (2018) web-link provided in the invitation to participate. Participants completed the informed consent prior to screening and survey questionnaires (see Appendix H and I). The online consent form was written verbatim as approved by the IRB. Individuals who did not qualify for the study based on their responses to the screening questionnaire were notified of ineligibility and thanked for their interest. Qualified participants had the option to select a “yes” or “no” response contained within the online consent form, with “yes” indicating voluntary agreement to participate. Copies of the consent form were stored electronically on a secured server. Consenting parents completed an online survey.

The online survey was offered to all adults equal to or greater than 18 years of age and registered in one of these organizations who self-identified as a parent and met eligibility criteria. The questionnaire took approximately 30 minutes to complete, as noted when pretested by two parent volunteers and two experienced researchers who responded to it prior to the start of the study. Participants were asked to complete the survey within one week. Email reminders were sent at the end of weeks one and two. After completion of the electronic survey, participants were thanked for their participation and received a $15 Amazon.com e-gift card as compensation for their time and effort.

At the end of the data collection period, the data were transferred and stored in electronic format and password-protected on a secure server within the investigators’ institution. Integrated with appropriate protection, the server conducted backups each night and was supported by institutional technology support services. Identifiable data were collected, such as name, phone number, and email address for participant e-gift card compensation tracking.

Measures

Demographic information related to parental characteristics and adolescent characteristics were collected to describe the diversity of the sample and for associations with outcomes. Two components of the Resiliency Model were tested: 1) critical event, which was defined as the adolescent’s frequency of AAC device use; and 2) family functioning was the outcome, which was referred to as adaptation. The critical event data identified three groups of families based on the frequency of use of the AAC device by the adolescent. Data on the type of device and the severity of the adolescent's communication function were also collected.

Parental (including Family) Characteristics. Demographic data were collected that included self-reported parental factors to describe the characteristics of the participants under investigation. The data included: age, sex, race, ethnicity, education, marital status, family size, annual income, employment status, respondent relationship to the adolescent, environmental geography of family home (i.e., urban, suburban, rural), and primary language(s) spoken in the home (see Table 3.1).

Adolescent Characteristics (Reported by Parents). Parents completed the online survey that included items regarding their adolescent's age, sex, race, primary DD diagnosis, and other conditions, communication function, type of AAC device currently utilized, and the frequency of AAC device use. While most of the characteristics are self-explanatory, the Communication Function Classification System (CFCS) was used to assess communicative functioning of the adolescent as reported by the parent (Hidecker et al., 2017; Hidecker et al., 2011). The CFCS is a validated discriminative tool that allows parents, clinicians, and researchers to categorize children's communication skills into one of five exclusive levels (ranging from I through V) based on how the adolescent interacts in everyday situations requiring communication (Hidecker et al., 2017; Hidecker et al., 2011). The levels vary by familiarity of communication partner, the adolescent's pace of communicative interactions, and the adolescent's success of sending and receiving messages. Adolescents categorized in Level I function best, whereas those in Level V have the most difficulty (Hidecker et al., 2017; Hidecker et al., 2011). The interrater reliability of CFCS has been reported from .66-.98 (Hidecker et al., 2011). The validity of the CFCS was reported in preschool children with speech and language disorders, as well as children with cerebral palsy ages 2 to 18 years (Hidecker et al., 2017; Hidecker et al., 2011). Two different categories surrounding AAC were considered: type of AAC and frequency of use. The type of AAC device was divided into three categories: low-technology (i.e., AAC with no battery or computer component), mid-technology (i.e., AAC with battery component only), and high-technology (i.e., AAC with computer component) (Baxter et al., 2012; Holyfield, 2017; Moorcroft et al., 2019).

Frequency of AAC Device Use. The frequency of AAC device use by the adolescent was reported by parents in terms of "the total number of minutes per week"; which included both weekday and weekend AAC device utilization. The total number of minutes per week the AAC device was utilized by the adolescent was divided into three groups of families (i.e., low-usage, mid-usage, high-usage). While there are no established cut points on use, three frequencies of AAC use categories were created during the study's data analysis that were based on sample data distribution and the calculation of percentiles (Gelman & Park, 2008). Additionally, parents reported the settings (e.g., home, school, work, etc.) and types of activities (e.g., academic, social, medical, etc.), for which the adolescent used the AAC device.

Family Functioning (Adaptation). Adaptation, referred to as family functioning, was assessed using a recognized psychometric measure specific to families using AAC devices. The Family Impact of Assistive Technology Scale for Augmentative and Alternative Communication (FIATS-AAC) collected data about adaptation (Delarosa et al., 2012). FIAT-AAC is an 89-item family-report (by parents) questionnaire that measures functional change related to AAC interventions for children aged 3 to 18 years and their families. FIAT-AAC measures family functioning according to six dimensions (i.e., caregiver relief, energy, family roles, finances, security, and supervision) and adolescent functioning according to seven dimensions (i.e., behavior, communication, contentment, doing activities, education, self-reliance, and social versatility) (Delarosa et al., 2012). The items were scored on a 7-point Likert scale. The scale ranges from 7 (strongly agree) to 1 (strongly disagree). Item responses within each dimension are summed and divided by the number of valid responses to create a mean dimension, ranging from 1 (lowest level) to 7 (highest level). Higher scores suggest higher positive family functioning levels within a specific dimension. Summing the mean domain scores for all 13 dimensions calculates the total FIATS-AAC score. Total FIATS-AAC scores range from 13–91, with higher scores indicating higher levels of family functioning. The overall Cronbach's α of the FIATS-AAC scale is .91, with the parent/family-related subscale alpha's ranging from .68 to .99, and the child related subscale alpha's ranging from .66 to .90 (Delarosa et al., 2012). With respect for test-re-test reliability, the point estimates for intra-class correlation coefficients (ICCs) were from .86-.97 across the 13 domains (Delarosa et al., 2012). To understand the overall representation of family functioning, the sum score was used in analyses. The Cronbach's alpha for the total FIATS-AAC measure used in this study was .76.

Data analysis

Quantitative data were assessed for missing values and examined for outliers and inconsistencies (Hulley, et al., 2013). There was a range of 0.4 to 8.8% of missing values in the survey question responses across usage groups. To address missing data, a single imputation (SI) approach was used for analyses (Manly & Wells, 2015). The sample size of 84 was determined as a reasonable sample size for this study by the G*Power analysis with a significance level of $\alpha = 0.05$. Participation in the study was higher than expected (N=227). Descriptive analyses were conducted to describe adolescent and parental demographic characteristics, including calculation of the range, mean, and standard error for continuous variables and the frequency distribution for categorical variables.

To analyze research questions 1 and 2, two steps were taken. First, the three groups were determined based on the frequency of AAC device use by the adolescent. Percentiles were used to create a low use group (less than or equal to 33rd percentile rank), mid-use group (greater than 33rd percentile but less than or equal to the 66th percentile), and high-use group (greater than the 66th percentile) (Gelman & Park, 2008). Thus, the three frequency-of-usage categories were: (low-use Group 1 (0-170 minutes/week; n=61); mid-use Group 2 (171-319 minutes/week; n=53); high-use Group 3 (320-1740 minutes/week; n=113) based on data distribution. Overall, parents reported the mean total number of minutes per week that any type of AAC device was used by adolescents as 394.7 (SD=271.5) with a range of 0-1740. This survey was administered during the recent coronavirus pandemic when families were more confided to their homes, so we expect some bias in this report.

After the three groups were created, statistical analyses were conducted to test for differences in the characteristics among Groups 1, 2, and 3. Correlation and multiple linear regression analyses (MLRA) were conducted to examine the relationship between parental characteristics (age, sex, education, marital status, income, employment status, geographical area), adolescent characteristics (sex, race, primary disability diagnosis, age, communicative function, AAC technology device type), and family functioning (total FIATS-AAC mean score) based on the frequency of use of their adolescents' current AAC device. Table 3.5 illustrates the results of the MLR analysis examining the relationships between parental and adolescent characteristics and family functioning for the three groups based on usage. Examination of the correlation matrix revealed that parent age, education level, employment status, adolescent communication function, and the adolescent's AAC device type category were significantly associated ($p<.05$) with FIATS-AAC total score. Model assumptions were tested, and if model assumptions were met, parametric tests were conducted: Analysis of Variance (ANOVA), Pearson, Spearman. Pearson's correlation coefficient was used to analyze the relationship between parental and adolescent characteristics measured on a continuous scale, and family functioning (Schober et al., 2018). Spearman's rank correlation coefficient was calculated for parental and adolescent characteristics that were ordinal variables (Schober et al., 2018). For nominal variables, a phi coefficient was utilized for measuring associations (Khamis, 2008). A correlation matrix was generated for all the continuous variables used in the study including parental age, adolescent age, and family functioning (FIATS-AAC; Table 3.4).

For the MLRA, the F value was checked using an analysis of variance to determine whether the models had become significant. In order to avoid a problem with multicollinearity, the variance inflation factor (VIF) values of all independent variables had to be less than 2.1; and to evaluate the suitability of the models, the coefficient of determination (R^2) was checked. Additionally, the Normal Q-Q plot of standardized residual was checked.

For research question 3, a Kruskal-Wallis Test was conducted to test for overall differences in mean scores on the total FIATS-AAC across the three frequency-of-use groups. For statistically significant findings, post-hoc pairwise comparisons were conducted, and p-values of < 0.05 were considered statistically significant for all tests. SPSS 26 software was used to conduct all statistical analyses.

Results

Of the 270 families that expressed interest in participating in the study, 228 families consented and completed the online survey (84.4% response rate). Data from 227 families that completed the online survey are the focus of this paper (the survey from one family listed an adolescent's age that was not within the inclusion criteria for the study, and the case was excluded from the analysis).

Parental and Adolescent Demographic and Adolescent Clinical Characteristics (Total Sample)

The majority of parents were White (74%), Non-Hispanic/Latino (89%), and married or in a partnership (97%). Approximately 57% had annual family incomes between $51,000 and $90,000, and 41% had family incomes greater than $90,000. Most of the parents were employed full time (71%) (see Table 3.1). Family size ranged from two to five or more members, but most of the families had three or four members (87%). The mean parent age (n=227) was 43 years, and parents ranged in age from 25 to 54 years. Close to half of the parent respondents were fathers (45%) and slightly over half were mothers (53%). Forty-seven percent (n=108) of the parents obtained a bachelor's degree plus, 40% of the parents had some college credit but no degree, and 12% had no college credits. All families lived in the United States with most living in urban areas (74%), while just 2% lived in rural areas.

Parents indicated more than 64% (n=147) of the adolescents had a reported primary diagnosis of autism and 35% (n=80) with Down syndrome (see Table 3.2). Additionally, adolescent participants had a range of coexisting conditions such as developmental delays, learning and intellectual disabilities, speech-language difficulties, and genetic disorders. The average age of the adolescents was 15.2 years (SD= 1.4), and most adolescents were males (65%, n=147) with 35% (n=79) being females. Based on parents' report, many adolescents were White (74%), but American Indian/Alaskan Native and African American adolescent participant representation was at 19% (n=43) and 5% (n=11), respectively. Approximately, 11% (n=24) of the adolescents were Hispanic/Latino. Adolescent communication function ranged from Level I to Level V, with a majority (70%, n= 159) at Level I (best functioning), while 9% (n=20) of adolescents' communication function was not reported by their parent. Fifty-five percent (n=127) of the parents reported high-tech AAC device use, 30% (n=69) of the adolescents used mid-tech AAC devices, and 13% (n=29) of the adolescents utilized low-tech AAC devices. Parents reported that adolescents utilized the AAC device in one to four settings, with the majority using it in home, school, speech therapy, and social interactions.

Parental Demographic Description by Usage Group

Low-usage Group (Table 3.3). Most parents included were: White, Non-Hispanic/Latino, middle to upper-class, obtained a bachelor's degree or higher, married or in a partnership, and employed full time. Eighty percent of the parents reporting were mothers, and the mean parent age was 43.7 years (SD= 4.8) ranging from 34 to 53 years of age. All of the families lived in the United States, and a majority of the families lived in urban areas. The mean FIATS-AAC total score (family functioning) was 52.1 (SD= 2.27) and ranged from 41 to 65.

Mid-usage Group (Table 3.3). The majority of parents had the following characteristics: White, Non-Hispanic/Latino, middle to upper-class, obtained some college credits and/or a college degree, married or in a partnership, and employed full time. Most of the parents were mothers, and the mean parent age was 43.9 years (SD= 4.5) ranging from 38 to 52 years of age. All the families lived in the United States, and a majority of the families lived in urban areas. The mean FIATS-AAC total score (family functioning) was 52.1 (SD= 1.00) and ranged from 48 to 54.

High-usage Group (Table 3.3). Most parents had the following characteristics: White, Non-Hispanic/Latino, middle to upper-class, married or in a partnership, had some college education, and employed full time. A majority of the parents were fathers, and the mean parent age was 41.4 years (SD= 6.5) ranging from 25 to 54 years of age. All the families lived in the United States, and a majority of the families lived in urban areas. The mean FIATS-AAC total score (family functioning) was 52.7 (SD= 2.4) and ranged from 32 to 65.

Adolescent Demographic Description by Usage Group

Low-usage Group (Table 3.3). The majority of the adolescents in the low-usage group had the following characteristics: White, males, and had a primary diagnosis of Down syndrome. The average age of the adolescents were 15.4 years (SD= 1.7) ranging from 13-18 years. Adolescent communication function ranged from Level I to Level IV, with a majority at Level I (best functioning) and high-tech AAC device use by the adolescents.

Mid-usage Group (Table 3.3). Most of the adolescent participants in the mid-usage group were white males, and approximately half of the adolescents had a reported primary diagnosis of Down syndrome. The average age of the adolescents were 15.8 years (SD= 1.4) ranging from 13-18 years. Adolescent communication function ranged from Level I to Level IV, with a majority at Level I (best functioning) and high-tech AAC device use by the adolescents.

High-usage Group (Table 3.3). A majority of the adolescents in the high-usage group had the following characteristics: white, males, and had a primary diagnosis of autism. The average age of the adolescents were 14.9 years (SD= 1.1) ranging from 13-18 years. Adolescent communication function ranged from Level I to Level V, with a majority at Level I (best functioning) and high-tech AAC device use by the adolescents.

Usage Group Differences in Parental and Adolescent Demographic and Clinical Characteristics. Table 3.3 presents the parental and adolescent characteristics by usage group (e.g., high, mid, low). Statistically significant differences in parental characteristics were found between the three usage groups regarding sex (p < .001), race (p < .001), education (p < .001), income (p = .05), and employment status (p = .01). Eighty percent of the parents in the low-usage group were mothers; in contrast, 70% were mothers in the mid-usage group, and 32% were mothers in the high-usage group. For race, approximately 90% of the parents in the low-usage and mid-usage groups were white, whereas only 59% of parents were white in the high-usage group. For education, 90% of the parents in the low-usage group had obtained a bachelor's degree or higher, in contrast to the mid and high-usage groups at 58% and 16%, respectively. Approximately 56% of the parents in the low-usage group earned more than $90,000, in comparison to only 42% in the mid-usage group, and 33% in the high-usage group. For employment status, approximately 62% of the parents in the low-usage and mid-usage groups were employed full time, in contrast to 80% of parents in the high-usage group. On the other hand, no statistically significant group differences were found regarding parental age (p = .23), ethnicity (p = .79), and geographical area (p = .82).

Additionally, statistically significant differences in adolescent characteristics were found between the three usage groups regarding sex (p < .001), race (p < .001), primary disability diagnosis (p < .001), age (p < .001), communicative function (< .001), and AAC technology device type (p = .01). In the low-usage group and mid-usage groups approximately 50% of the adolescents were males in contrast to 78% of the adolescents being male in the high-usage group. For race, approximately 90% of the parents in the low-usage and mid-usage groups were white, whereas 59% of parents were white in the high-usage group. For primary disability diagnosis, 66% of the adolescents with DS were in the low-usage group, and 51% were in the mid-usage group, in contrast to only 12% of adolescents with DS being in the high-usage group. Also, for primary disability diagnosis, 35% of the adolescents with autism were in the low-usage group and 49% were in the mid-usage group; however, 68% of adolescents with autism were in the high-usage group. The mean age of adolescents was 15 years in the low and high-usage groups, and 16 years in the mid-usage group. In the high-usage group, 87% of the adolescents were at a communicative functioning of Level I (best functioning); in contrast, 80% were found in the mid-usage group, and 55% were in the low-usage group. Subsequently, low- and mid-usage groups had no adolescents in communicative functioning Level V, and only one adolescent was at Level V in the high-usage group. For AAC technology device type, approximately 55% of the adolescents in the low-usage and high-usage groups utilized a high-tech AAC device, in contrast to 60% of adolescents in the mid-usage group.

For the families in the low-usage group (Group 1), the total number of minutes per week the AAC device was used by adolescents ranged from 0 to 170 with a mean of 103.4 (SD= 64.2). The mean total number of minutes per week for the mid-usage group (Group 2) was 239.5 (SD=43.1) with a range of 171 to 319. For the families within the high-usage group (Group 3), the total number of minutes per week the AAC device was used by adolescents ranged from 320 to 1740 with a mean of 624.8 (SD= 186.2). Statistically significant differences were found between the three groups in total minutes per week and length of time the AAC devices were utilized ($p < .001$).

Family (parental) Functioning by Usage Groups. For the families in the low-usage group (Group 1) the total FIATS-AAC score ranged from 41 to 65 with a mean of 52.1 (SD= 2.3). The total FIATS-AAC score for the mid-usage group (Group 2) was 52.1 (SD=1.0) with a range of 48 to 54. For the families within the high-usage group (Group 3), the total FIATS-AAC score ranged from 32 to 65 with a mean of 52.7 (SD= 2.4). Accordingly, no statistically significant differences were found in the FIATS-AAC total scores by family groups (see Table 3.3).

Research Question 1: What is the association between <u>parental characteristics</u> and family functioning among three groups of families that differ in their frequency of AAC device use by the adolescent (i.e., low-usage, mid-usage, high-usage groups)?

Overall Associations (across all usage groups)

The relationship between the parental demographic study variables (e.g., age, sex, marital status, education, race, ethnicity, income, employment status, geographical area) and family functioning were analyzed. The results from research question 1 indicated that three variables (i.e., age, education level, employment status) were significantly associated with family functioning across usage groups. There was a significant negative association between age and family functioning ($r = -.15$, $p<.05$). Younger aged parents reported higher family functioning. There was a significant negative association between education categories and family functioning ($r= -.14$, $p< .05$) among the usage groups. Parents with lower levels of education reported higher family functioning. Additionally, there was a statistically significant difference in family functioning scores between the different levels of employment status, $F(2, 222) = 13.67$, $p < .001$, ή=.33. Parents who worked full time reported higher scores for family functioning than parents who worked part time or were not currently working. Relationships among major study variables are summarized in Table 3.4.

Table 3.5 shows the results of the MLR analyses. Initially, after entry of the parent age, education level, employment status, adolescent communication function, and the adolescent's AAC device category into the model, the Normal Q-Q plot of standardized residual for the FIATS-AAC total score revealed three outlier cases that had a residual greater than 3.3 or less than -3.3 (Tabachnick & Fidell, 2007). Therefore, in the second step of the MLR analyses, the three outlier cases were excluded from the analysis (n=224; model 2; Table 3.5). In model 1, the results of the MLRA revealed that after entering parental education level, employment status, parental age, AAC device type, and adolescent communicative function into the model, only adolescent communicative function was a statistically significant predictor of family functioning ($p <.05$).

Research question 2: What is the association between adolescent characteristics and family functioning among three groups of families that differ in their frequency of AAC device use by the adolescent (i.e., low-usage, mid-usage, high-usage groups)?

Overall Associations (across all usage groups)

The relationship between the adolescent study variables (i.e., age, sex, race, primary DD diagnosis, communicative function, type of AAC device) and family functioning was examined. This section will cover overall associations in addition to usage groups. There was a significant positive association across AAC usage groups and family functioning ($r_s = .38$, $p<.01$). In addition to this finding, it was observed that two variables (i.e., communicative function, type of AAC device) were significantly associated with family functioning across usage groups. There was significant negative association between communicative function and family functioning ($r_s= -.29$, $p< .01$). Among adolescents with better communicative functioning, parents reported higher levels of family functioning. [Note: the communicative function variable is reversed coded, so adolescents in Level I function best and those in Level V function least well, so the numeric relationship is negative]. AAC device type (low-tech, mid-tech, high-tech) was significantly associated with family functioning ($r = .16$, $p< .05$). Family functioning was statistically significantly higher in adolescents utilizing high-tech devices than both low-tech and mid-tech devices. Relationships among major study variables are summarized in Table 3.4.

Additionally, there was a statistically significant association between adolescent communication function and the type of AAC device [X^2 (8, n = 227) = 38.52, p < .001, Cramer's V .27]. The proportion of adolescents in communication function Level I utilizing low-tech AAC devices was .13, whereas the proportion for the mid-tech to high-tech ranged from .40 to .47. Furthermore, a Chi-square test for independence indicated a statistically significant association between the AAC device type (e.g., low-, mid-, high-tech) and the frequency of AAC device use [X^2 (4, n = 227) = 13.03, p=.01, Cramer's V=.17]. The proportion of low-tech devices used by adolescents across the frequency of AAC device use groups ranged from .06 to .23. Second, the proportion of mid-tech devices used by adolescents across the frequency of AAC device use groups ranged from .23 to .38. Third, the proportion of high-tech devices used by adolescents across the frequency of AAC device use groups ranged from .54 to .60. However, the results of the MLRA revealed that the overall interaction between adolescent communication function, the AAC device type, and family functioning was non-significant.

The results for research question 2 indicated there were some relationships with adolescent demographic characteristics associated with family functioning among the three usage groups. There was a weak negative association between family functioning and adolescent communicative function. Lastly, adolescents who utilized higher levels of AAC technology devices reported higher levels of family functioning.

Table 3.5 shows the results of the MLR analyses. In model 1, the results of the MLRA revealed that adolescent AAC technology device category (e.g., low-tech, mid-tech, high-tech) was not a statistically significant predictor to family functioning in the model. However, the results of the final model (model 2) revealed a statistically significant negative association between adolescent communication function and the FIATS-AAC total score ($p<.001$). Indicating that greater adolescent communication functioning difficulty is associated with lower family functioning. Further examination of the results between adolescent communication function and family functioning (FIATS-AAC total score) indicated adolescent communicative function level IV ($\beta = -5.12$) had the strongest predictive relationship with family functioning. As the communicative functioning increased (i.e., adolescent with more difficulty communicating), there was a predicted decrease of 5.12 units on the family functioning scale. According to the CFCS measure, adolescents categorized in Level I function best, whereas those in Levels IV and V have the most difficulty (Hidecker et al., 2017; Hidecker et al., 2011).

Research question 3: What are the between group (raw unadjusted) differences in family functioning based on frequency of AAC device use (i.e., low usage, mid-usage, high-usage groups)?

There are three steps to examining this. The first step is to examine raw differences between the three groups. The second step is to examine associations over all between covariates, groups, and outcomes. The third step is to perform a MLR to adjust for covariates to estimate the adjusted association between the usage categories and the family functioning scores.

Differences Among Groups and Total Family Functioning. The data for the frequency of use variable for the three family groups were not normally distributed; therefore nonparametric statistical techniques were ideal for analyses in this study. The Kruskal-Wallis Test is the non-parametric alternative to a one-way between groups analysis of variance (Pallant, 2010). Hence, a Kruskal-Wallis Test (see Table 3.6) revealed a statistically significant difference in family functioning levels across three different AAC usage groups (Gp1, n = 61: low-usage;

Gp2, n = 53: mid-usage; Gp3, n = 113: high-usage), X^2 (2, n = 227) = 34.54, p = .000. A pairwise post-hoc comparison test was conducted to test for differences in family functioning between the three groups of families. A pairwise comparison indicated that the mean family functioning score for Group 3 (high-usage) was significantly higher than Group 1 (low-usage) and Group 2 (mid-usage). Group 1 (low-usage) and Group 2 (mid-usage) did not differ significantly from each other.

Discussion

Findings from this study provide important insights into factors associated with family functioning and illustrates future research directions for families of adolescents with DD utilizing AAC technology. In Research Question 1, it was found that the parental characteristics associated with family functioning were: parental employment status, education level, parental age. Parents who were younger, worked, and with less education were associated with higher levels of family functioning. These factors are not easily modifiable but suggest the need for interdisciplinary professionals to assess these factors and work to connect families with a variety resources for optimal family functioning. Personal factors are important to understand and acknowledge to accommodate the additional barriers or obstacles that may be present for specific families (Moorcroft et al., 2019). For example, personal factors may indicate possible challenges with technology literacy, affordability of AAC technology device purchases/personalization, or intermittent continuity of support for an adolescent.

Results for Research Question 2 revealed that the adolescent characteristics associated with higher family functioning was the type of AAC device used and levels of adolescent communicative function. This indicates that families who have adolescents with better communication functioning levels and use more advanced technological AAC devices may experience higher levels of family functioning. Previous research indicates that families report stress because of the communication demands related to the child's disability whereas the complexity of AAC technology can be a strategy to assist with these communication demands (Anderson et al., 2015; Borg et al., 2015; Brady et al., 2006; Donohue et al., 2015; Goldbart & Marshall, 2004; Jones et al., 1998; Schlebusch et al., 2016). Further, results from participants in this study revealed that adolescent communication function is associated with the FIATS-AAC total score. This finding may suggest that families of adolescents with better communicative functioning skills may contribute to higher family functioning. However, results surrounding communicative functioning from this study suggests the need for future research with a larger sample size of adolescents with varying levels of communicative functioning for further exploration. Results from this study also support that families can respond and adapt to the implementation of their adolescent's use of an AAC device. However, the distinctions in family functioning among the groups may inherently center around the adolescent's communication skills as well as the complexity of the AAC technology which suggests the need for additional research exploring these areas. Findings from this study indicate the overall interaction between adolescent communication function, the AAC device type, and family functioning was non-significant, but may suggest a need for larger sample sizes in future studies to extensively examine.

Finally, for Research Question 3, no significant differences were found in family functioning among the low-usage and mid-usage groups. However, in the high-usage group, family functioning was significantly higher than both the low-usage and mid-usage groups. Findings from the study support the belief that many families of adolescents with autism and/or Down syndrome utilize AAC devices with varying frequency. Specifically, the high-usage AAC frequency group had significantly higher levels of family functioning compared to the low-usage and mid-usage groups. This suggests the increased AAC device use of the adolescent may support higher parental reporting of specific family and adolescent dimensions within the FIATS-AAC measure, leading to an overall higher family functioning level.

Findings from this study are supported by others (Delarosa et al., 2012) reflecting that successful integration of AAC technology into an adolescent's life requires enormous support and adaptation from family members. This study on family functioning points to the benefit of guidance from a family theoretical framework, such as Resiliency Model of Family Stress, Adjustment, and Adaptation (McCubbin et al., 1996). This research specifically targeted model linkages between adolescent and parent characteristics and family functioning. Many additional linkages within this model are yet to be examined. Often the literature in the area of families of adolescents with DD using AAC is lacking conceptual underpinning; whereas this study provides a model for a theoretical foundation. For example, the McCubbin et al. (1996) framework would help in the examination of why some families undergoing similar experiences (i.e., adolescent utilizing AAC) may respond differently and to assess family risks or patterns of functioning given certain situations. Therefore, a clear conceptualization of the issues through an appropriate family systems model would add structure to understanding family well-being. More consistent use of a theoretical framework will facilitate comparison across studies and lead to greater depth when planning interventions to optimize adolescent outcomes which are essential to family quality of life.

Limitations and Future Directions

Generalizability is limited by the use of convenience sampling and self-reporting. Given families in the study were sought from online support organizations, social media, and registries, the sample may have a greater knowledge of resources to manage their adolescent's disability than families who are not part of online organizations. Additionally, families without internet access could not be included in the study. Yet, as many studies have converted to online data collection due to the global pandemic, the data from this study may be more comparable to future work as online data collection may become more common. Consistent with previous research, families who participated in the study were primarily white, married, middle to upper class, and lived in urban areas. In future research, creative approaches to reaching and recruiting more diversified participants is warranted (West et al., 2020).

Overall, this study extends the science in several key directions. In contrast to prior studies, this study focused on varying DD diagnoses, communication function levels, types of AAC systems utilized as well as the frequency with which the devices were used. This work extends previous research that did not focus on understanding the variation in family and adolescent characteristics, such as race, socioeconomic status, marital status, employment, income, and education to comprehend outcomes of families with adolescents using AAC technology (West et al., 2020). Variability in research makes comparison between studies challenging, but this study provides an example that can be used in future study reports to assist with understanding the barriers and supports these factors may present for families. Additionally, this study utilized the FIATS-AAC total score to measure family functioning specific to the population of interest: families of adolescents utilizing AAC (Delarosa et al., 2012; Ryan et al., 2018). Additional research is needed to understand the multiple dimensions within the FIATS-AAC measure that may impact the families and adolescents with complex communication needs using AAC.

Implications for Practice

From this study, it is evident that family functioning plays a central role in their ability to adapt to AAC device use by adolescents. However, findings also indicate diverse parental and adolescent characteristics are important to assess in adolescent AAC device utilization to accommodate for possible obstacles and vulnerability that may be present for families. The findings suggest the importance of identifying potential risk factors, such as socioeconomic status, employment, education, age of parent, communicative function, and type of AAC technology. Families in this study were able to function and endure the challenges utilizing AAC devices within similar frequency of usage (time) considerations. Findings provide an opportunity for diverse teams of professionals, such as researchers, speech-language pathologists, healthcare providers, nurses, family experts, educators, and technology engineers to collaborate in assessing and identifying at-risk families. Frequently families of adolescents with DD often interact with a wide range of service providers and professionals to manage needs. Thus, by building interprofessional collaborations and working across disciplines to design and provide individualized family interventions to improve family adaptation to AAC devices will enhance outcomes for adolescents and families.

Conclusion

Our findings give new insight into the distinct concerns impacting family functioning during a critical developmental time frame of adolescence. This research adds to the knowledge base concerning family involvement and support to assist with communication technology use and enhance the quality-of-life outcomes for adolescents with DD. Although this study examines families within adolescents' frequency of AAC usage groups (e.g., time), our findings suggest that is not the most important factor associated with family functioning. Our findings help expand understanding of the supports needed for families to respond to the demands of daily life surrounding adolescents with DD utilizing AAC.

APPENDICES

Appendix A: Parental Characteristics

Table 3.1

Parental Characteristics (N = 227)

Characteristics	n	%
Sex		
Male	103	45.4
Female	120	52.9
Missing	4	1.8
Marital status		
Married or in a partnership	221	97.4
Not married	5	2.2
Prefer not to disclose	1	0.4
Education		
No college	28	12.3
Some college	90	39.6
Bachelor’s degree	63	27.3
Bachelor’s degree plus	45	19.8
Missing	1	0.4
Respondent relationship		
Biological parent	203	89.4
Adoptive parent	10	4.4
Missing	14	6.2
Race		
American Indian or Alaska Native	37	16.3
Black or African American	18	7.9
White	167	73.6
Other	1	0.4
Missing	2	0.9
Ethnicity		
Hispanic or Latino	24	10.6
Not Hispanic or Latino	201	88.5
Missing	2	0.9
Family size		
Two	3	1.3
Three	115	50.7
Four	83	36.6
Five	23	10.1
More than five	2	0.9
Missing	1	0.4
Income		
Less than $50,000	5	2.2
$51,000 to $90,000	129	56.8
More than $90,000	93	41.0
Employment status		

Table 3.1 (cont'd)

Employed full time	161	70.9
Employed part time	54	23.8
Not currently working	10	4.4
Missing	2	0.9
Geographical area		
Urban	167	73.6
Suburban	53	23.3
Rural	5	2.2
Missing	2	0.9
Primary language		
English	215	94.7
Spanish	0	0
Missing	12	5.3
	Mean (SD)	Range
Age (years)	42.8 (5.66)	25-54

Appendix B: Adolescent Characteristics

Table 3.2

Adolescent Characteristics (N = 227)

Characteristics	n	%
Sex		
Male	147	64.8
Female	79	34.8
Missing	1	0.4
Race		
American Indian or Alaska Native	43	18.9
Black or African American	11	4.8
White	169	74.4
Missing	4	1.8
Primary DD Diagnosis		
Autism	147	64.8
Down syndrome	80	35.2
Other Chronic Conditions		
Developmental delay	21	9.3
Intellectual disability	16	7.0
Learning disability	10	4.4
Speech language disorder	6	2.6
Hearing impaired	1	0.4
Genetic disorder	1	.0.4
Communication function (overall effectiveness of communication performance)		
Level 1	159	70.0
Level 2	4	1.8
Level 3	36	15.9
Level 4	7	3.1
Level 5	1	0.4
Missing	20	8.8
Primary AAC device/system		
Low-tech[a]	29	12.8
Mid-tech[b]	69	30.4
High-tech[c]	127	55.9
Missing	2	0.9
	Mean (SD)	Range
Age (years)	15.24 (1.4)	13-18
Number of settings AAC used	2.26 (0.8)	1-4
Number of activities AAC used	2.22 (1.10)	0-7
AAC Length of time used (months)	14.10 (18.8)	0-135
Total minutes per week AAC used	394.7 (271.5)	0-1740

Note. AAC= Augmentative and alternative communication; DD= Developmental disability.

Table 3.2 (cont'd)

[a]Low-tech refers to AAC with no battery or computer component; [b]Mid-tech refers to AAC with battery component only; [c]High-tech refers to AAC with computer component.

Appendix C: Parent/Adolescent Characteristics and Family Functioning by Usage Group

Table 3.3

Parent and Adolescent Characteristics and Family Functioning by Usage Group (N = 227)

Characteristic	Group 1 (Low-usage) (n = 61)			Group 2 (Mid-usage) (n = 53)			Group 3 (High-usage) (n = 113)			
	M	SD	Range	M	SD	Range	M	SD	Range	p
Family functioning (Total FIATS-AAC score)	52.1	2.3	41-65	52.1	1.00	48-54	52.7	2.4	32-65	.096
Parent										
Parent age (years)	43.7	4.8	34-53	43.9	4.5	38-52	41.4	6.5	25-54	.23
	n	%		n	%		n	%		p
Sex										.00
Male	12	20.0		16	30.2		75	68.2		
Female	48	80.0		37	69.8		35	31.8		
Race										.00
American Indian/Alaska Native	0	0		0	0		37	33.0		
Black/African American	6	9.8		5	9.6		7	6.3		
White	55	90.2		46	88.5		66	58.9		
Prefer not to disclose	0			1	1.9		1	0.9		
Ethnicity										.79
Hispanic/Latino	5	8.3		6	11.5		13	11.5		
Not Hispanic/Latino	55	91.7		46	88.5		100	88.5		
Education										.00
No college	0			0			28	24.8		
Some college	6	10.0		17	32.1		67	59.3		
Bachelor's degree	30	50.0		19	35.8		14	12.4		
Bachelor's degree plus	24	40.0		17	32.1		4	3.5		
Missing	1	1.7								
Marital status										.30
Married or in a partnership	59	96.7		52	98.1		110	97.3		

Table 3.3 (cont'd)

Not married	2	3.3		0			3	2.7		
Prefer not to disclose	0			1	1.9		0			
Income										.05
Less than $50,000	1	1.6		2	3.8		2	1.8		
$51,000 to $90,000	26	42.6		29	54.7		74	65.5		
More than $90,000	34	55.7		22	41.5		37	32.7		
Employment status										.01
Employed FT	38	62.3		33	62.3		90	79.6		
Employed PT	19	32.2		19	35.8		16	14.2		
Not currently working	2	3.4		1	1.9		7	6.2		
Missing	2	3.3		0			0			
Geographical area										.82
Urban	47	77.0		37	69.8		83	73.5		
Suburban	12	19.7		15	28.3		26	23.0		
Rural	2	3.3		1	1.9		2	1.8		
Missing	0			0			2	1.8		
	M	SD	Range	M	SD	Range	M	SD	Range	
Adolescent										
Adolescent age (years)	15.4	1.7	13-18	15.8	1.4	13-18	14.9	1.1	13-18	.00
AAC Length of Time Used (months)	3.96	10.1	0-66	6.87	16.3	1-108	22.1	19.5	2-135	.00
Total minutes per week AAC used	103.4	64.2	0-170	239.5	43.1	171-319	624.8	186.2	320-1740	.00
	n	%		n	%		n	%		p
Primary DD diagnosis										.00
Autism	21	34.4		26	49.1		100	68.4		
Down syndrome	40	65.6		27	50.9		13	11.5		
Sex										.00
Male	32	53.3		27	50.9		88	77.9		
Female	28	46.7		26	49.1		25	22.1		
Race										.00
American Indian/Alaska Native	6	10.5		1	1.9		36	31.9		
Black/African American	0			1	1.9		10	8.8		
White	51	89.5		50	96.2		67	59.3		

Table 3.3 (cont’d)

Communicative function							.00
Level 1	31	55.4	39	79.6	89	87.3	
Level 2	1	1.8	1	2.0	2	2.0	
Level 3	21	37.5	8	16.3	7	6.9	
Level 4	3	5.4	1	2.0	3	2.9	
Level 5	0	0	0	0	1	0.5	
AAC device							.01
Low-tech[a]	14	23.3	8	15.1	7	6.3	
Mid-tech[b]	13	21.7	13	24.5	43	38.4	
High-tech[c]	33	55.0	32	60.4	62	55.4	
Missing	1	1.6	0		1	0.9	

Note. Groups were determined by total minutes of AAC device use per week.
AAC= Augmentative and alternative communication; DD= Developmental disability; FIATS-AAC= Family Impact of Assistive Technology Scale for Augmentative and Alternative Communication; FT=Full time; HS=High school; PT=Part time.
[a] Low-tech refers to AAC with no battery or computer component. [b] Mid-tech refers to AAC with battery component only. [c] High-tech refers to AAC with computer component.

Appendix D: Multiple Correlations and Associations

Table 3.4

Multiple Correlations and Associations Between Major Study Variables (N=227)

	1	2	3	4
1. Parent age	-			
2. Adolescent age	.17*	-		
3. FIATS-AAC score	-.15*	.03	-	
4. AAC usage groups	-.11	-.11	.38**	-

Note. AAC= Augmentative and Alternative Communication; FIATS-AAC= Family Impact of Assistive Technology Scale for Augmentative and Alternative Communication.
*p=.05
**p=.01

Appendix E: Multiple Linear Regression Analysis

Table 3.5

Multiple Linear Regression Analysis Among Usage Groups between Family Functioning and Parental and Adolescent Characteristics (n=224)

Model	Variable	B	SE	t	p	95% CI	
						LL	UL
1	Intercept	51.77	1.18	43.82	0.00	49.44	54.10
	Usage Groups				0.16		
	Group 1 (Low-usage)	-0.49	0.29	-1.68	0.09	-1.06	0.08
	Group 2 (Mid-usage)	-0.45	0.26	-1.69	0.09	-0.97	0.07
	Group 3 (High-usage)	0.00					
	Education Level				0.42		
	No College	0.67	0.43	1.56	0.12	-0.18	1.52
	Some College	0.28	0.30	0.92	0.36	-0.32	0.88
	Bachelor's degree	0.33	0.29	1.17	0.24	-0.23	0.89
	Bachelor's degree plus	0.00					
	Employment status				0.11		
	Full time	0.96	0.48	2.01	0.05	0.02	1.90
	Part time	0.71	0.52	1.36	0.18	-0.32	1.74
	Not currently working	0.00					
	AAC device				0.13		
	Low-tech[a]	0.31	0.28	1.11	0.27	-0.24	0.87
	Mid-tech[b]	0.43	0.22	1.94	0.05	-0.01	0.87
	High-tech[c]	0.00					
	Communicative function				0.00**		
	Level 1	0.38	0.54	0.70	0.49	-0.69	1.45
	Level 2	-0.27	0.78	-0.35	0.73	-1.82	1.27
	Level 3	0.24	0.62	0.39	0.70	-0.98	1.45
	Level 4	-4.72	0.78	-6.08	0.00	-6.25	-3.19
	Level 5	0.00					
	Parent Age	-0.02	0.02	-0.91	0.36	-0.05	0.02
	R^2=.423						
2	Intercept	52.48	0.53	98.22	0.00	51.43	53.53
	Usage groups				0.00**		
	Group 1 (Low-usage)	-0.68	0.23	-2.99	0.00	-1.12	-0.23
	Group 2 (Mid-usage)	-0.73	0.22	-3.29	0.00	-1.16	-0.29
	Group 3 (High-usage)	0.00					
	Communicative function				0.00**		
	Level 1	0.49	0.55	0.90	0.37	-0.58	1.57
	Level 2	-0.40	0.79	-0.50	0.62	-1.96	1.16
	Level 3	0.08	0.59	0.14	0.89	-1.08	1.24
	Level 4	-5.12	0.76	-6.74	0.00	-6.62	-3.62
	Level 5	0.00					
	R^2=.379						

Table 3.5 (cont'd)

Note. CI= Confidence interval; LL=Lower limit; UL= upper limit. Dependent variable: FIATS-AAC total score.
[a]Low-tech refers to AAC with no battery or computer component. [b]Mid-tech refers to AAC with battery component only. [c]High-tech refers to AAC with computer component.

Appendix F: Kruskal-Wallis Test of Family Functioning

Table 3.6

Kruskal-Wallis Test of Family Functioning by Groups of Families (N = 227)

Groups of Families	n	Mean rank	sd	df	p
Low to Mid usage (1 to 2)	61	84.52	12.33	2	.467
Low to High usage (1 to 3)	53	93.49	10.43		.000*
Mid to High usage (2 to 3)	113	139.53	10.93		.000*

*p< 0.05

Appendix G: Project Summary

Dear Families and Caregivers,

Are you a parent or caregiver of a teenager, 13–18 years-old, who uses augmentative and alternative communication (AAC)?

Figure 3.1: Examples of AAC

If so, you are invited to participate in a project conducted through the Michigan State University College of Nursing. In this study, we are seeking to learn about family/caregiver perspectives and experiences with augmentative and alternative communication (AAC) devices/technology utilized by your teenager who has complex communication needs (CCN). This project may help you realize your valuable expertise.
Please consider participating in this project.

You will be asked to complete the following activities:

- ○ An online questionnaire (approximately 30 minutes to complete)
- ○ Once the online survey is completed, you will be asked if the study office can contact you via email to inquire about scheduling a confidential recorded telephone interview (approximately 30–45 minutes) about your families' perspective of the benefits, challenges, and supports in the use of your teenager's communication technology.

Families or caregivers who meet eligibility criteria and complete the online survey and interview will receive a total of $35 in Amazon.com e-gift cards. If you are interested in participating in this study, please click on the following link to determine your eligibility.

Link: FAMILY_SURVEY

Any information you provide in the project will NOT be connected with your name or your teenager. Only group data without identifiers will be reported in the project outcomes.

If you have questions about this project, please contact me. Thank you again for your time and assistance.

Patricia West, MS, RN—Primary Investigator
westpatr@msu.edu

Appendix H: Screening and Consent

Screening Protocol

Participants will be eligible if:

a. they are a parent/caregiver of an adolescent aged 13–18 years with CCN
b. a neurodevelopmental disability diagnosis of autism and/or Down syndrome using AAC
c. understand written and spoken English
d. have access to the internet

The survey will be offered to all registered members or followers of the following organizations who self-identify as a parent and meet eligibility criteria:

a. DS-Connect Registry
b. Autism Society of Michigan
c. Apraxia Kids

The survey will be distributed through organizations' 1) official website, 2) social networking page, and/or 3) listserv.

Screening Questionnaire

Greetings!
Thank you for your interest in participating in this project.

You are invited to participate in a research study by an investigator at Michigan State University College of Nursing. This study is seeking to learn about family/caregiver perspectives and experiences with augmentative and alternative communication (AAC) devices/technology utilized by teenagers with complex communication needs (CCN). We hope that improving our understanding of family's experiences with communication technology, we can develop more effective resources to support teenagers and their families as they develop.

Please answer the questions below. This short questionnaire provides a few screening questions to determine if you are eligible to participate in the study. If you meet the criteria for the study, a consent form and questionnaire will be provided that will help us learn more about your parent/caregiver experiences with AAC. The questionnaire will take approximately 30 minutes to complete.

- ○ Are you a parent or caregiver of a teenager/adolescent who is at least 13 years-old and younger than 19 years of age?
- ○ Has your child received a diagnosis of Down syndrome and/or Autism?
- ○ Does your child currently use an augmentative and alternative communication (AAC) device to communicate (for example: picture or choice boards, Bigmack, Step-by-Step, Cheap Talk, Go Talk, Super Talker, iPad or iDevices with apps, PRC Accent/Vanguard, Lightwriter, or other devices)

  - Does your child have a hearing impairment?
  - Is your child's communication disorder the result of an accident, illness, trauma, or progressive medical condition (e.g., brain accident/injury, muscular dystrophy, brain tumor, or other)?

Message for ineligible participants: Thank you for your time and interest in this research study. Unfortunately, you are NOT eligible for this study.

Message for eligible participants: Thank you for your interest in the research study. You have completed the information needed. You are eligible to continue on with the questionnaire.

*Consent Form (in online survey):

Parent and family experiences with adolescent AAC device use.

1. Explanation of the research and what you will do:
    - You are being asked to participate in a research study investigating parental and family experiences of your teenager/adolescent's use of an AAC (augmentative and alternative communication) device. As part of the study you will be asked to complete the following activities:
        - An online questionnaire (approximately 30 minutes)
        - Contacted to inquire about possibly scheduling a more in-depth personal telephone interview within one to two weeks (approximately 30–45 minutes)

    *Participants can complete the online questionnaire and not the telephone interview if preferred.

    - To participate in this research project, you must be at least 18 years of age, a parent/caregiver of a teenager/adolescent with complex communication needs between the ages of 13 and 18 years old who uses AAC.
2. Your rights to participate, say no, or withdraw:
    - Participation in this research project is voluntary. You have the right to say no to the online questionnaire and/or the telephone interview at any time. You have the right to withdraw from the study at any time. You do not have to answer any questions that you do not want to answer.
3. Costs and compensation for being in the study:
    - For participating in this research study, you will be emailed a $15 Amazon.com e-gift card after the completion of the online survey and a $20 Amazon.com e-gift card after the completion of the telephone interview.
4. Contact information for questions and concerns.
    - If you have questions or concerns about this study, please contact the researcher, Patty West, westpatr@msu.edu

5. By clicking the button below, you indicate your voluntary agreement to participate in the online questionnaire.
    - Yes
    - No
6. By clicking the button below, you indicate your voluntary agreement to be contacted to inquire about participating in a follow up telephone interview. We will contact you via email and/or phone to confirm a date and time for the telephone interview.
    - Yes
    - No

*Participants can complete the online questionnaire and not the telephone interview if preferred.

Name: (first, middle initial, last name)
Email address: ___________________________
Phone number: ___________________________

Appendix I: Online Survey

Instructions: The following questions ask about your adolescent/teenager. Please fill in the blank or click the item that matches your answer.

What is your adolescent/teenager’s date of birth? (Format: month/year; for example: 09/2000)
Month (mm) ______________
Year (yyyy) _______________

What is your adolescent/teenager's sex?
- ○ Male
- ○ Female
- ○ Prefer not to disclose

Which of the following best describes your adolescent/teenager’s race? Please select one or more.
- ○ American Indian or Alaska Native
- ○ Asian
- ○ Black or African American
- ○ Pacific Islander
- ○ White
- ○ Other __________
- ○ Prefer not to disclose

Which one of the following best describes your adolescent/teenager's primary condition or diagnosis?
- ○ Autism, Autism Spectrum Disorder, and/or Pervasive Developmental Disorder
- ○ Apraxia or Childhood Apraxia of Speech
- ○ Intellectual/Cognitive disability
- ○ Down syndrome

Has a doctor or other health care professional EVER told you that your adolescent/teenager has: Please select all that apply.
- ○ Autism, Autism Spectrum Disorder, Pervasive Developmental Disorder
- ○ Cerebral Palsy
- ○ Down syndrome
- ○ Developmental delay
- ○ Intellectual disability/Cognitive disability
- ○ Learning disability
- ○ Speech or other language disorder
- ○ Hearing impaired
- ○ Other ________

Does your adolescent/teenager consistently and effectively alternate between conveying a message and receiving a message with **familiar** communication partners? (e.g., parent, sibling, teacher, etc.)

- ○ Yes
- ○ No

Does your adolescent/teenager consistently and effectively alternate between conveying a message and receiving a message with **unfamiliar** communication partners? (e.g., store clerk, grocery cashier, etc.)

- ○ Yes
- ○ No

Does your adolescent/teenager usually maintain a conversation at a comfortable pace with communication partner?

- ○ Yes
- ○ No

Is your adolescent/teenager effective at conveying a message and/or receiving a message at least some of the time with communication partners?

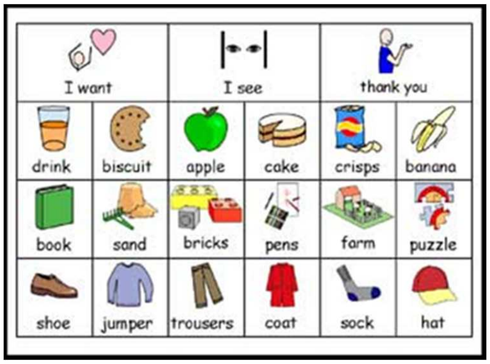
- ○ Yes
- ○ No

What is the **primary or current** augmentative and alternative communication (AAC) system/device your adolescent/teenager uses to communicate?

○ No-tech communication (e.g. sign language, gestures)

Figure 3.2: Example of No-tech

○



○ Low-tech communication-No battery or computer component (e.g. picture exchange, choice boards)

Figure 3.3: Example of Low-tech

○ Mid-tech communication- Battery component only (e.g. Step-by-Step, Cheap Talk, Go Talk, Super Talker)

Figure 3.4: Example of Mid-tech

○ High-tech communication- Computer component (e.g. iPad or iDevices with apps, PRC Accent/Vanguard, Lightwriter)

Figure 3.5: Example of High-tech

How long has your adolescent/teenager used their **primary/current** AAC communication system/device? (in months)

Months _________

How many hours in a typical weekday does your adolescent/teenager use their AAC communication device?

Hours _______
Minutes _____

How many hours in a typical weekend (Saturday and Sunday) does your adolescent/teenager use their AAC communication device?

Hours _______
Minutes _____

In what settings does your adolescent/teenager use the AAC communication system/device? (Please check all that apply)

○ Home
○ School
○ Friends
○ Work
○ Other ___________

During what types of activities does your adolescent/teenager use the AAC system? (Please check all that apply)

○ Academic
○ Social
○ Leisure/recreation
○ Religious
○ Medical
○ In person
○ Online
○ Mobile device use (e.g. iPad, iPhone)
○ Job/employment
○ Other __________________

Instructions: The following questions ask about your family and yourself. Please fill in the blank or click the circle that matches your answer.

In your family, how are you related to this teenager/adolescent?

○ Biological parent
○ Adoptive parent
○ Stepparent
○ Foster-parent
○ Legal guardian
○ Other __________

What is your sex?

- ○ Male
- ○ Female
- ○ Prefer not to disclose

What year were you born?

Year ___________

Are you of Hispanic or Latino/a origin?

- ○ Yes
- ○ No
- ○ Prefer not to disclose

Which of the following racial/ethnic group(s) do you most closely identify? Please select one or more.

- ○ American Indian or Alaska Native
- ○ Asian
- ○ Black or African American
- ○ Pacific Islander
- ○ White
- ○ Other
- ○ Prefer not to disclose

What is the primary language in your home?

- ○ English
- ○ Spanish
- ○ Other _________

What is your marital status?

- ○ Married
- ○ Not married, but living with partner
- ○ Never married
- ○ Divorced
- ○ Separated
- ○ Widowed
- ○ Prefer not to disclose

What is the highest level of school you completed?

- Some high school; No diploma
- High school graduate or GED completed
- Some college credit, but no degree
- Associates Degree
- College graduate (Bachelor’s Degree)
- Graduate degree (Master’s Degree or higher)
- Prefer not to disclose

How many **family members** currently live in your household? (**including yourself)
(Family is defined as anyone related to the teenage/adolescent by blood, marriage, adoption, or through foster care.)

- One
- Two
- Three
- Four
- Five
- More than five

How many **children** live in the household? (*children less than 19 years of age)

- One
- Two
- Three
- Four
- Five
- More than five

What is your current employment status?

- Employed full time
- Employed part-time
- Unemployed/not currently working
- A Homemaker
- Retired
- Unable to work

What is your current household income?

- Less than $30,000
- $31,000 to $50,000
- $51,000 to $70,000
- $71,000 to $90,000
- $91,000 to $110,000
- More than $100,000

Where are you geographically located?

○ USA
○ Canada
○ Mexico
○ Europe
○ Other ____________

Which of the following best describes the area you live in?
○ Urban (high population, usually close to regional downtown)
○ Suburban (outlying areas surrounding larger cities)
○ Rural (very thinly populated, more likely to have farms and forest)

PLEASE READ: This questionnaire will help us to learn a bit about you, your teenager/adolescent, and your family life as it relates to your teenager/adolescent's face-to-face communication. Please complete the questionnaire by saying how much you agree with each of the following statements. For instance, the first item says: 'My child needs help from others when communicating.' If you strongly agree with this statement because your child always needs help from others when communicating, click '7'. If you strongly disagree because your child never needs help, then click '1'. Click one of the other numbers if you agree or disagree to a lesser amount. Please click **only one rating for each statement**.

Please indicate how much you agree with each statement and click only one rating for each statement.

	Strongly Agree (7)	Agree (6)	Somewhat Agree (5)	Neither Agree nor Disagree (4)	Somewhat Disagree (3)	Disagree (2)	Strongly Disagree (1)
My child needs help from others when communicating.	○	○	○	○	○	○	○
My child lets me know if something is wrong.	○	○	○	○	○	○	○
I need more support from family members when caring for my child	○	○	○	○	○	○	○
I find it easy to play with my child.	○	○	○	○	○	○	○
My child needs a lot of help to be understood.	○	○	○	○	○	○	○
Being independent improves my child's self-esteem.	○	○	○	○	○	○	○
My child tells me what she/he wants.	○	○	○	○	○	○	○
My child has a tough time starting a conversation with people.	○	○	○	○	○	○	○

If my child got lost, she/he could ask someone for directions.	○	○	○	○	○	○	○
Others share the caregiving responsibilities for my child.	○	○	○	○	○	○	○
My child tells me about her/his day.	○	○	○	○	○	○	○
My child’s communication disability affects my ability to work outside the home.	○	○	○	○	○	○	○
It is hard for me to get anything else done when my child is at home.	○	○	○	○	○	○	○
My child likes to be independent.	○	○	○	○	○	○	○
My child can phone for help in an emergency.	○	○	○	○	○	○	○
I need help from professionals to care for my child.	○	○	○	○	○	○	○
More than one person is required to help my child communicate.	○	○	○	○	○	○	○

My child knows how to take turns during conversations.	○	○	○	○	○	○	○
My child is learning to communicate independently.	○	○	○	○	○	○	○
My family needs to give up many other luxuries so my child can have the devices she/he needs.	○	○	○	○	○	○	○
My child communicates with other people on the phone.	○	○	○	○	○	○	○
All family members take turns supporting my child when going out into the neighborhood.	○	○	○	○	○	○	○
My child is very sociable.	○	○	○	○	○	○	○
My child communicates with family members.	○	○	○	○	○	○	○
I feel my child is safe if I leave her/him with another babysitter and/or caregiver.	○	○	○	○	○	○	○

My child communicates with people with whom she/he is less familiar.	○	○	○	○	○	○	○
I find it tiring to help my child communicate.	○	○	○	○	○	○	○
My child’s communication disability affects family finances.	○	○	○	○	○	○	○
I do most of the caregiving for my child at home.	○	○	○	○	○	○	○
We watch our finances because of my child’s communication disability.	○	○	○	○	○	○	○
Other people understand my child.	○	○	○	○	○	○	○
It is very demanding saying what my child wants to others.	○	○	○	○	○	○	○
My child knows how to keep a conversation going.	○	○	○	○	○	○	○
Everyone in my family knows how to communicate with my child.	○	○	○	○	○	○	○
My child plays with friends.	○	○	○	○	○	○	○

Communication devices for my child make it difficult for my family to afford anything else.	○	○	○	○	○	○	○
My child tells me when she/he is afraid.	○	○	○	○	○	○	○
My child’s independence is increasing.	○	○	○	○	○	○	○
My child communicates her/his ideas.	○	○	○	○	○	○	○
Much of my time during the day is spent helping my child to communicate.	○	○	○	○	○	○	○
My child participates in community activities.	○	○	○	○	○	○	○
My child tells me when she/he feels sick.	○	○	○	○	○	○	○
My child needs my help to communicate with others.	○	○	○	○	○	○	○
My child converses well with friends.	○	○	○	○	○	○	○
It is hard work helping my child with homework.	○	○	○	○	○	○	○

My child could never go out in the neighborhood on her/his own.	○	○	○	○	○	○	○
My child prefers to communicate with me rather than other family members.	○	○	○	○	○	○	○
My child socializes with others at mealtime.	○	○	○	○	○	○	○
My child's teacher is satisfied with my child's performance in school.	○	○	○	○	○	○	○
Other family members need to help me care for my child.	○	○	○	○	○	○	○
My child must be with others to be content.	○	○	○	○	○	○	○
I have difficulty managing my child's behavior.	○	○	○	○	○	○	○
My child can spend a long time doing one activity.	○	○	○	○	○	○	○
My child can communicate with others.	○	○	○	○	○	○	○
My child enjoys school.	○	○	○	○	○	○	○

I need longer breaks from watching my child.	○	○	○	○	○	○	○
My child gets frustrated easily.	○	○	○	○	○	○	○
I have little time to get chores done around the house.	○	○	○	○	○	○	○
My child behaves well around me.	○	○	○	○	○	○	○
I have trouble coping with the demands of caring for my child.	○	○	○	○	○	○	○
My child participates in the classroom.	○	○	○	○	○	○	○
My child likes to explore her/his surroundings.	○	○	○	○	○	○	○
My child acts appropriately toward other family members.	○	○	○	○	○	○	○
My child wants to be with me when I leave the room.	○	○	○	○	○	○	○
I would like to get breaks from caring for my child.	○	○	○	○	○	○	○
My child is performing well in school.	○	○	○	○	○	○	○

I would like to spend more time with my other family members.	○	○	○	○	○	○	○
My child gets bored easily.	○	○	○	○	○	○	○
My child can play games.	○	○	○	○	○	○	○
My child is well behaved at school.	○	○	○	○	○	○	○
I must take my child with me when I go from one room to another.	○	○	○	○	○	○	○
I need to get more things done around the house.	○	○	○	○	○	○	○
My child can be happy when I am not holding her/him.	○	○	○	○	○	○	○
I am concerned about my child’s safety when she/he is left alone.	○	○	○	○	○	○	○
My child participates in extra-curricular activities at school.	○	○	○	○	○	○	○
My child can use her/his hands to play.	○	○	○	○	○	○	○
I need help to take care of my child.	○	○	○	○	○	○	○

I am satisfied with my child's achievement of personal goals at school.	○	○	○	○	○	○	○
My child feels self-confident.	○	○	○	○	○	○	○
A family member needs to be near my child during the day.	○	○	○	○	○	○	○
I wish my child could give me a few minutes to myself each day.	○	○	○	○	○	○	○
I am concerned about the way my child behaves.	○	○	○	○	○	○	○
My child can control toys without help.	○	○	○	○	○	○	○
My child is proud of her/his schoolwork.	○	○	○	○	○	○	○
My child can be happy when left alone to play.	○	○	○	○	○	○	○
My child needs me nearby to do many activities.	○	○	○	○	○	○	○
My child disrupts her/his classmates.	○	○	○	○	○	○	○
I can manage my child on my own.	○	○	○	○	○	○	○

My child likes to be near me.	○	○	○	○	○	○	○

Thank you for completing this questionnaire. We appreciate your time and willingness to help us understand your perspectives and experiences with augmentative and alternative communication (AAC) devices utilized by your teenager/adolescent.

If you have any questions about this survey, please contact Patty West, primary investigator, for this project at westpatr@msu.edu.

We could still use your voluntary assistance in helping us understand a more detailed description of your perspectives with supporting your adolescent’s augmentative and alternative communication use. Would you be willing to participate in a follow up recorded interview?

○ Yes
○ No

Thank you again for your time and assistance! Please enter your information below to receive an emailed $15 Amazon.com e-gift card for completion of the online survey.

First Name ____
Last Name ____
Email Address ____

“Yes” response (see below):

Thank you again for your assistance and voluntarily agreeing to participate with the second part of the research study. Please complete the following information. But please note that some participants may or may not be contacted for this part of the research study. If you are contacted for the interview portion of the study, after completion of the interview you will receive an emailed $20 Amazon.com e-gift card.

Patty West, primary investigator for this project, will contact you via email to confirm the date and time of your recorded interview session. We are looking forward to touching base with you soon.
Thank you again for your time and assistance!

First Name ____
Middle Initial ____
Last Name ____
Email Address ____

REFERENCES

REFERENCES

Anderson, K. L., Balandin, S., & Stancliffe, R. J. (2015). Alternative service delivery models for families with a new speech generating device: Perspectives of parents and therapists. *International Journal of Speech-Language Pathology*, *17*(2), 185–195. https://doi.org/10.3109/17549507.2014.979876

Angelo, D. H. (2000). Impact of augmentative and alternative communication devices on families. *Augmentative and Alternative Communication*, *16*(1), 37–47.

Bailey, R. L., Parette, H. P., Stoner, J. B., Angell, M. E., & Carroll, K. (2006). Family members' perceptions of augmentative and alternative communication device use. *Language, Speech, and Hearing Services in Schools*, *37*, 50–60. https://ajslp.pubs.asha.org/doi/full/10.1044/0161-1461%282006/006%29

Baxter, S., Enderby, P., Evans, P., & Judge, S. (2012). Barriers and facilitators to the use of high-technology augmentative and alternative communication devices: A systematic review and qualitative synthesis. *International Journal of Language & Communication Disorders*, *47*(2), 115–129. doi: 10.1111/j.1460-6984.2011.00090.x

Bourke-Taylor, H., Cotter, C., & Stephan, R. (2013). Young children with cerebral palsy: Families self-reported equipment needs and out-of-pocket expenditure. *Child: Care, Health, and Development*, *40*(5), 654–662. https://doi.org/10.1111/cch.12098

Borg, S., Agius, M., & Agius, L. (2015). A user and their family's perspective of the use of a low-tech vs a high-tech AAC system. *Studies in Health Technology and Informatics, 217*, 811–818. doi: 10.3233/978-1-61499-566-1-811

Brady, N., Skinner, D., Roberts, J., & Hennon, E. (2006). Communication in young children with Fragile X Syndrome: A qualitative study of mothers' perspectives. *American Journal of Speech Language Pathology*, *15*(4), 353–364. https://ajslp.pubs.asha.org/doi/full/10.1044/1058-0360%282006/033%29

Center for Disease Control and Prevention. (2019). Increase in developmental disabilities among children in the United States. Retrieved from https://www.cdc.gov/ncbddd/developmentaldisabilities/features/increase-in-developmental-disabilities.html

Clarke, M. T., Newton, C., Griffiths, T., Price, K., Lysley, A., & Petrides, K. V. (2011). Factors associated with the participation of children with complex communication needs. *Research in Developmental Disabilities*, *32*, 772–780. https://doi.org/10.1177%2F0031512517708528

Delarosa, L., Horner, S., Eisenberg, C., Ball, L., Renoni, A., & Ryan, S. E. (2012). Family impact of assistive technology scale: Development of a measurement scale for parents of children with complex communication needs. *Augmentative and Alternative Communication*, *28*(3), 171–180. doi: 10.3109/07434618.2012.704525

Donohue, D.K., Bornman, J., & Granlund, M. (2015). Household size is associated with unintelligible speech in children who have intellectual disabilities: A South African study. *Developmental Neurorehabilitation*, *18*(6), 402–406. doi: 10.3109/17518423.2014.890256

Gelman, A. & Park, D.K. (2008). Splitting a predictor at the upper quarter or third and the lower quarter or third. *The American Statistician*, 62(4), 1-8. doi: 10.1198/000313008X366226

Goldbart, J., & Marshall, J. (2004). "Pushes and pulls" on the parents of children who use AAC. *Augmentative and Alternative Communication*, *20*(4), 194–208. https://doi.org/10.1080/07434610400010960\

Henderson, S., Skelton, H., & Rosenbaum, P. (2008). Assistive devices for children with functional impairments: Impact on child and caregiver function. *Developmental Medicine and Child Neurology*, 50(2), 89-98. doi: 10.1111/j.1469-8749.2007.02021.x

Hidecker, M.J., Cunningham, B.J., Thomas-Stonell, N., Oddson, B., & Rosenbaum, P. (2017). Validity of the Communication Function Classification System for use with preschool children with communication disorders. *Developmental Medicine & Child Neurology*, 59, 526-530. doi: 10.1111/dmcn.13373

Hidecker, M.J., Paneth, N., Rosenbaum, P., Kent, R., Lillie, J., Eulenberg, J.B., Chester, K., Johnson, B., Michalsen, L., Evatt, M., Taylor, K. (2011). Developing and validating the Communication Function Classification System for individuals with cerebral palsy. *Developmental Medicine & Child Neurology*, 53, 704-710. doi: 10.1111/j.1469-8749.2011.03996.x

Holyfield, C., Drager, K. D. R, Kremkow, J. M. D., & Light, J. (2017) Systematic review of AAC intervention research for adolescents and adults with autism spectrum disorder. *Augmentative and Alternative Communication*, 33(4), 201–212. doi: 10.1080/07434618.2017.1370495

Hulley, S. B., Cummings, S. R., Browner, W. S., Grady, D. G., & Newman, T. B. (2013). *Designing clinical research*. (4th ed.). Philadelphia, PA: Wolters Kluwer.

Jones, S. D., Angelo, D. H., & Kokoska, S. M. (1998). Stressors and family supports: Families with children using augmentative & alternative communication technology. *Journal of Children's Communication Development*, *20*(2), 37–44. https://journals.sagepub.com/doi/abs/10.1177/152574019902000205

Khamis, H. (2008). Measures of association: How do we choose? *Journal of Diagnostic Medical Sonography*, 24(3). 155-162. https://doi.org/10.1177/8756479308317006

Manly, C.A. & Wells, R.S. (2015). Reporting the use of multiple imputation for missing data in higher education research. Research in Higher Education, 56, 397-409. doi: 10.1007/s11162-014-9344-9

Marshall, J., & Goldbart, J. (2008). 'Communication is everything I think.' Parenting a child who needs augmentative and alternative communication (AAC). *International Journal of Language & communication Disorders*, *43*(1), 77–98. doi: 10.1080/13682820701267444

McCubbin, M. A., Thompson, A., & McCubbin, H. I., (1996). *Family assessment: Resiliency, coping and adaptation*. Madison, WI: University of Wisconsin-Madison.

McNaughton, D., Bryen, D., Blackstone, S., Williams, M., & Kennedy, P. (2012). Young adults with complex communication needs: Research and development in AAC for a "Diverse" population. Assistive Technology, 24, 45-53. doi: 10.1080/10400435.2011.648715

McNaughton, D., Rackensperger, T., Benedek-Wood, E., Krezman, C., Williams, M. B., & Light, J. (2008). "A child needs to be given a chance to succeed": Parents of individuals who use AAC describe the benefits and challenges of learning AAC technologies. *Augmentative and Alternative Communication*, *24*(1), 43–55. doi: 10.1080/07434610701421007

Moorcroft, A., Scarinci, N., & Meyer, C. (2019). A systematic review of the barriers and facilitators to the provision and use of low-tech and unaided AAC systems for people with complex communication needs and their families. *Disability and Rehabilitation: Assistive Technology*, 14(7), 710-731. doi: 10.1080/17483107.2018.1499135

Pallant, J. (2010). *SPSS survival manual*. (4th ed.). New York: McGraw-Hill.

Ryan, S.E., Shepherd, T.A., Renzoni, A.M., Servais, M., Kingsnorth, S., Laskey, C., Ward, K., & Bradley, K. (2018). Responsiveness of a parent-reported outcome measure to evaluate AAC interventions for children and youth with complex communication needs. *Augmentative and Alternative Communication*, 34(4), 348-358, doi:10.1080/07434618.2018.1520296

Schlebusch, L., Dada, S., & Samuels, A. E. (2017). Family quality of life of South African families raising children with Autism Spectrum Disorder. *Journal of Autism Developmental Disorders*, *47*, 1966–1977. doi: 10.1007/s10803-017-3102-8

Schlebusch, L., Samuels, A. E., & Dada, S. (2016). South African families raising children with autism spectrum disorders: Relationship between family routines, cognitive appraisal, and family quality of life. *Journal of Intellectual Disability Research*, *60*(5), 412–423. doi: 10.1111/jir.12292

Schober, P., Boer, C., & Schwarte, L. A. (2018). Correlation coefficients: appropriate use and interpretation. *Anesthesia & Analgesia*, 126(5), 1763-1768. doi:10.1213/ANE.0000000000002864

Smith, M.M. (2015). Adolescence and AAC: Intervention challenges and possible solutions. *Communications Disorders Quarterly*, 36(2), 112-118. doi: 10.1177/1525740114539001

Sievers, S.B., Trembath, D., & Westerveld, M. (2018). A systematic review of predictors, moderators, and mediators of augmentative and alternative communication (AAC) outcomes for children with autism spectrum disorder. *Augmentative and Alternative Communication*, 34(3), 219-229. doi: 10.1080/07434618.2018.1462849

Tabachnick, B.G. & Fidell, L.S. (2007). *Using multivariate statistics* (5th ed.). Boston: Pearson Education.

Van Riper, M. (2007). Families of children with Down syndrome: Responding to "A change in plans" with Resilience. *Journal of Pediatric Nursing*, *22*(2), 116–128. doi:10.1016/j.pedn.2006.07.004

Van Riper, M. (2000). Family variables associated with well-being in siblings of children with Down syndrome. *Journal of Family Nursing*, *6*(3), 267–286.

West, P., Van Riper, M., Wyatt, G., Lehto, R., Douglas, S.N., & Robbins, L. (2020). Adaptation to technology use in families of children with complex communication needs: An integrative review and family theory application. *Journal of Family Nursing*, 26(2), 153-178. https://doi.org/10.1177/1074840720915536

Zablotsky, B., Black, L.I., Maenner, M.J., Schieve, L.A., Danielson, M.L., Bitsko, R.H., Blumberg, S.J., Kogan, M.D., & Boyle, C.A. (2019). Prevalence and trends of developmental disabilities among children in the United States: 2009–2017. *Pediatrics*, 144(4):e20190811

CHAPTER FOUR: PERCEPTIONS OF FAMILIES WITH ADOLESCENTS UTILIZING AUGMENTATIVE AND ALTERNATIVE COMMUNICATION TECHNOLOGY: A QUALITATIVE APPROACH

Abstract

Purpose: The aim of this study was to explore parent-reported factors contributing to family adaptation among families with adolescents diagnosed with autism and/or Down syndrome (DS) utilizing augmentative and alternative communication (AAC) technology. Although family involvement is critical to successful AAC device utilization, little is known about how families adapt to technology. Nurses are well-positioned in a variety of practice settings to assess vulnerable families and assist with identifying resources and navigating complex service systems. This study qualitatively describes families' experiences related to several interacting variables of the Resiliency Model, including demand, type, appraisal, resources, problem-solving/coping, that helped shape the outcome of adaptation to AAC technology.

Design and Methods: Semi-structured interviews were conducted with eight parents of adolescents with autism and/or DS (aged 13-18). Recorded interviews were transcribed, and two independent reviewers coded and analyzed the data. Comparisons across all families' thematic summaries were examined for patterns.

Results: Analysis revealed five themes that described aspects of family adaptation: *Contextual Strains and Influences, Continuum of Person-First Approach, Opening Doors, Facilitators of Support,* and *Planning is Key*.

Conclusions: Findings highlighted the challenges and demands associated with raising an adolescent using an AAC device, as well as the attributes, resources, perceptions, and strategies that either contributed or hindered family adaptation.

Practice Implications: AAC technology is readily available for adolescents with DD, and it is essential that nurses assess key model components to support families in integrating and using the technology.

Introduction

Approximately 17% of children aged 3 to 17 years in the United States have one or more developmental disabilities (DD), which may impair speech requiring an alternative mechanism to communicate [Center for Disease Control (CDC), 2019]. Augmentative and alternative communication (AAC) technology systems can help overcome complex communication needs (CCN) by enhancing capacity for communication exchange and socialization. The most common neurodevelopmental disabilities associated with language impairments involve children with autism spectrum disorder (ASD) and Down syndrome (DS), and these children commonly receive speech and language services (Martin et al., 2018). Consequently, children with physical impairments, communication difficulties, and/or developmental delays are at a high risk for health problems due to their ever-changing health and social, educational, and community needs as they become adolescents (King et al., 2002). When communication functioning is compromised, adolescents face barriers to successful participation in school, workplace, community, and home; limiting independence in their emotional, educational, social and vocational life (Allen & Babin, 2013; Lewis et al., 2004; Moriatry & Gillon, 2006). Most notably during this critical time of adolescent development, families are adapting and transitioning from pediatric to adult services while evaluating resources and navigating complex service systems (Burke, 2017; Lindo et al., 2016).

Families are essential in the management of a child's disability and are the most significant partners for adolescents who use AAC, but their role is often underestimated (Baxter et al., 2012; Saito & Trunbull, 2007; Parette & Angelo, 1996; Seligman & Darling, 2007). Technology in the form of AAC devices supports everyday communicative interactions. However, an adolescent's successful integration of technology into daily life is dependent on family engagement in the process (McNaughton et al., 2008; Parette et al., 2000).

Despite recognized benefits to using AAC, families-especially parents-experience challenges when supporting their adolescents in the use of this technology (Angelo, 2000; Bailey et al., 2006; Brady et al., 2006; Marshall & Goldbart, 2008). Recent advances in technology, such as apps, mobile i-devices, and numerous social media platforms, have increased the complexity involved with integrating AAC devices into daily life (Light et al., 2019; McNaughton & Light, 2013; Meder & Wegner, 2015). Although the positive impact of AAC technology is known, research has yet to explain the family experience as parents adapt to challenges associated with adjusting to what is required to help their adolescent be successful with the advancing AAC technology and how nurses can support adolescents with DD and the families they care for. Nurses in hospitals, schools, primary care, and specialty clinics are being exposed to increasing numbers of diverse families of adolescents with DD who have been using AAC technologies to improve communication exchange. Such devices can be useful within the family as well as with health care professionals. Nurses can significantly contribute to coordinating AAC interventions within plans of care while partnering with families (Hemsley, et al, 2011; McNaughton et al., 2010; Wilson & Peterson, 2018).

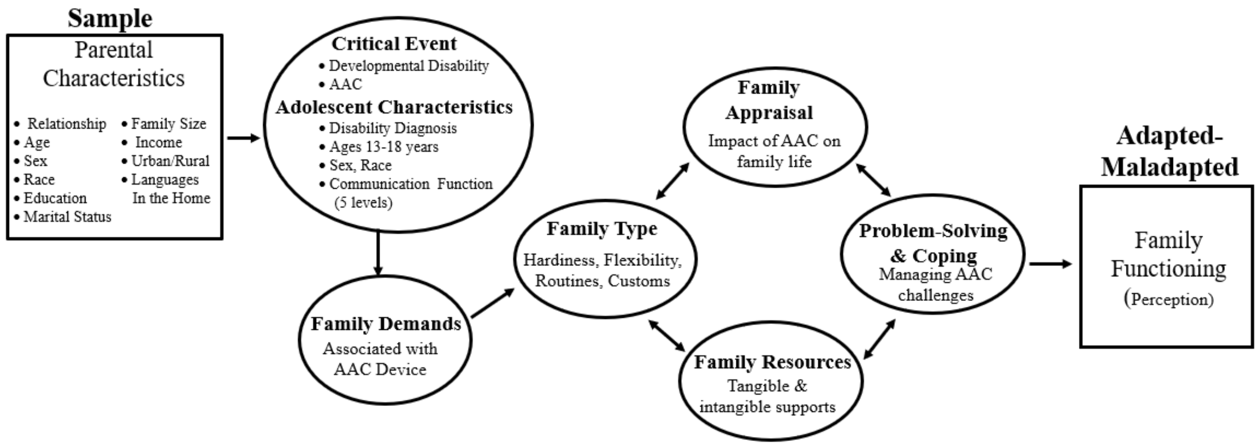
Families face challenges in multiple areas while supporting adolescent's AAC technology use. Based on the Resiliency Model of Family Stress, Adjustment, and Adaptation (1996), five key concepts to explore include: demands, type, appraisal, resources, and problem solving/coping (McCubbin et al., 1996). Unfortunately, limited research exists concerning the impact of AAC technology among families in these five areas, all of which are purported to lead to family adaptation. (West et al., 2020). Much of the literature emphasizes parental/caregiver challenges, demands, and stresses associated with AAC device use, but potential issues that have not been adequately explored include family type/typologies, appraisal, and problem solving/coping (West et al., 2020). Research is needed to explain why families undergoing similar experiences (i.e., adolescent utilizing AAC) may respond differently regarding the five areas (i.e., family demands, family type, family appraisal, family resources, and family problem-solving) to shape the family process and outcomes of adaptation (Van Riper, 2000). The lack of empirical evidence regarding the perspectives of families who have adolescents with DD utilizing AAC devices leaves a gap in knowledge about family adaptation and increases the risk for negative outcomes of adolescents and their families. Therefore, a comprehensive understanding of the reasons underlying family responses within the phenomenon can contribute to the science and guide the practice of nursing.

Purpose and Conceptual Underpinnings

Guided by the Resiliency Model of Family Stress, Adjustment, and Adaptation (1996), this study aims to explore parent-reported factors contributing to family adaptation among families with adolescents diagnosed with autism and/or DS utilizing AAC technology. Specifically, the model's key interacting components including family demands, type, appraisal, resources, and problem solving/coping (see Figure 4.1), that shape family processes and outcomes of adaptation, were qualitatively explored to enhance the understanding of outcomes of family adaptation to AAC use. These components, except family type which needs further explanation (West et al., 2020), have been cited in the literature as also being relevant to the outcome of family functioning.

Research aimed at understanding factors that support and help families of adolescents with CCN adapt to their communication challenges is needed, especially in the areas of family type, appraisal, and problem-solving and coping (West et al., 2020). Understanding the experiences of families will assist in developing future interventions, and possibly exploring family type/typologies to assist with explaining predictions of family risks or patterns of functioning given certain situations. Thus, existing research is inadequate and additional work needs to be pursued.

Figure 4.1: Adapted Conceptual Resiliency Model in Families Utilizing AAC



Adapted from McCubbin et al., 1996

Since the Resiliency Model has been utilized in studies of families of children with various chronic conditions and has been empirically tested in diverse family member makeups and ethnic groups from many different countries (Choi, 2015; McCubbin et al., 1996; Van Riper, 2007; 2000), it is ideal to assist with an in-depth understanding of the perspectives of families who have adolescents with DD utilizing AAC. The research question guiding this study was:

1) What are parents' perceptions of family demands, type, appraisal, resources, and problem-solving/coping associated with family adaptation when an AAC device was used by an adolescent with DD in the family?

Methods

Study Design

The study utilized semi-structured interviews, a qualitative research method which provided an in-depth investigation into the experiences and perceptions of parents of adolescents utilizing AAC technology. Interviews were selected as the most suitable design to answer the research question related to families' adaptation to AAC devices. Interviews allow for probes to explore specific areas of inquiry, which can provide new insights into conceptual relationships about a phenomenon (Glesne, 2011). IRB approval was obtained prior to the start of the study, and the Consolidated Criteria for Reporting Qualitative Research (COREQ) guidelines were used to support comprehensive reporting of the study (Tong et al., 2007).

Participants and Setting

A sample of eight family members participated in the on-line interviews from their homes. A purposeful sample of parents that included mothers, fathers, and/or primary caregivers: foster parent, legal guardian, of adolescents aged 13–18 years were enrolled. A family was defined as a unit of at least one parent and an adolescent with a DD. Parents were the respondents for the family.

Inclusion Criteria. Parents were included in the study if their adolescent: 1) was diagnosed with autism and/or Down syndrome; 2) was currently using an AAC device; 3) the parent understood written and spoken English; and 4) the parent had Internet access.

Exclusion Criteria. Families of adolescents with a DD and an acquired communication disability that resulted from an accident, illness, or trauma were not included.

Recruitment

Families were recruited through online recruitment registries (e.g., ResearchMatch, DS-Connect) and via the Internet from the Autism Society of Michigan, Apraxia Kids support organizations, and a social networking site (Facebook). ResearchMatch and DS-Connect are online nationwide volunteer health registries supported by the National Institutes of Health, which include large populations of volunteers who consented to be contacted by researchers. In total, 66 parents who completed a survey for a related research project were approached to participate in a follow-up interview to gain additional insights into the research topic. Nine parents responded by email to express interest in participating in the study. A total of 8 parents participated in the study, and one parent did not respond to follow up contacts.

The study was approved by the investigator's university IRB prior to beginning the study, including approval to use online enrollment through ResearchMatch and DS-Connect. Potential participants learned of the study from a brief project summary (see Chapter 3, Appendix G) online through: 1) the organizations' official website; 2) social networking page; and/or 3) listserv. Potential participant volunteers accessed the online informed consent and screening questions via a Qualtrics© (2018) web-link provided in the invitation to participate. Participants completed the informed consent prior to screening and demographic questions (see Chapter 3, Appendix H and I). The online consent form was written verbatim as approved by the IRB. Twenty-three individuals who did not qualify for the study were notified of ineligibility and thanked for their interest. Qualified participants had the option to select a "yes" or "no" response contained within the online consent page, with "yes" indicating voluntary agreement to participate. Copies of the consent were stored electronically on a secured server.

Participants who volunteered for an interview were contacted by email to schedule their interview which was conducted via Zoom© (2021). After completion of the interview, participants were thanked for their participation and received a $20 Amazon.com e-gift card as compensation for their time and effort.

Data collection

A demographic questionnaire was completed by parent participants to obtain information about parental and adolescent characteristics included in the adapted conceptual model (see Figure 4.1). Parental data included: age, sex, race, education, marital status, family size, annual income, respondent relationship to the adolescent, environmental geography of family home, and primary language(s) spoken in the home. Adolescent characteristics included: sex, race, age, primary DD diagnosis, and other conditions, communication function, type of AAC device currently utilized, and length of time the AAC device had been used. While most of the characteristics are self-explanatory, the Communication Function Classification System (CFCS) was used to assess communicative functioning of the adolescent as reported by the parent (Hidecker et al., 2017; Hidecker et al., 2011). Adolescents categorized in Level I function best, and those in Level V have the most difficulty (Hidecker et al., 2017; Hidecker et al., 2011).

A semi-structured interview was conducted with parents via Zoom© (2021) using an interview guide developed by the investigator to prompt participants to describe their experiences in the following areas as guided by the Resiliency Model components: (1) demands and challenges associated with supporting the adolescent's AAC device use, (2) types of family attributes and traits influenced by the adolescent's use of AAC to explain predictions of family risks or patterns of functioning, (3) the appraisal of the perception of managing AAC within family life, (4) the tangible and intangible family resources or strengths to support the adolescent, and (5) problem-solving/coping approaches to assist or resolve AAC issues. With participants' permission, interviews were recorded using the Zoom© (2021) audio technology. All interviews were conducted by the investigator who was trained in individual interviewing methodology and had no previous relationships with the study participants. Additionally, the investigator took field notes during each interview as part of the research protocol. The interviews lasted between 44 and 81 minutes. Interviews were conducted between November 2020 and February 2021.

After completion of each participant interview, data were transferred to a password-protected secure server within the investigators' institution. Each recording was stripped of personal identifiers. Landmark Associates, Inc.©, a professional transcription company with a focus on academic and qualitative research, conducted the transcription. At the end of the data collection period, all data were transferred and stored in electronic format and password-protected on the same secure server. Integrated with appropriate protection, the server conducted backups each night and was supported by institutional technology support services. Identifiable data were collected, such as name, phone number, and email address only for scheduling of the interview and participant Amazon.com e-gift card compensation tracking.

Data analysis

Descriptive analyses were conducted to describe the adolescent and parent/family demographic characteristics. Qualitative data analyses were conducted using Microsoft Word and Excel (Glesne, 2011). The Resiliency Model components, assisted with category formation to code the data (Creswell & Creswell, 2018). First, the interviews were transcribed and checked for accuracy. Next, to verify the accuracy of the data, member checking, also known as participant validation, was utilized (Birt et al., 2016). Each participant was sent a summary of the analyzed data to provide a chance to reflect on their experiences creating a potential opportunity to add comments and/or edits to the summary. None of the participants requested modifications to the interview summary they were sent. Next, two independent researchers coded the data to develop thematic summaries of each family's interview (Creswell & Creswell, 2018). The investigator developed initial codes after reviewing the entire data set, and the second reviewer independently coded the data set using the initial codes identified by the investigator. During this process, the second reviewer verified codes and any emerging codes and themes. The authors met to discuss discrepancies and refine coded data, themes, and subthemes together during the analysis process to reach final consensus. Throughout the coding process both the investigator and second reviewer selected exemplar quotes to support and illustrate each theme. A sample of eight participants was sufficient to reach saturation, a joint decision made by the interviewer and expert researchers. Finally, thematic analysis was used to analyze the study data (Creswell & Creswell, 2018), in which comparisons across all families' thematic summaries were grouped by family adaptation model components and examined for patterns among families supporting adolescent AAC use.

Results

Participants included eight mothers and the majority were White (87.5%), Non-Hispanic/Latino (100%), and married (75%) (see Table 4.1). Although the interviews were open to either parent, no fathers volunteered. Family size ranged from two to five or more members. The mean parent age (n=8) was 48.9 years, and ages ranged from 40 to 53 years of age. Fifty percent (n=4) of the parents had a bachelor's degree, 37.5% (n=3) a graduate degree, and one participant had some college credit but no degree. Participants were of varying employment statuses and income levels. All families lived in the United States, and a majority of the families lived in suburban areas (62.5%).

Parents reported that four of the adolescents had a reported primary diagnosis of autism and four adolescents with Down syndrome (see Table 4.2). Additionally, adolescent participants had a range of coexisting conditions such as, developmental delays, learning and intellectual disabilities, and speech-language disorders. The average age of the adolescents was 14.9 years (SD= 1.7), and the majority of adolescents were males 87.5% (n=7) with one female. The majority of the adolescent participants were White (87.5%) and one African American adolescent participant was represented. Adolescent communication function ranged from Level 3 to Level 4, with a majority (62.5%; n= 5) at Level 3. Seven of the parents reported high-tech AAC device use by the adolescents, and one of the adolescents utilized a low-tech AAC device. Parents reported the mean total number of minutes per week that any type of AAC device was used by adolescents was 645 (SD=600.2) with a range of 55-1740.

Research Question: What are parents' perceptions of family demands, type, appraisal, resources, and problem-solving/coping associated with family adaptation when an AAC device was used by an adolescent with DD in the family?

Themes. Parent perspectives from the qualitative data were organized into categories based on the Resiliency Model's interacting components (McCubbin et al., 1996). Then the subthemes and themes were derived within each category of family: (1) demands, (2) type, (3) appraisal, (4) resources, and (5) problem-solving/coping (see Table 4.3). Five themes emerged from the eight interviews. Major themes to emerge were: *Contextual Strains and Influences, Continuum of Person-First Approach, Opening Doors, Facilitators of Support,* and *Planning is Key*. Subthemes that emerged within the themes are provided in Table 4.3.

Demands. Demands are strains, stressors, or challenges faced by the family (McCubbin et al., 1996).

Theme 1: Contextual Strains and Influences. All participants described challenges associated with supporting their adolescent's AAC device use. Four subthemes emerged within this theme as provided in Table 4.3. Parents described the first subtheme as *adolescent personal challenges* surrounding adolescents' lack of motivation and interest to use the AAC device. For example, in six of the eight families interviewed, the adolescents had developed alternative methods to communicate with others (e.g., gestures, American Sign Language [ASL], sounds).

> She's very social, very outgoing. She has learned to adapt without much language at all. I always use the example when she was younger, she got my son's entire football team to play duck, duck, goose in the middle of the field without a single word, so she's adapted. (P8)
>
> We don't use it [AAC] as much as we should. Because I do understand his verbal. I need to get better because he's not gonna have me for the rest of his life. He needs to have a system to communicate his desires for peas and french rries. (P3)

Additionally, some parents stated that challenging behaviors interfere with AAC use. For example, one mother indicated "I would be afraid that he would just chuck it across the store or something, 'cause he just sometimes does that [when] he's just overwhelmed and all of a sudden…there goes his iPad and the potential to break the device." (P4) Other parents reported the adolescents' lack of access and interest in using the device. Sometimes the AAC device is not readily available in a convenient location for an evolving need or conversation. One parent stated, "We have a two-floor house. I almost wish we could have two of [them] so you weren't downstairs and he's upstairs. He isn't very good at bringing it with him". (P5) Consequently, some parents perceived the adolescent associated the AAC device with school use and not integrating it into home use. As one parent conveyed, "She never has wanted ever to use her device at home. It’s a combination of she associates the device with school… I’m a student. This is my house. This isn’t my school.” (P8)

The second subtheme described by the parents was *technology challenges*. Parents indicated technological issues with AAC devices: programming, symbolization, portability, durability, appearance, and lack of parental training. Half of the parents interviewed indicated the AAC device had limited vocabulary within the device and often parents deleted some things to add new vocabulary for the needs of the adolescent at the time. As one mother stated, "There's a frustration on our part, 'cause not everything is in his talker. I mean, it's not a complete human language device.” (P7) Another parent indicated, “There’s not 100 percent in there [AAC] of choices that he would make on a daily basis, so you just have to live with it and be conscientious with it as you go to update it.” (P1)

Parents in five of the families experienced frustration with the confusion of what the symbols represented and the lack of vocabulary in the AAC device to represent familiar interests and activities of the adolescent. For example, one mother stated, “It's super complex. [He] can get it, but none of the pictures match what the word is… "help" is a person in a bathtub with a shower over them. It's like, how does that relate to the word "help"…There's no connection.” (P6) Another parent indicated, “they [speech therapists] didn't want to put Elmo in it. They wanted him to say "little red monster." That just drove me crazy…why should he have to go [to] little red monster… for him to get there, that was seven buttons.” (P7)

A majority of the parents discussed challenges with the design of the AAC devices. This raised issues for families surrounding concerns for breaking of the device as well as the lack of mobility to take the device to different environments for usage. As one parent stated, “We haven’t been that great always bringing his device, ’cause it is—it’s clanky and it’s awkward.”

(P5) Additionally, many parents discussed the appearance of the AAC device as concerning. If the AAC device is an iPad, it seems to blend into current technology options, but the screen can easily break, the casing can be “clunky”, so it does not fit into a pocket for easier accessibility during communication opportunities. As one mother indicated, “We need something that looks more—like a teenager would look at, but yet be able for her to understand it.” (P8)

Another challenge expressed by parents interviewed was the lack of training they received regarding the AAC device. For example, a mother indicated,

> I guess I felt like I entered the space when it was certainly not new… that there tended to be a lot of education about the product and what it could do in the world of education, for educators, for aids, for mentors…but there was very little out there for parents to learn. (P1)

Another parent stated, “…[With] me not being familiar enough with the device and the program it uses… I take twice as long to find anything, and asking her, she can’t help me.” (P8). One mother expressed, “I can definitely attest to the frustrations of trying to use an AAC device with a child who’s unwilling, and a parent who’s not smart enough to figure out where everything is on it.” (P4)

The third subtheme described by the parents was *school challenges.* Parents reported issues with AAC use at school concerning: (1) school staff’s lack of knowledge about AAC and transition planning, (2) need for integration of AAC into lessons and classrooms, and (3) inconsistent school-home interfacing and goals. Half of the parents perceived there was limited AAC technology knowledge in the school environments which in turn recreated the continual need for re-training and parental communication with staff as their adolescent progressed in their educational trajectory. For example, one mother stated, “ My challenges are with that going into a whole new classroom is getting everybody on board to be trained again…I think it makes a huge difference if the people in the classroom that are with him all day long know.” (P5) Another parent expressed frustration, "…sometimes I'll bring him to his private speech therapy, and the [AAC] volume will be all the way turned down. That infuriates me. That's like putting duct tape over a kid's mouth…This is his voice…that's just wrong." (P6)

Parents acknowledged frustration with limited integration of classroom vocabulary into the programming of the AAC device for adolescent participation and involvement. One mother stated, "It was kind of frustrating because [in his science class] they were doing a unit on volcanos, but they didn't give any of the vocabulary for me to put into his talker, but they expected him to take quizzes." (P7) Additionally, a majority of parents expressed concerns with inconsistent goals and collaboration for AAC use between school and home. "The overlooked piece is the home-school interface. I think the assumption is they go home, and they use the devices to talk to you at home, and…it's not been that at all." (P8) Other parents expressed:

> During an entire day of school, he had said the name of eight planets. That's all he said all day long with his Proloquo. He didn't say hi to anybody, bye, I'm mad, I'm sad, I'm tired, go away—nothing. So I said to [the speech therapist], What can we do about this? She's like, No, that's really good. He said the name of eight planets. (P2)

> They [school personal] had a password on it [AAC device] that took almost three months for them to give to me, because … it was finally to the point where my mom had passed away, and I'm like, how is he supposed to express anything if you're not letting me change what's on here. That's finally what did it, is it was finally a big major life thing. (P7)

The fourth subtheme described by the parents was *family challenges.* Parents stated family challenges included: (1) financial and insurance constraints for purchased, repairs, maintenance, and replacement of AAC devices, (2) lack of support and isolation, and (3) societal views. Parents in half of the families interviewed had experienced difficulties with insurance and the expenses associated with the AAC device. One mother stated, "If you apply to Medicaid, you have to jump through a ton of requirements…Do we really need that many hoops? Are people cheating the system to get an AAC device…?" (P3) Another parent indicated insurance resources varied by geographical regions; “in Illinois they don’t have a Medicaid waiver, but in Ohio they do. Suddenly, we had a bunch of resources that we didn’t have before.” (P5)

Parents in five families described feeling isolated from other adolescents and parents using AAC. One mother expressed the lack of interactions with other parents facing AAC challenges; “you really don’t meet that many other parents unless you’re going to a large therapy center that does that sort of thing.” (P5) Another mother stated, “He's in the middle. They have things for the younger kids, and then they have things for the older kids. He's in that middle where he doesn't quite fit either group yet.” (P6) Additionally, a parent indicated,

[I] wish there was just a better help for older kids …with AAC, because that’s what I’m noticing. I’m noticing that lots of—even with the AAC groups…it’s targeted to all little kids, most of it is (P2)

Finally, for some parents, they experienced unfavorable societal interactions when their adolescent used AAC in public domains. One mother expressed the lack of supportive public disability policies for AAC technology accessibility on an airplane and the need to obtain extraordinary documentation so her son could travel with his “voice”. As she stated, “So there's definitely a level of ignorance…We bring a [doctor] note onto a plane, for example, saying we need to leave this on. It's not gonna crash the plane. It's an iPad.” (P7) For example, another mother indicated,

> We still get looks when we go out. Having the AAC device is intended to make communication easier. If the other half has never heard of, or never seen these things, and it’s not part of their world, we can seem alien. We can really look out of place. (P3)

Type. Type refers to a basic set of family attributes, traits, or patterns that help shapes how a family operates or behaves to help shape outcomes (McCubbin et al., 1996).

Theme 2: Continuum of Person-First Approach. Participants described family strengths and characteristics centered on a continuum of person-first approaches assisting with adolescent's use of AAC. A person-first approach places the value on the person before the disability to promote inclusion and integration into society (Snow, 2013). Parents in all eight families described advocacy as a key asset when an adolescent uses AAC. One mother stated, "This is his talker, and it's different than everything else, and I feel like that's vital for somebody who can't talk any other way." (P5)

> You shouldn't have to fight this hard to have somebody help your kid learn how to communicate, and …it should be obvious to the speech therapy world that this is a huge need and it needs to be addressed directly instead of just like, "We're gonna get around to that one of these decades.(P2)

> We've put in place as many plans as we can to help him be able to be successful if he is able to go to in-person school, get people ready for him and his device and how that works for him. (P7)

> His private speech therapist said ask for a second device [to] keep it at school. We have a tech meeting next week …I'm going to kick and scream to get it. I don't want it for me. He needs it, though, because otherwise what's he gonna do? (P7)

Additionally, parents in all eight families described inclusion as a key attribute. "Inclusion is my passion. Any way you can make inclusion easier is the best." (P6). Another mother stated, "There are safety reasons, but at the same time, I want to…be able to allow her to be as independent as she can." (P8) Many parents also focused on their adolescent's abilities and accomplishments. "My kid… his victories don't look like anybody else's victories." (P3)

> I think just sometimes realizing, 'cause he doesn't have tons and tons of speech, right? …sometimes he can answer a yes or no question; sometime[s] he can't. Sometimes he can give you a whole bunch of information; other times he can't give you anything. It's one of those hit or miss things, so sometimes when he's doing things or showing us something or you're sitting next to him while he's on it and you watch… it makes you really realize how intelligent he is and how capable he is, and that there's just so much more to him than his ability to speak eloquently. (P4)

Other characteristics conveyed by families that helped shape their adolescent's AAC use included persistency, patience, tolerance, and flexibility. As one mother expressed, "I would say those are kind of our strengths, is just that trying to keep communication open, trying to remind ourselves of patience, and give a little bit of grace when we can." (P7)

Appraisal. Appraisal is how a family views a situation and their perceived ability to manage the related demands (McCubbin et al., 1996).

Theme 3. Opening Doors. Across families, parents perceived the AAC device as a positive tool creating opportunities for their adolescents and families. However, parents also described some negative aspects too. Three subthemes emerged within this theme as provided in Table 4.3. The first subtheme depicted by the parents was the *perceived adolescent's benefits of AAC*. Parents in all eight families expressed the importance of the AAC device to help reduce barriers and frustrations in communication. "I think he has slowly coming in to realizing there's benefits to using it." (P5) Other parents expressed,

> It really is, aside from a little bit of sign language, the only way he is able to express himself and to have people really understand what he's saying and then either give him what he wants or give him—whether it's something or a response even. (P7)
>
> He's thrilled to be able to say what he's thinking. It's made a huge difference. He's thrilled to be able to say what he wants to eat and drink. He's thrilled to be able to say where he wants to go, what he wants to do. (P2)

Additionally, parents described how AAC increases opportunities for social connections and their adolescents' desire for those connections. For example, a mother stated, "When [my son] was able to bring his iPad to school…the typical kids were like, "Wow! That's pretty cool. You get to bring yours. That was fun!" (P1) Parents also discussed the increased learning opportunities as well as the pride and happiness they saw in their adolescent when communication exchanges were successful. As one parent illustrated,

> It’s really opened up—I mean, he’s not a fluent speaker on his AAC device, but I find he’s starting—he would never be a kid that would say hi to somebody when they came up, but now he wants to—he knows and he wants to say hello. (P5)

> He did a monkey habitat [for science class]. I programmed [AAC] for that. He had to know where the buttons were and what order to press them in, but he was able to get up in front of the class and do a presentation, which he would not have been able to do without it. (P6)

The second subtheme exemplified by the parents was the *perceived family benefits of AAC* use by adolescents. Parents in all eight families expressed many advantages for families when their adolescents utilized AAC. For example, parents indicated disability awareness, along with compassion and empathy was displayed by their typically developing (TD) children to other individuals with disabilities. “The boys [using AAC] have definitely changed my girls [siblings] and for the better…Look at them now, how it's changed them… for the better." (P6) One mother stated, “we've always tried with both of our boys to point out all of the good things that come from having [a] special needs [sibling].” (P7) Several parents discussed that AAC usage increased opportunities for learning more about their adolescent and built connections with other family members. For example, a mother indicated, “We would have never known that [puzzles], to even know that was an interest. It just opened up a world and a way for him to communicate with us.” (P1) Another mother described,

> We have family and friends that spread out all across the country. We try to share when we get some cool interactions either at therapy or somethin’ at home... I just share little things on Facebook or Instagram just so others can see what he’s doing.(P5)

The third subtheme represented by the parents were *concerns for the future*. The majority of parents expressed concerns for their adolescents as they transition to adulthood. The parents’ primary worries described the lack of resources and guidance surrounding employment, housing, medical, and legal areas. One mother stated, “I’ve never gotten from her how her day was in school. Ever. What am I gonna do when she goes into a job setting?” (P8) Another parent expressed, “Mine is the kid who will definitely fall through the cracks if there isn’t someone out there looking out for him. That is probably my biggest worry, what will happen when I’m gone.” (P1) Parents described how services are so vastly different for older children than younger ones. For example, “Pretty much you go off a cliff when you turn 21. You get all this help and then it’s like, Good luck!” (P8) As another mother noted:

> I remember when he was first diagnosed people swooped in, tested, evaluated, and told me I have a child with autism. This is what we’re gonna do. I haven’t had quite that same reaction in high school…Nobody’s swooping in. You’re just left floundering and trying to build your own community and your own network, and your own plan with not a lot of access to resources, no time to develop it. (P3)

Resources. Resources are the positive strengths and capabilities of individual family members, the family unit, and their associated community (McCubbin et al., 1996).

Theme 4: Facilitators of Support. Parents described tangible and intangible family resources to support the challenges associated with adolescent AAC device use. Three subthemes emerged within this theme as provided in Table 4.3. The first subtheme depicted by the parents was *social capital*. The participants described many networks of relationships that were helpful with the challenges they faced as their adolescents utilized AAC. For example, parents used social media, such as particular Facebook groups for families of children with disabilities as well as AAC sites (e.g., Language Acquisition through Motor Planning; [LAMP]). Many parents mentioned support groups for themselves and their adolescent, such as UPS for Down syndrome group. One mother stated, “…several Down-syndrome-specific advocacy groups are constantly doing education and programming targeted to different milestones in life.” (P1) Additionally, in all eight families interviewed, parents spoke about the assistance and guidance they received from interdisciplinary professionals, such as special education teacher, speech therapists, occupational therapists, nurses, school administrators, and AAC centers. As one mother indicated, “[we are] very fortunate to have a very progressive special ed teacher who turned us on to it [AAC], and we were very fortunate to be able to provide that [AAC] to him.” (P1) Another mother stated,

> …because we live in a college town, we’ve hired a speech therapy student to work with [our son] for a couple hours a week which is kind of play for him more than it is. It’s fun to have college students to come in. I had a lot of friends that had kids of AAC just because we all went to the same center (P5)

Other areas of social capital conveyed by some of the parents were support from their adolescents’ siblings and peers, as well as their extended family members. For example, a few mothers stated,

> One of my [older] daughters was like, here, we can do Google photos and you can take a picture of that, and then if it's something like recently popular that [AAC] can find, and so that's been helpful. It's just really cool. (P4)
>
> Neurotypical kids, like some of our family friends, they really think it’s cool that he’s …like talking with an iPad, which it gives them something they can come over and talk to him. It’s not as awkward…They think it’s cool. (P5)

The second subtheme illustrated by the parents was *adolescent strengths*. Parents described the interests and personalities of the adolescents were helpful with meeting the challenges associated with AAC use. According to half of the parents, many adolescents enjoyed the use of technology. As one mother stated, “he just takes to technology in a way that is pretty amazing… and he enjoys it.” (P1) Another mother indicated, “From the other room I hear my kid on his device, putting in his number sequences, talking to himself about the highways he’s gonna go to, and it’s a comfort to both of us” (P3). Other parents noted adolescent characteristics, such as easy-goingness, great memory, desire for routines and socialization assists with AAC use. A mother described:

> She’s very easy going. She’s routine oriented... observes everything, and she learns once and she doesn’t forget it. In her world, she’s like, You don’t understand. I’m happy.

She's at a level where she's content. Just the social aspect is all she's looking for. (P8)

The third subtheme portrayed by the parents was *family's strengths*. Across families, parents indicated that education, financial resources, respite, and internet resources are key assets in assisting their adolescent with AAC use. As one parent stated, "I read about [AAC in] the New York Times [it] had some story about there was this thing you can put on an iPad, and it has buttons and you can talk with it. I thought… that would be amazing." (P2) Many parents discussed their use of the internet to "do research, to figure things out" (P5) and educate themselves by taking online classes. Some families indicated the financial ability to pay-out of pocket for an AAC device, private speech therapy, and attend conferences with AAC resources to assist them. Other families discussed the importance of respite services and camps. One mother acknowledged respite services taking her son to a store, "…they would talk about [the outing]—he loves elevators, so they would talk about the elevator and the buttons on the elevator, and then he would talk about liking it [with his AAC]. (P2) Another parent stated the importance of time away from an adolescent to rejuvenate; "Get a break…'cause we both have figured out, you've got to give yourself a break a little." (P7)

Problem-solving/coping. Problem-solving and coping (PSC) are specific actions taken by individual family members or the family unit to manage challenges, as well as processes and skills to acquire, allocate, and use resources that reduce strains and modify negative family appraisals (McCubbins et al., 1996).

Theme 5: Planning is Key. Parents described several PSC approaches to support the challenges associated with adolescent AAC device use. Three subthemes emerged within this theme as provided in Table 4.3. The first subtheme illustrated the importance of *preventing issues.* Across families, parents expressed the necessity to think ahead so they were averting potential opportunities for issues surrounding AAC use. Families indicated continual education and training of interdisciplinary professionals was key as their adolescents were transitioning within the school system. Parents conveyed the important strategy of utilizing Individualized Education Programs (IEPs) within their school settings to assist with their adolescents' goals. For example, one mother stated, "We made sure [in the IEP]…that staff is gonna be trained on his device. We've also asked for the school district to get a second device to use actually currently now, because now there's no modeling going on." (P7) Another mother suggested she was gratified to help other families in her school district that would use AAC in the future. She stated, "I was pleased because it [IEP] set a lot of groundwork for future parents coming and asking for that technology to be used." (P1) Other parents indicated the need to circumvent damage to AAC devices and put preventive strategies in place to keep it from falling and banging, while calculating potential triggers for behaviors that may incur breakage to the device.

The second subtheme expressed by the parents was *preparation for the future*. Across families, parents had experienced the continued need to plan for the future even though that seemed unclear for some families. For example, a mother acknowledged:

> Our goal will always assume to be that [our son] would live with us long-term, but the more fruitful we can make his life and enriching, whether that be a job or whether that be program things he can do. No one wants to sit at home with Mom all day, as much as I would love that. (P1)

One mother was trying to work with her son's AAC use to communicate with healthcare professionals, so "in the future it'll help us when he's not feeling well." (P5) Other parents were trying to plan the next AAC device purchase, scouting training/instructional programs and employment opportunities, as well as contemplating the how the integration of their adolescents' skills, interests, and AAC communication are suited for their communities. As one mother indicated, "so that's kind of what I'm thinking for him is I'd like to help him to have something that he's really interested in, and that's something he could do that—it's like a grown-up thing or something.” (P4)

The final subtheme depicted by the parents was *adjusting resources*. Although parents reported benefits of their adolescent using AAC devices, sometimes the parents needed to modify how the device worked within their families. For example, parents described how they utilized their iPhones to supplement additional communication. “I definitely have had to pull out my iPhone and work through something with him on my iPhone that he was trying to explain. Sometimes it's just a matter of …here's an example”. (P4) Another parent used the AAC device to communicate and assist with smoother transitions from one activity to the next for the adolescent. “Whereas a lot of times it's more effective to say, 10-minute warning, 5-minute warning… so that helps him to not have a meltdown perhaps.” (P3) Additionally, a mother used the AAC to explain events and scheduling of their adolescent’s day.

> We’ll pull up the Proloquo2go, “Today, we’re going on a field trip” or “Aunt [so in so] is picking you up,” and it’s been very helpful for us to be able to build those sentences and have that visual support for him to hopefully understand… the transition before it occurs. (P1)

The Resiliency Model components of family: demands, type, appraisal, resources, and problem-solving/coping assisted in illuminating a narrative from parents of adolescents with DD using AAC devices. The five major themes that emerged were: *Contextual Strains and Influences, Continuum of Person-First Approach, Opening Doors, Facilitators of Support, Planning is Key*. These findings provide new and unique discoveries on parental perspectives surrounding family adaptation for adolescents using AAC device. Overall, parents detailed not only the challenges and demands associated with raising an adolescent using an AAC device but also expressed attributes, resources, perceptions, and strategies that either contributed or hindered family adaptation.

Discussion

Using the Resiliency Model, this qualitative study aimed to understand parent-reported factors that shape family adaptation to adolescents' AAC device use. The results of the analysis highlight how parents appraised and coped with the associated stressors and challenges, and how they described the utilization of their resources and family attributes to manage. The analysis also underscores the importance of supporting the needs of families during the critical developmental period of adolescence.

Theme 1: Contextual Strains and Influences

Findings in the model component of *demands* within the theme of *Contextual Strains and Influences*, supported and elaborated on some of the findings of prior AAC research surrounding children of various ages with DD (West et al., 2020). For example, parents described adolescents' challenging disability behaviors and attitudes towards AAC, technology challenges and limitations, lack of training time to learn AAC, lack of knowledge from professionals surrounding AAC use, financial and insurance constraints, limited support and isolation, and limited societal AAC awareness continue to be issues for families. Narratives of parents not discovered in prior research evolved around the lagging AAC device design for adolescents, necessity for integration of AAC into lessons and classrooms, lack of transition planning, and the lack of supportive public disability policies for AAC technology accessibility.

This information suggests the need for further development and advancement of AAC technology designs to assist families and adolescents with their needs and concerns. Additionally, findings promote the necessity for interdisciplinary professionals to participate in training, education, and professional development opportunities surrounding AAC technology integration across professional fields in collaboration with individuals with DD using AAC.

Furthermore, progress has been made in disability issues within the United States in the last fifty years, yet individuals with disabilities and their families are still marginalized, excluded, and segregated (Snow, 2013). Hence, these findings suggest AAC technology is another area of public policy that should be examined to reduce barriers. The policy process must be inclusive of families and adolescents with communication disabilities, for "nothing about us without us", is key to strengthening this area.

Theme 2: Continuum of Person-First Approach

Findings in the model component of *type* within the theme of *Continuum of Person-First Approach* is a unique exploration in research utilizing the Resiliency Model. Prior to this qualitative study, existing research was lacking. Thus, the most prevalent family patterns and attributes described by parents of adolescents with DD using AAC were advocacy and inclusion. Across families, parents continually expressed how important a person-first approach is for individuals with disabilities. This finding is congruent within the disability population in which promotion of collaborative and empowering approaches focuses on strengths rather than problems or deficits (Moorcroft et al., 2019; Snow, 2013).

Theme 3: Opening Doors

Findings in the model component of *appraisal* within the theme of *Opening Doors*, supported prior research findings. Across families, parents recognized AAC as a positive tool for their adolescent as well as their families. Consistent with findings from other studies, the AAC device improved the adolescent's quality of life, supported language and literacy development, communication competence, increased social connections, and potential opportunities for the future (Angelo, 2000; Bailey et al., 2006; Batorowiczet al., 2014; Borg et al., 2015; Singh et al., 2017). In addition, findings from the study emphasized the compassion, empathy, and disability awareness behaviors parents perceived that TD siblings and extended family displayed from interacting with adolescents using AAC. Consequently, parents also experienced negative or conflicting perceptions concerning the future of their adolescents. Parents expressed worry and apprehension to manage not only future AAC challenges, but what employment, health, housing, and legal matters they face next encompassing potential young adult with complex communication needs.

These findings indicate that involvement of TD siblings and extended family within interactions of adolescents using AAC may promote an extension of disability awareness and acceptance. Hence, easing possible societal attitudes and unfamiliarity of AAC systems to promote inclusion of adolescents with disabilities using communication technologies. Additionally, findings suggest the need for increased interprofessional collaboration and coordination of services for parents to plan for adolescent's progression into young adulthood surrounding community integration into a full spectrum of services, including employment, health, housing, and legal entities.

Theme 4: Facilitators of Support

Findings in the model component of *resources* within the theme of *Facilitators of Support*, were factors that enhanced family adaptation to AAC use. This expected theme was consistent with prior research (Crisp et al., 2014; Moorcroft et al., 2019; West et al., 2020). For example, prior research indicated family routines, greater income, cultural perspectives, informational supports, and access to community disability resources and professional collaborations/partnerships enhanced ongoing adaptation of AAC device use (Angelo, 2000; Meder & Wegner, 2015; Schlebusch et al., 2017; West et al., 2020). However, parents in this study felt adolescents' traits, interests, and personalities were valuable subtle assets that improved family adaptation of AAC device utilization. Additionally, parents cited respite care as a facilitator of not only parental reprieve but of increased opportunities for adolescent communication exchanges with the AAC device outside of family spheres. Findings from previous studies suggest respite care assists with reducing parental psychological distress and burden (Whitmore, 2016).

Theme 5: Planning is Key

Findings in the model component of *problem-solving/coping* within the theme of *Planning is Key* indicated that parents identified problem-focused and self-reliant coping strategies to prevent and avert potential issues surrounding AAC. Consistent with findings from other studies, parents indicated that becoming an “educated consumer” of AAC with active involvement in device selection, information seeking strategies, and seeking alternative service models with a collaborative family-professional approach were strategies to assist with the demands of managing AAC technology (Allaire et al., 1991; Anderson et al., 2015; Anderson et al., 2014; Blosser et al., 1994). Contrary to previous research, parents in this study described the use of IEPs, laying the foundation for AAC use for future families, preparing for the unclear future, and adjusting resources to assist with the demands associated with adolescent AAC device. These findings suggest the need for interdisciplinary professionals to assist parents in developing and enhancing coping strategies, as well as identifying supportive resources.

Implications for Practice

This study has several implications for nursing practice. First, this study addressed a gap in the literature by exploring the perspectives of families who have adolescents with DD utilizing AAC devices to understand family adaptation and improve the outcomes of adolescents and their families. New knowledge was generated to explain why families undergoing similar experiences (i.e., adolescent utilizing AAC) may respond differently depending on the five areas within the Resiliency model (i.e., family demands, family appraisal, family resources, and family problem-solving/coping). Findings contributed to a clearer theoretical illustration of the phenomenon to guide nursing practice. For example, nurses are an essential resource for families of adolescents with DD and are well positioned in a variety of practice settings to enhance and facilitate interprofessional collaboration. Hence, as parents in this study indicated continual planning and advocacy for their adolescent with a DD is a constant concern across every developmental stage. Therefore, nurses are well positioned to assess family risks and implement problem-solving/coping strategies and seek resources/consultation from a wide range of interdisciplinary professionals and community resources to assist in the coordination of services for families of adolescents with DD utilizing communication technologies.

Secondly, nurses need to increase their competence with AAC technology in their practices (Finke et al., 2008). This should begin in nursing education in both the undergraduate and graduate levels. Preparing the future nursing workforce in novel ways in both didactic and clinical rotations surrounding AAC technology is key to promote health, healing, and hope for those who are most vulnerable. By acknowledging the diversity and unique perspectives needed by nurses who care for individuals with DD and their families to build a culture of inclusivity will positively impact health outcomes. For example, nurses work in various practice settings (e.g., schools, hospitals, clinics) encountering a broad spectrum of pediatric patients with developmental disabilities. Communication is pivotal for not only interactions with parents, but also inclusion of the adolescent with DD using AAC.

Lastly, nurses play a pivotal role for improving family support and communication across complex service systems. During adolescence, families are transitioning from pediatric to adult services, and seeking partnerships with health care professionals and community resources to assist with coordination of services. Adolescents with DD using communication technology are more vulnerable to health problems, chronic conditions, and poor patient-provider communication interactions. Hence, nurses are in key positions with access and knowledge to assist families who have adolescents with DD utilizing AAC devices to improve their quality of life and outcomes. Results from the study have potential to guide and explore supportive interventions for components of the Resiliency Model.

Limitations and Future Research Directions

Although this study provides important insights several limitations are noted. First, the small sample size within the study may limit generalizability of the findings and not reflect the views of all families of adolescents with autism or Down syndrome. However, saturation was reached within our data and since this work represents a new area of investigation, it provides a backdrop for future quantitative studies including the development of measurement tools to address key variables of family adaptation around AAC device use. This type of groundbreaking work in a novel area provides important information for investigators focused on improving family adaptation in the era of new technology. Given families in the study were sought from online support organizations and registries, the sample may represent individual families with higher education or greater knowledge of resources to manage their adolescent's disability. Additionally, families without internet access are not included in the study. As such future research should explore ways to include families from lower socioeconomic groups with who may have limited knowledge of resources. Lastly, the adolescent perspectives would have broadened the scope of this study. Future research should explore ways to gain their perspectives on these topics.

Conclusions

In this study the Resiliency Model offers a unique conceptual approach to advancing the science through a more structured lens to ground family science and nursing practice involving families of adolescents using AAC. This study lays the foundation for the development of future interventions by identifying modifiable model components from the perspectives of vulnerable families. The parental/caregiver challenges, demands, and stresses associated with AAC device use across developmental time frames have historically been the focus of studies, and these data provide a new parental view on this topic and other matters specific to adolescents with DD. By acknowledging the unique perspectives of families, nurses can transform practice to improve the care of children and adolescents with DD.

APPENDICES

Appendix A: Characteristics of Parents

Table 4.1

Characteristics of Parents (N = 8)

Characteristic	n	%
Sex		
Male	0	0
Female	8	100
Marital Status		
Married	6	75
Windowed	1	12.5
Prefer not to disclose	1	12.5
Education		
Some college credit, no degree	1	12.5
College graduate (Bachelor's degree)	4	50.0
Graduate degree (Master's or higher)	3	37.5
Respondent Relationship		
Biological parent	6	75
Adoptive parent	2	25
Race		
White	7	87.5
Prefer not to disclose	1	12.5
Ethnicity		
Hispanic or Latino	0	0
Not Hispanic or Latino	8	100
Family Size		
Two	2	25
Three	1	12.5
Four	0	0
Five	3	37.5
More than five	2	25
Income		
Less than $30,000	1	12.5
$31,000 to $50,000	1	12.5
$51,000 to $70,000	2	25
$71,000 to $90,000	0	
$91,000 to $110,000	2	25
More than $100,000	2	25
Employment Status		
Employed full time	2	25
Employed part time	3	37.5
Unemployed/not currently working	1	12.5
Homemaker	2	25
Geographical Area		
Urban	2	25

Table 4.1 (cont'd)

Suburban	5	62.5
Rural	1	12.5
Primary Language		
English	8	100
Spanish	0	0
	Mean (SD)	Range
Age (years)	48.9 (4.4)	40-53

Appendix B: Characteristics of Adolescents

Table 4.2

Characteristics of Adolescents (N = 8)

Characteristic	n	%
Sex		
Male	7	87.5
Female	1	12.5
Race		
Black or African American	1	12.5
White	7	87.5
Primary DD Diagnosis		
Autism	4	50%
Down syndrome	4	50%
Other Chronic Conditions		
Autism, ID, DD, LD, SLD		
Communication function		
Level 1	0	0
Level 2	0	0
Level 3	5	62.5
Level 4	3	37.5
Level 5	0	0
Primary AAC device/system		
Low-tech[a]	1	12.5
Mid-tech[b]	0	0
High-tech[c]	7	87.5
	Mean (SD)	Range
Age (years)	14.9 (1.7)	13-18
AAC Length of time used (months)	73.9 (45.1)	18-135
AAC Time used per week (minutes)	645 (600.2)	55-1740

Note. AAC= Augmentative and alternative communication; DD= Developmental disability; ID=Intellectual disability; LD=Learning disability; SLD= Speech-language disorder.
[a] Low-tech refers to AAC with no battery or computer component; [b] Mid-tech refers to AAC with battery component only; [c] High-tech refers to AAC with computer component.

Appendix C: Qualitative Themes

Table 4.3

Qualitative Themes Grouped by Family Adaptation Components

Component	Themes	Sub-themes	Example quote
Family Demands	1. Contextual Strains and Influences	1a. Adolescent personal challenges 1b. Technology challenges 1c. School challenges 1d. Family challenges	P8: "Just his desire to use it. He'll hide it at school. He just doesn't like to use it. Just motivation I guess is the hard part. To get him motivated to use it." P3: "I wish… There was a way to make this more usable for the common man." P6: "Another really frustrating thing…is sometimes I'll bring him to his private speech therapy, and the [AAC] volume will be turned all the way down. That infuriates me. That's like putting duct tape over a kid's mouth. This is his voice. If he has no volume, that's just wrong. I have mentioned that to the school." P7: "We have been called out multiple times [at shows/movies] for letting him have his talker out, and we have even brought an extra towel so that it would be underneath a towel, and then he could look underneath and tell us something."
Family Type	2. Continuum of Person-First Approach	2a. Advocacy 2b. Inclusion	P2: "I think I reached a point where I stopped taking no for an answer. I used to be really shy and didn't want to bother anybody for anything…but I'm not [for my son]."

Table 4.3 (cont’d)

			P7: “The AAC provides one possible route to communication with my son. I still would like to hold out hope that it will someday magically open the door to his closed mind.”
Family Appraisal	3. Opening Doors	3a. Perceived adolescent benefits of AAC 3b. Perceived family benefits of AAC 3c. Concerns for future	P1: “I think the AAC, the main thing that has occurred is giving him an opportunity to really expand his world and be heard in a way that he wasn’t before. I think that’s been very, very helpful to him”
			P4: It's [AAC] effective to me because he's learned and advanced so much. I can't even imagine raising him 20 years ago… I'm sure I would've figured it out, but I just think it would have been a lot harder to figure a lot of this stuff out and actually tap into all the potential that he has.”
			P5: “The challenge is, how are we gonna move forward? Do we want to piecemeal it ourselves, or do we wanna go through the company to buy it? How much is that gonna do? That’s been a little bit of a financial challenge…Obviously, we’re seeing—right now, it’s not the time to stop ’cause we’re seeing great strides.”
Family Resources	4. Facilitators of Support	4a. Social capital 4b. Adolescent strengths 4c. Family strengths	P5: “One thing I’ve learned from moving so much is every state is different, and you never really find out what’s going on until you actually move there or you find some wonderful mom, one who tells you all the rules. They always help. There’s always

Table 4.3 (cont’d)

			a good special needs mom in each city that gives you the details.” P8: “She also has the memory of an elephant…She knows more of that screen, what’s on that computer and her iPad, than I do.” P3: “Much of my life is spent online. Thank goodness there’s an internet. I can look things up when I’m having a particularly rough time with him.”
Family Problem-solving & Coping	5. Planning is Key	6a. Preventing issues 6b. Preparation for the future 6c. Adjusting resources	P4: Well, like with it breaking…We invested in a hundred-dollar case for it so that it would be protected.” P5: “We’ve been really working on trying to tell us what he’s feeling. Hopefully, in the future it’ll help us when he’s not feeling well. ’Cause that’s a really difficult thing for us ’cause if he’s sick, he can’t tell us that he’s not feeling well.” P6: “We used to go bowling…and he'd bring it [AAC] there to order his french fries. The people that worked there thought it was awesome. Just to do that and getting it [AAC] out in public more with him, I think is important.”

Note. AAC= Augmentative and alternative communication.

REFERENCES

REFERENCES

Allen, L. F., & Babin, E. A. (2013). Associations between caregiving, social support, and well-being among parents of children with childhood apraxia of speech. *Health Communication*, 28, 586–576. https://www.tandfonline.com/doi/abs/10.1080/10410236.2012.703120

Angelo, D. H. (2000). Impact of augmentative and alternative communication devices on families. *Augmentative and Alternative Communication*, *16*(1), 37–47.

Bailey, R. L., Parette, H. P., Stoner, J. B., Angell, M. E., & Carroll, K. (2006). Family members' perceptions of augmentative and alternative communication device use. *Language, Speech, and Hearing Services in Schools*, *37*, 50–60. https://ajslp.pubs.asha.org/doi/full/10.1044/0161-1461%282006/006%29

Batorowicz, B., Campbell, F., VonTetzchner, S., King, G., & Missiuna, C. (2014). Social participation of school-aged children who use communication aids: The views of children and parents. *Augmentative and Alternative Communication*, *30*(3), 237–251. https://doi.org/10.3109/07434618.2014.940464

Baxter, S., Enderby, P., Evans, P., & Judge, S. (2012). Barriers and facilitators to the use of high-technology augmentative and alternative communication devices: A systematic review and qualitative synthesis. *International Journal of Language & Communication Disorders*, *47*(2), 115–129. doi: 10.1111/j.1460-6984.2011.00090.x

Birt, L., Scott, S., Cavers, D., Campbell, C., & Walter, F. (2016). Member checking: A tool to enhance trustworthiness or merely a nod to validation? *Qualitative Health Research*, 26(13), 1802-1811. https://doi.org/10.1177/1049732316654870

Borg, S., Agius, M., & Agius, L. (2015). A user and their family's perspective of the use of a low-tech vs a high-tech AAC system. *Studies in Health Technology and Informatics, 217*, 811–818. doi: 10.3233/978-1-61499-566-1-811

Brady, N., Skinner, D., Roberts, J., & Hennon, E. (2006). Communication in young children with Fragile X Syndrome: A qualitative study of mothers' perspectives. *American Journal of Speech Language Pathology*, *15*(4), 353–364. https://ajslp.pubs.asha.org/doi/full/10.1044/1058-0360%282006/033%29

Burke, S.M. (2017). The use of technology by adolescents with intellectual and developmental disabilities. *Journal of Pediatric Nursing*, 37, 134-135. http://dx.doi.org/10.1016/j.pedn.2017.06.019

Center for Disease Control and Prevention. (2019). Developmental disabilities. Retrieved from https://www.cdc.gov/ncbddd/developmentaldisabilities/features/increase-in-developmental-disabilities.html

Choi, H. (2015). Adaptation in families of children with down syndrome: A mixed-methods design. *Journal of Korean Academy of Nursing*, 45(4), 501-512.

Creswell, J.W. & Creswell, J.D. (2018). *Research design: Qualitative, quantitative, and mixed methods approaches*. (5th ed.). Los Angeles, CA: Sage.

Finke, E.H., Light, J., & Kitko, L. (2008). A systematic review of the effectiveness of nurse communication with patients with complex communication needs with a focus on the use of augmentative and alternative communication. *Journal of Clinical Nursing*, 17, 2102-2115. doi:10.1111/j.1365-2702.2008.0273x.

Glesne, C. (2011). *Becoming qualitative researcher: An introduction*. (4th ed.). Boston, MA: Pearson.

Hemsley, B., Balandin, S., & Worral, L. (2011). Nursing the patient with complex communication needs: Time as a barrier and facilitator to successful communication in hospital. *Journal of Advanced Nursing*, 68(1), 116-126. doi:10.1111/j.1365-2648.2011.05722x

Hidecker, M.J., Cunningham, B.J., Thomas-Stonell, N., Oddson, B., & Rosenbaum, P. (2017). Validity of the Communication Function Classification System for use with preschool children with communication disorders. *Developmental Medicine & Child Neurology*, 59, 526-530. doi: 10.1111/dmcn.13373

Hidecker, M.J., Paneth, N., Rosenbaum, P., Kent, R., Lillie, J., Eulenberg, J.B., Chester, K., Johnson, B., Michalsen, L., Evatt, M., Taylor, K. (2011). Developing and validating the Communication Function Classification System for individuals with cerebral palsy. *Developmental Medicine & Child Neurology*, 53, 704-710. doi: 10.1111/j.1469-8749.2011.03996.x

King, G., Tucker, M. A., Baldwin, P., Lowry, K., LaPorta, J., & Martens, L. (2002) A life needs model of pediatric service delivery: Services to support community participation and quality of life for children and youth with disabilities. *Physical & Occupational Therapy in Pediatrics*, *22*(2), 53–77. https://www.tandfonline.com/doi/abs/10.1080/J006v22n02_04

Lewis, B. A., Freebairn, L. A., Hanse, A., Taylor, H., Lyengar, S., & Shriberg, L. D. (2004). Family pedigrees of children with suspected childhood apraxia of speech. *Journal of Communication Disorders*, *37*, 157–175. doi: 10.1016/j.jcomdis.2003.08.003

Light, J., McNaughton, D., Beukelman, D., Koch Fager, S., Fried-Oken, M., Jakobs, T., & Jakobs, E. (2019). Challenges and opportunities in augmentative and alternative communication: Research and technology development to enhance communication and participation for individuals with complex communication needs. *Augmentative and Alternative Communication*. 35(1), 1-12. doi: 10.1080/07434618.2018.1556732

Lindo, E. J., Kliemann, Combes, B. H., & Frank, J. (2016). Managing stress levels of parents of children with developmental disabilities: A meta-analytic review of interventions. *Family Relations*, 65, 207–224. doi: 10.1111/fare.12185

Marshall, J., & Goldbart, J. (2008). 'Communication is everything I think.' Parenting a child who needs augmentative and alternative communication (AAC). *International Journal of Language & communication Disorders*, *43*(1), 77–98. doi: 10.1080/13682820701267444

Martin, G.E., Bush, L., Klusek, J., Patel, S., & Losh, M. (2018). A multimethod analysis of pragmatic skills in children and adolescents with Fragile X syndrome, autism spectrum disorder, and Down syndrome. *Journal of Speech, Language, and Hearing Research*, 61(12), 3023-3037. doi: 10.1044/2018_JSLHR-L-18-0008

McCubbin, H.I., Thompson, A.I., & McCubbin, M.A. (1996). *Family assessment: Resiliency, coping and adaptation: Inventories for Research and Practice*. Madison, WI: University of Wisconsin-Madison.

McNaughton, D., & Light, J. (2013). The iPad and mobile technology revolution: Benefits and challenges for individuals who require augmentative and alternative communication. *Augmentative and Alternative Communication, 29*(2), 107-116. doi: 10.3109/07434618.784930

McNaughton, D., Balandin, Kennedy, P., & Sandmel, T. (2010). Health transitions for youth with complex communication needs: The importance of health literacy and communication strategies. *Journal of Pediatric Rehabilitation Medicine*, 3(4), 311-318. doi:10.3233/PRM-2010-0143

McNaughton, D., Rackensperger, T., Benedek-Wood, E., Krezman, C., Williams, M. B., & Light, J. (2008). "A child needs to be given a chance to succeed": Parents of individuals who use AAC describe the benefits and challenges of learning AAC technologies. *Augmentative and Alternative Communication*, *24*(1), 43–55. doi: 10.1080/07434610701421007

Meder, J., & Wegner, J.R. (2105). iPads, mobile technologies, and communication applications: a survey of family wants, needs, and preferences. *Augmentative and Alternative Communication*, 31(1), 27-36. doi: 10.3109/07434618.2014.995223

Moorcroft, A., Scarinci, N., & Meyer, C. (2019). A systematic review of the barriers and facilitators to the provision and use of low-tech and unaided AAC systems for people with complex communication needs and their families. *Disability and Rehabilitation: Assistive Technology*, 14(7), 710-731. doi: 10.1080/17483107.2018.1499135

Moriarty, B., & Gillon, G. (2006). Phonological awareness intervention for children with childhood apraxia of speech. *International Journal of Language & Communication Disorders*, *41*, 713–734.

Parette, H. P., Brotherson, M. J., & Blake Huer, M. (2000). Giving families a voice in augmentative an alternative communication decision-making. *Education and Training in Mental Retardation and Developmental Disabilities*, *35*(2), 177–190.

Saito, Y. & Turnbull, A. (2007). Augmentative and alternative communication practice in the pursuit of family quality of life: A review of the literature. *Research & Practice for Persons with Severe Disabilities*, *32*(1), 50–65.

Schlebusch, L., Dada, S., & Samuels, A. E. (2017). Family quality of life of South African families raising children with Autism Spectrum Disorder. *Journal of Autism Developmental Disorders*, *47*, 1966–1977. doi:10.1007/s10803-017-3102-8

Seligman M. & Benjamin Darling, R. (2007). *Ordinary families, special children: A systems approach to childhood disability*. (3rd ed.). New York, NY: Gilford Press.

Singh, S. J., Hussein, N. H., Kamal, R. M., & Hassan, F. H. (2017). Reflections of Malaysian parents of children with developmental disabilities on their experiences with AAC. *Augmentative and Alternative Communication*, *33*(2), 110–120. doi: 10.1080/07434618.2017.1309457

Snow, K. (2013). *Disability is natural: Revolutionary common sense for raising successful children with disabilities*. (3rd ed.). San Antonio, TX: BraveHeart Press.

Tong, A., Sainsbury, P., & Craig, J. (2007). Consolidated criteria for reporting qualitative research (COREQ): A 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*, 19(6), 349-357

Van Riper, M. (2007). Families of children with Down syndrome: Responding to “A change in plans” with Resilience. *Journal of Pediatric Nursing*, *22*(2), 116–128. doi:10.1016/j.pedn.2006.07.004

Van Riper, M. (2000). Family variables associated with well-being in siblings of children with Down syndrome. *Journal of Family Nursing*, *6*(3), 267–286.

West, P., Van Riper, M., Wyatt, G., Lehto, R., Douglas, S.N., & Robbins, L. (2020). Adaptation to technology use in families of children with complex communication needs: An integrative review and family theory application. *Journal of Family Nursing*, 26(2), 153-178. https://doi.org/10.1177/1074840720915536

Whitmore, K.E. (2016). Respite care and stress among caregivers of children with autism spectrum disorder: An integrative review. *Journal of Pediatric Nursing*, 31, 630-652. http://dx.doi.org/10.1016/j.pedn.2016.07.009

Wilson, S.A. & Peterson, C.C. (2018). Medical care experiences of children with autism and their parents: A scoping review. *Child: Care, Health and Development*, 44(6), 807-817. doi: 10.1111/cch.12611

CHAPTER FIVE: CONCLUSIONS

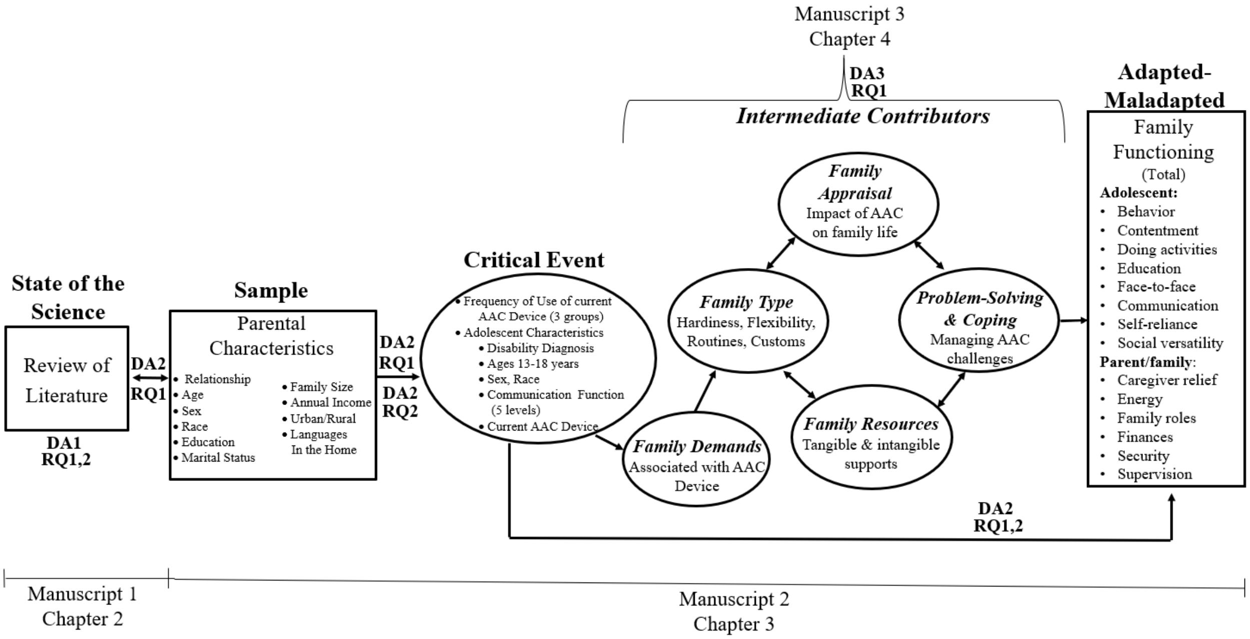
The importance of supporting families of children with developmental disabilities (DD) is evident based on the recent estimates in the United States (U.S.) revealing that one in six (about 17%) children aged 3 to 17 years have one or more DD [Center for Disease Control (CDC), 2019]. Data indicates DD, such as autism are increasing in the U.S., and estimates suggest approximately 50,000 teenagers with autism spectrum disorder (ASD) will enter adulthood each year (Roux et al., 2013). Additionally, Down syndrome (DS) is the most common abnormal chromosomal condition diagnosed in the United States (CDC, 2018). This condition carries a spectrum of unique lifelong concerns for health, development, and education for affected individuals. The most common neurodevelopmental disabilities associated with language impairments are ASD and DS, and these individuals are more likely to be receiving speech and language services into adolescence (Martin et al., 2018). Hence, with the growing number of adolescents with DD moving into adulthood, impairments in speech and/or communication are a critical area of development often challenging individuals with DD and creating care-giving stress of their families (Holyfield et al., 2017).

Literature supports the use of augmentative and alternative communication (AAC) technology systems to enhance capacities for communication exchange and socialization for adolescents with DD. However, an adolescent's successful integration of technology into daily aspects of life is dependent on familial engagement in the process (McNaughton et al., 2008; Parette et al., 2000). Despite recognized benefits to using AAC, families, especially parents, experience challenges when supporting the adolescent in the use of this technology (Angelo, 2000; Bailey et al., 2006; Brady et al., 2006; Marshall & Goldbart, 2008). Unfortunately, little was known about the familial experience as they adapt to challenges associated with adjusting to what was required to help their adolescent be successful with the advancing AAC technology. Thus, the purpose of this mixed methods dissertation was to examine important but often overlooked concepts associated with family adaptation to AAC devices among families of adolescents with DD within an established family framework.

Model Linkage

McCubbin & McCubbin's (1996) Resiliency Model of Family Stress, Adjustment, and Adaptation was utilized to conceptualize family adaptation, the key concept for this dissertation. The model served as a guiding framework for understanding a series of interacting components that shape family processes and outcomes of adaptation. The model components are: critical event/stressor, family demands, family type, family appraisal, family resources, and family problem solving/coping. This mixed methods study utilized selected model factors for the quantitative and qualitative phases of this dissertation to address specific research questions in each of the three manuscripts (see Figure 5.1; Table 5.1).

Figure 5.1 Operational Resiliency Model with Research Questions



Note. DA represents dissertation aim; RQ represents research question.

This dissertation utilized the three-manuscript format. Manuscript 1 (Chapter 2) was an integrative review of the literature guided by the Resiliency Model of Family Stress, Adjustment, and Adaptation (McCubbin et al., 1996) which explored the state of the science on family adaptation among children and adolescents with DD utilizing AAC technology for communication (West et al., 2020). Manuscript 2 is a cross-sectional descriptive study which examined the relationship between parental and adolescent characteristics and adaptation across three groups of families based on the frequency of adolescents' use of AAC who have been diagnosed with autism and/or DS. Manuscript 3 (Chapter 4) utilized a qualitative approach to explore parent-reported factors contributing to family adaptation among families with adolescents diagnosed with autism and/or DS who use AAC technology. Overall, this dissertation provided evidence of the multiple factors associated with family adaptation to AAC devices among families of adolescents with DD and contributes to a better understanding of key issues that impact families.

Overview of Manuscript 1

Research has identified the complex role the family systems play in the variability of outcomes and the well-being of individual family members, including parents/caregivers of children with DD utilizing AAC technology to support communication. However, little work has been conducted on the theoretical bases of AAC research while utilizing an established framework to advance the science through a more structured lens. Therefore, the operational model (see Figure 5.1) component that was evaluated in Manuscript 1 is "***State of the Science***". Manuscript 1 was an examination of both quantitative and qualitative research concerning family adaptation in families of children with complex communication needs (CCN) who use AAC. The primary aim of the review was to assess the conceptual foundations of family adaptation utilizing the Resiliency Model while synthesizing the related literature. Key findings from the review by West et al., 2020 included: (1) the reported parental/caregiver challenges, increased demands, and stresses associated with AAC device use in children with CCN in which some families adapt successfully to AAC technology integration, but there is limited understanding of the multifactorial phenomenon; (2) a wide range of DD within the studies and across studies, such as autism, DS, and other genetic conditions yielding unique severity of symptoms and challenges making comparisons across groups of families difficult; (3) diversity of the samples in terms of size, age, gender, socioeconomic status, marital status, family household members, and education was inconsistently reported across studies, (4) the lack of consistency in the use of measurement instruments with reported psychometric properties to understand functional and contextual factors specific to AAC use that impact the everyday lives of children and families; and (5) the lack of a theoretical model/framework to explain the interaction of family components (i.e., family demands, family type, family appraisal, family resources, and family problem-solving/coping) that lead to a better understanding of family adaptation to a child's AAC device use. Therefore, a gap in understanding and measuring factors that support and help families of children with DD adapt to the child's communication challenges was needed, especially in the model component areas of family type, appraisal, and problem-solving and coping. Hence, with the utilization of the McCubbin et al. (1996) model to explain why families undergoing similar experiences (i.e., child utilizing AAC) may respond differently depending on interacting components that shape the family process and outcomes of adaptation (Van Riper, 2000) led to the work in the subsequent manuscripts in this dissertation to fill the gaps in research.

Overview of Manuscript 2

Although the literature identified in Manuscript 1 justified the use of the Resiliency Model (McCubbins et al., 1996) in this area of research, the methodological limitations detected in the literature need to be addressed in future research, which led to Manuscript 2 of this dissertation. Manuscript 2 is a cross-sectional descriptive design which examined the relationship between parental and adolescent characteristics and adaptation across three groups of families based on frequency of adolescents' use of AAC devices. Families of adolescents (ages 13–18) with autism and/or DS using an AAC device, understood written and spoken English, and had internet access were recruited through online recruitment registries and support organizations. Family was defined as a unit of at least one parent/caregiver and an adolescent. The Qualtrics© (2018) online survey was offered to all adults registered in these organizations who self-identified as a parent, met eligibility criteria, and completed informed consent.

Family adaptation has not been specifically examined within the critical developmental stage of adolescence since much of the published research has focused on families of young children (McNaughton & Light, 2015; West et al., 2020). Additionally, limited research has focused on understanding the variation in family and adolescent characteristics, such as race, socioeconomic status, marital status, age, education, communication function, DD challenges, AAC type and frequency of device use to comprehend outcomes of families with individuals using AAC technology. Hence, this variability in research made comparability between studies inconclusive. It is unclear why some families adapt and function successfully to challenges associated with AAC technology integration and others struggle or abandon the AAC system.

Therefore, the operational model (see Figure 5.1) components that were evaluated in Manuscript 2 include: (1) ***sample***, (2) ***critical event***, and (3) ***adapted/maladapted***. Parental and adolescent characteristics were collected to describe the diversity of the sample and for associations with outcomes. The critical event data identified three groups of families (i.e., low-usage, mid-usage, high-usage) based on the frequency of use of the AAC device by the adolescents. Percentiles were used to create a lower use group less than or equal to 33rd percentile rank, the mid-use group greater than 33rd percentile but less than or equal to the 66th percentile, and the high-use group greater than the 66th percentile (Gelman & Park, 2008).While there are no established cut points on use, three length of AAC use categories were created based on sample data distribution. Data on the type of device (i.e., low-technology-AAC with no battery or computer component, mid-technology-AAC with battery component only, and high-technology- AAC with computer component) (Baxter et al., 2012; Holyfield et al., 2017; Moorcroft et al., 2019a), and the severity of the adolescent's communication function utilizing the Communication Function Classification System (CFCS) were also collected. Adaptation, referred to as family functioning, was assessed using a recognized psychometric measure, the Family Impact of Assistive Technology Scale for Augmentative and Alternative Communication (FIATS-AAC), specific to families using AAC devices. Overall, this manuscript extended the science in several key directions, but further exploration of the Resiliency Model components of demands, type, appraisal, resources, and problem solving/coping was needed. This led to the work in manuscript 3.

Overview of Manuscript 3

The Resiliency Model of Family Stress, Adjustment, and Adaptation (1996) guided the qualitative study aim in Manuscript 3, exploring parent-reported contributing factors of family adaptation among adolescents' AAC use during the critical developmental stage of adolescence. From the perspective of the Resiliency Model, key interacting components shape family processes and outcomes of adaptation. The operational (see Figure 5.1) model components that were examined include the "***Intermediate Contributors***": demands, type, appraisal, resources, and problem solving/coping. These components have been cited in the literature as relevant to the outcome of family functioning, except type which needed further exploration (West et al., 2020).

Manuscript 3 utilized a semi-structured interview methodology to probe and explore specific areas of inquiry to gain insight into conceptual relationships about a phenomenon (Creswell & Creswell, 2018). A sub-sample of participant families of adolescents (ages 13–18) with autism and/or DS with an AAC device recruited for Manuscript 2 were identified as potential participants for the qualitative study. Family was defined as a unit of at least one parent/caregiver and an adolescent. Parents were the respondents for the family. An online demographics questionnaire was completed by participants who met eligibility criteria and completed informed consent. A semi-structured interview using Zoom© (2021) audio technology for recording was conducted with parents using an interview guide (see Chapter 1, Appendix). The interview guide prompted participants to describe their experiences in the following areas as guided by the Resiliency Model variables: (1) ***demands*** and challenges associated with the adolescent's AAC device use, (2) ***types*** of family attributes and traits influenced by the adolescent's use of AAC to explain predictions of family risks or patterns of functioning, (3) the ***appraisal*** of the perception of managing AAC within family life, (4) the tangible and intangible family ***resources*** to support the adolescent, and (5) ***problem solving/coping*** approaches to assist or resolve AAC issues. In this study the Resiliency Model offers a unique conceptual approach to advancing the science through a more structured lens to ground family science and nursing practice involving families of adolescents using AAC. Since this work represents a new area of investigation, it provided a backdrop for future quantitative studies including the development of measurement tools to address key variables of family adaptation surrounding AAC device use. This type of groundbreaking work in a novel area provides important information for investigators focused on improving family adaptation in the era of new technology.

Additionally, this manuscript laid the foundation for the development of future interventions by identifying modifiable model components from the perspectives of vulnerable families. The parental/caregiver challenges, demands, and stresses associated with AAC device use across developmental time frames have historically been the focus of studies, and these data provide a new parental view on this topic and other matters specific to adolescents with DD.

Limitations of the Overall Dissertation

This dissertation has several limitations. In Manuscript 1, recognition of the conceptual and methodological limitations of the studies evaluated in the integrative review were important to note. Most of the studies did not identify a theoretical framework to guide the research nor include a specific definition of adaptation. Further, diversity of the samples in terms of size, age, gender, socioeconomic status, marital status, family household members, and education was inconsistently reported across studies. Sample sizes varied widely across studies, with no study justifying their selected sample size. Most studies incorporated descriptive cross-sectional designs, participant self-reporting, and utilization of limited measures with reported psychometric properties constraining the findings. Lastly, although grey literature was assessed in multiple databases, it is possible that studies were not reached utilizing key search terms.

In Manuscripts 2 and 3 convenience sampling and self-reporting limits the generalizability of the findings and may not reflect the views of all families of adolescents with autism or DS. Given participant families were sought from online registries and support organizations, the sample may have a higher education level or more knowledge of resources than families who are not part of these organizations. Consistent with previous research, families who participated in the quantitive and qualitative studies were primarily white, married, educated, middle to upper class, and lived in urban areas. Lack of Internet access restricted inclusion of families within the study. Lastly, adolescent perspectives, rather than only parent, would have extended the scope of the studies.

Implications of Overall Dissertation

This dissertation work has implications for nursing research, practice, education, and policy.

Nursing Research. This work presents a unique conceptual approach to advancing the science through a more structured lens to ground family science and family-focused nursing practice among families of children using AAC (West et al., 2020). This study lays the foundation for the continued development of a program of innovative interdisciplinary pediatric research by evaluating modifiable model components from the perspectives of vulnerable and diverse families. Findings contribute to the development of tailored interventions to assist families of adolescents with DD adapt to new communication technologies. Next steps include not only expertise of nurse scientists, but also engaging diverse professionals, such as speech-language pathologists, healthcare providers, family experts, educators, and technology engineers to further maximize outcomes for families of children with DD.

Nursing Practice. Effective communication is an essential foundation of nursing practice, and children with DD are more vulnerable to chronic health conditions leading to interactions with a wide range of healthcare professionals throughout their lifetime. Since effective communication is essential to enhance coping and positive experiences with health services for both families and children with DD, nurses should have competence in the use of AAC technologies (Hemsley et al., 2011). Additionally, nurses practice in a variety of settings (e.g., schools, hospitals, clinics) and are well positioned as a key resource for assessing family needs to assist parents in identifying appropriate resources and navigating complex service systems to achieve optimal outcomes from pediatric to adult service transitions. But the lack of empirical evidence regarding the perspectives of families who have adolescents with diverse DD utilizing AAC devices leaves a gap in understanding family adaptation. This demonstrated the need for a clearer picture of the phenomenon to guide nursing practice. All three manuscripts in this dissertation acknowledge the diversity and unique perspectives of families so nurses can transform practice to improve the care of children with DD.

Nursing Education. Findings from this dissertation will be applied to promote excellence in nursing education and research by preparing a future nursing workforce with knowledge to support vulnerable and diverse individuals with DD throughout their life span and across both national and global settings. This work contributes to the profession of nursing by educating nurse educators and the next generation of nurses in novel ways about AAC technology to promote health, healing, and hope among those who are most vulnerable. Additionally, the three manuscripts presented in this dissertation promote a culture of integrity and equality by exemplifying respect for the diversity of others.

Currently, in undergraduate and graduate nursing programs, there is a gap in the education curricula surrounding the unique understanding of nursing practice and research that is involved in caring for neurodiverse individuals with DD throughout the lifespan, especially in adolescence and transitions into adulthood. Research indicates the need for education in nursing schools in both didactic and clinical rotations that focuses on caring for individuals with disabilities (Finke et all, 2008; Wilson & Peterson, 2018). This dissertation work contributes to advancing the education of future nurses by acknowledging the diversity and unique perspectives needed by nurses who care for individuals with DD and their families to build a culture of inclusivity that will positively impact health outcomes. The rise in DD in the United States demands that the future nursing workforce have the knowledge, skills, and innovation, as well as compassion, caring, and integrity, to support this diverse population and advance the science of nursing education and the scholarship of teaching to bolster commitment to the common good.

Policy. Families of adolescents with DD face unique challenges, and the three manuscripts in this dissertation highlighted the lived experiences of families with complex communication needs utilizing AAC. Policies are needed to reduce the barriers for access to communication technology, increase the education of society and interdisciplinary healthcare professionals to understand and support the needs of children and adults with DD and their families. This dissertation emphasized the important role families play for individuals with DD using AAC, as well as the importance of other professionals across various settings, such as in schools, communities, and medical fields. National organizations, such as the Alliance on Disability in Health Care Education, Association of University Centers on Disabilities (AUCD), and American Association on Health and Disability (AAHD) recognize the barriers and disparities in the health of children and adults with disabilities. Unfortunately, research on barriers in health care provides evidence that communication difficulties are the primary issue that obstructs medical assessment and management of individuals with DD (Alliance for Disability in Health Care Education, 2018). Hence, additional policies that support increased funding for research needs to create inclusive health for people with disabilities that supports the equity so “everyone deserves a voice” to improve outcomes.

Conclusions

In summary, this mixed methods dissertation study guided by an established family nursing framework contributed to the state of the science by examining important but often neglected concepts relative to how families adapt to adolescent AAC technology use. Findings will contribute to the development of tailored interventions to assist families of adolescents with DD adapt to new communication technologies.

APPENDIX

Table 5.1

Research Aims, Questions, and Model Components

Research Aims	**Model Components**	**Research Questions**
1. Evaluate the state of the science on family adaptation among children and adolescents with DD utilizing an AAC device for communication.	State of Science	1. What is the state of the science regarding family adaptation when there is a child in the family with DD who utilizes AAC devices to support communication?
		2. How common is the use of a family conceptual model to guide a review of the literature on family adaptation to AAC technology?
3. Examination of associations between parental characteristics, adolescent characteristics, and family functioning based on frequency of use of their adolescents' current AAC device.	Parental Characteristics, Critical Event Adapted/maladapted	1. What is the association between parental characteristics and family functioning among groups of families that differ in their frequency of AAC device use by the adolescent (i.e., low-usage, mid-usage, high-usage groups)?
	Critical Event, Adapted/maladapted	2. What is the association between adolescent characteristics and family functioning among groups of families that differ in their frequency of AAC device use by the adolescent (i.e., low-usage, mid-usage, high-usage groups)?
		3. What are the between group differences in family functioning based on frequency of AAC device use by the adolescent (i.e., low-usage, mid-usage, high-usage groups)?

Table 5.1 (cont'd)

4. Through interviews, qualitatively explore parent-reported contributing factors of family adaptation among adolescents' AAC use employing the Resiliency Model during the critical developmental stage of adolescence.	Intermediate contributors, Adapted/maladapted	1. What are parents' perceptions of demands, type, appraisal, resources, and problem-solving/coping associated with family adaptation when an AAC device is used by an adolescent with DD in the family?

REFERENCES

REFERENCES

Allaire, J.H., Gressard, R.P., Blackman, J.A., & Hostler, S.L. (1991). Children with server speech impairments: Caregiver survey of AAC use. *Augmentative and Alternative Communication*, *7*(4), 248–255.

Alliance for Disability in Health Care Education (2018). *Core Competencies on Disability for Health Care Education*. Peapack, NJ: Alliance for Disability in Health Care Education. http://www.adhce.org/

Anderson, K. L., Balandin, S., & Stancliffe, R. J. (2015). Alternative service delivery models for families with a new speech generating device: Perspectives of parents and therapists. *International Journal of Speech-Language Pathology*, *17*(2), 185–195. https://doi.org/10.3109/17549507.2014.979876

Anderson, K. L., Balandin, S., & Stancliffe, R. J. (2014). Australian parents' experience of speech generating device (SGD) service delivery. *Developmental Neurorehabilitation, 17*(2), 75–83. doi: 10.3109/17518423.2013.857735

Angelo, D. H. (2000). Impact of augmentative and alternative communication devices on families. *Augmentative and Alternative Communication*, *16*(1), 37–47.

Bailey, R. L., Parette, H. P., Stoner, J. B., Angell, M. E., & Carroll, K. (2006). Family members' perceptions of augmentative and alternative communication device use. *Language, Speech, and Hearing Services in Schools*, *37*, 50–60. https://ajslp.pubs.asha.org/doi/full/10.1044/0161-1461%282006/006%29

Baxter, S., Enderby, P., Evans, P., & Judge, S. (2012). Barriers and facilitators to the use of high-technology augmentative and alternative communication devices: A systematic review and qualitative synthesis. *International Journal of Language & Communication Disorders*, *47*(2), 115–129. doi: 10.1111/j.1460-6984.2011.00090.x

Blosser, J. L. (1994). Recommendations for clinicians based on parents' experiences. *Clinics in Communication Disorders*, *4*(4), 246–253.

Brady, N., Skinner, D., Roberts, J., & Hennon, E. (2006). Communication in young children with Fragile X Syndrome: A qualitative study of mothers' perspectives. *American Journal of Speech Language Pathology*, *15*(4), 353–364. https://ajslp.pubs.asha.org/doi/full/10.1044/1058-0360%282006/033%29

Center for Disease Control and Prevention. (2019). Developmental disabilities. Retrieved from https://www.cdc.gov/ncbddd/developmentaldisabilities/features/increase-in-developmental-disabilities.html

Center for Disease Control and Prevention. (2018). Facts about Down syndrome. Retrieved from https://www.cdc.gov/ncbddd/birthdefects/downsyndrome.html

Creswell, J.W. & Creswell, J.D. (2018). *Research design: Qualitative, quantitative, and mixed methods approaches*. (5th ed.). Los Angeles, CA: Sage.

Finke, E.H., Light, J., & Kitko, L. (2008). A systematic review of the effectiveness of nurse communication with patients with complex communication needs with a focus on the use of augmentative and alternative communication. *Journal of Clinical Nursing*, 17, 2102-2115. doi:10.1111/j.1365-2702.2008.0273x.

Gelman, A. & Park, D.K. (2008). Splitting a predictor at the upper quarter or third and the lower quarter or third. *The American Statistician*, 62(4), 1-8. doi: 10.1198/000313008X366226

Hemsley, B., Balandin, S., & Worral, L. (2011). Nursing the patient with complex communication needs: Time as a barrier and facilitator to successful communication in hospital. *Journal of Advanced Nursing*, 68(1), 116-126. doi:10.1111/j.1365-2648.2011.05722x

Holyfield, C., Drager, K. D. R, Kremkow, J. M. D., & Light, J. (2017). Systematic review of AAC intervention research for adolescents and adults with autism spectrum disorder. *Augmentative and Alternative Communication*, *33*(4), 201–212. doi: 10.1080/07434618.2017.1370495

Martin, G.E., Bush, L., Klusek, J., Patel, S., & Losh, M. (2018). A multimethod analysis of pragmatic skills in children and adolescents with Fragile X syndrome, autism spectrum disorder, and Down syndrome. *Journal of Speech, Language, and Hearing Research*, 61(12), 3023-3037. doi: 10.1044/2018_JSLHR-L-18-0008

McNaughton, D. & Light, J. (2015). What we write about when we write about AAC: The past 30 years of research and future directions. *Augmentative and Alternative Communication*, *31*(4), 261–270, doi: 10.3109/07434618.2015.1099736

McNaughton, D., Rackensperger, T., Benedek-Wood, E., Krezman, C., Williams, M. B., & Light, J. (2008). "A child needs to be given a chance to succeed": Parents of individuals who use AAC describe the benefits and challenges of learning AAC technologies. *Augmentative and Alternative Communication*, *24*(1), 43–55. doi: 10.1080/07434610701421007

Moorcroft, A., Scarinci, N., & Meyer, C. (2019a). A systematic review of the barriers and facilitators to the provision and use of low-tech and unaided AAC systems for people with complex communication needs and their families. *Disability and Rehabilitation: Assistive Technology*, 14(7), 710-731. doi: 10.1080/17483107.2018.1499135

Marshall, J., & Goldbart, J. (2008). 'Communication is everything I think.' Parenting a child who needs augmentative and alternative communication (AAC). *International Journal of Language & communication Disorders*, *43*(1), 77–98. doi: 10.1080/13682820701267444

McCubbin, M. A., Thompson, A., & McCubbin, H. I., (1996). *Family assessment: Resiliency, coping and adaptation*. Madison, WI: University of Wisconsin-Madison.

Parette, H. P., Brotherson, M. J., & Blake Huer, M. (2000). Giving families a voice in augmentative an alternative communication decision-making. *Education and Training in Mental Retardation and Developmental Disabilities*, *35*(2), 177–190.

Roux, A.M., Shattuck, P.T., Cooper, B.P., Anderson, K.A., Wagner, M., & Narendorf, S.C. (2013). Postsecondary employment experiences among young adults with an autism spectrum disorder. *Journal of American Academy of Child & Adolescent Psychiatry*, 52(9), 931-9.

Van Riper, M. (2000). Family variables associated with well-being in siblings of children with Down syndrome. *Journal of Family Nursing*, *6*(3), 267–286. https://doi.org/10.1177/107484070000600305

West, P., Van Riper, M., Wyatt, G., Lehto, R., Douglas, S.N., & Robbins, L. (2020). Adaptation to technology use in families of children with complex communication needs: An integrative review and family theory application. *Journal of Family Nursing*, 26(2), 153-178. https://doi.org/10.1177/1074840720915536

Wilson, S.A. & Peterson, C.C. (2018). Medical care experiences of children with autism and their parents: A scoping review. *Child: Care, Health and Development*, 44, 807-817. doi: 10.1111/cch.12611