Children with Mental Retardation / Intellectual Disability: The Function of Adaptive Behavior and Parental Stress Across Childhood

Wendy Westwood

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CHILDREN WITH MENTAL RETARDATION / INTELLECTUAL DISABILITY:
THE FUNCTION OF ADAPTIVE BEHAVIOR AND PARENTAL STRESS ACROSS
CHILDHOOD

A Dissertation
Submitted to the School of Education

Duquesne University

In partial fulfillment of the requirements for
the degree of Doctor of Philosophy

By
Wendy Kay Westwood

December 2010
Dissertation

Submitted in Partial Fulfillment of the Requirements for the Degree of Doctor of Philosophy (Ph.D.)

School Psychology Doctoral Program

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CHILDREN WITH MENTAL RETARDATION / INTELLECTUAL DISABILITY: THE FUNCTION OF ADAPTIVE BEHAVIOR AND PARENTAL STRESS ACROSS CHILDHOOD

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ABSTRACT

CHILDREN WITH MENTAL RETARDATION / INTELLECTUAL DISABILITY:
THE FUNCTION OF ADAPTIVE BEHAVIOR AND PARENTAL STRESS ACROSS
CHILDHOOD

By
Wendy Kay Westwood
December 2010

Numerous studies have investigated the relationship between child functioning, problematic child behaviors, and parental stress. However, previous research has not fully examined variables of parental stress across adaptive behavior and the lifespan span of a child with MR/ID. The present study investigated parental stress differences among children’s adaptive behavior and childhood life stages, according to the family life cycle theory. Stress was examined in parents of a child with a disability whose age fell in the life cycle stages of preschool, school age, or adolescence. Results indicated that parents of preschool and school age children with disabilities ($M = 31.17, SD = 3.01$) on average do not have as many different stress levels (low, middle, and high) as the adolescence life stage group ($M = 31.58, SD = 3.70$). Additionally, most parents in the sample had children whose adaptive scores were extremely low across adaptive behavior domains; however,
the social domain presented the most variability. In the adolescence life stage, the linear combination of adaptive behavior was significantly related to the parent stress measure. The conceptual and the social domain of the ABAS-II respectfully contributed the most to parental stress. Deficits in the practical domain did not appear to impact stress. Additionally, the present study provided further interpretation through a content analysis of a case interview question on stress.
DEDICATION

This dissertation is dedicated to my mother and best friend, Karen, for her consistent support throughout all my educational endeavors. I would not be where I am today without her unconditional encouragement, love, support, faith assistance, consultation, proof reading, and constant pushing for me to be my best. She taught me how to read and write in the first place and provided me with another set of eyes to read over my countless papers throughout the years. Mom, you are my rock. This dissertation or any of my accomplishments in life could have not been completed without you.
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Chapter I: INTRODUCTION

Children with Mental Retardation / Intellectual Disability:

The Function of Adaptive Behavior and Parental Stress

Parenting is inherently a highly stressful job. Parents’ reaction to and coping of stress depends on a variety of individual, family, and environmental factors. A parent of a child with Mental Retardation/Intellectual Disability (MR/ID) has greater demands placed upon them by caring for a child with special needs and many challenges to overcome to avoid unhealthy stress. To understand the parental demands of this diagnosis, one must consider the nature of MR/ID. MR/ID is generally characterized by varying subnormal intellectual functioning levels and deficits in varying adaptive behavior degrees of concomitant emotional, physical, or medical conditions, occurring early in a child’s life (Hodapp & Dykens, 2003; Luckasson et al., 2002). Depending on the severity and adaptability of the child with MR/ID, the involvement of childcare demands increases. Therefore, in some instances everyday tasks of feeding, toileting, traveling, and communicating are more physically and emotionally demanding for parents who have children with MR/ID. Stressors, tensions, and hardships associated with a family’s management of an MR/ID diagnosis can compound to result in overwhelmed, stressed parents (Baker et al., 2003; Dyson, 1997; Haveman, van Berkum, Reijnders, & Heller, 1997; Smith, Oliver, & Innocenti, 2001; Spratt, Saylor, & Macias, 2007), while another family may view the added stress as a challenge and become stronger in the process (McCubbin & Patterson, 1983). Within the United States, a copious amount of families deal with these challenges.
Significance of the Problem

The onset of MR/ID may be recognized at any time within childhood or adolescence. Generally, the more severe the deficits, the earlier MR/ID will be apparent and consequently diagnosed. Variations in the age that a child is diagnosed can be exemplified in children with Down syndrome. Children with Down syndrome are typically diagnosed with MR/ID soon after birth because of distinct physical characteristics; whereas diagnoses without identifiable physical differences, such as autism, may not be diagnosed until they encounter intellectual or adaptive difficulties (Siklos & Kerns, 2006). Also, MR/ID may originate after a traumatic brain injury within childhood. For a child’s diagnosis of MR/ID, deficits are observed in both intellectual functioning and an area of adaptive behavior. Often, research utilizes solely an Intelligence Quotient (IQ) based testing model. This practice may contribute to variations in results due to the availability of tests and the inability of IQ tests to measure adaptive functioning.

Children with severe and profound MR/ID benefit from assessments that emphasize adaptive behavior or real life skills, such as grooming, dressing, safety, safe food handling, school rules, ability to work, money management, cleaning, making friends, social skills, and personal responsibility (Luckasson et al., 2002). Adaptive behavior can be expressed by a range of complex conceptual, social, and practical skills observed and rated in adaptive measure techniques (Harrison & Oakland, 2003; Luckasson et al., 2002). The measurements of adaptive behavior are sensitive to variations in functioning. Therefore, a simple way to avoid introducing error to a study...
created by diagnosis specific confounding variables is to account for adaptive behavior within the study.

Prevalence. Inconsistency of definitive diagnostic criterion involving intelligence and adaptive based procedures creates prevalence discrepancies within the published literature. Theoretically, researchers can use the normal bell curve to estimate the number of individuals whose IQ falls below the established criterion score, indicating current prevalence (Urbina, 2004). When a diagnosis is based on intellectual abilities measured by an Intelligent Quotient (IQ) score of 2 standard deviations below the mean, then about 3% of the total population may be considered MR/ID (Luckasson et al., 2002; Urbina, 2004). However, if classification is based on the need for support as Hodapp and Dykens (2003) reported, approximately 1% of the population can be considered as having significant mental (cognitive) limitations. The Centers for Disease Control and Prevention (CDC) addresses prevalence by inventorying those individuals who seek assistance due to their deficits.

The CDC utilized the U.S. Department of Education and the Social Security Administration’s database to determine the number of people living with MR/ID in the United States. The study concluded that in 1993 about 1.5 million, 0.76% individuals, 6 through 64 years of age, were diagnosed with MR/ID (Centers for Disease Control and Prevention [CDC], 1996). Prevalence may be even more frequent than the CDC states since the utilized data was educationally based and did not account for individuals not enrolled in public education programs, including those who had dropped out of school (CDC, 1996). In 1991, the CDC established the Metropolitan Atlanta Developmental Disabilities Surveillance Program (MADDSP) to provide regular, systematic monitoring
of the prevalence for select developmental disabilities, according to various demographic characteristics of children and their mothers (Karapurkar-Bhasin, Brocksen, Nonkin-Avchen, & Van Naarden Braun, 2006). The participants ascertained by MADDSP were identified by actively seeking information from records of service providers. Therefore, a small percentage of children, with milder forms of the disabilities that did not seek treatment, may not have been identified. None the less, the overall prevalence for MR/ID was 1.55% of children (under age 18) in 1996 and 1.2% of children in 2000 (Karapurkar-Bhasin et al., 2006). The majority of individuals diagnosed with MR/ID, 65% in 1996 and 61% in 2000, received a diagnosis before the age of 8.

The frequency of an individual being diagnosed with MR/ID is sometimes determined by severity levels which in turn affects prevalence rates. Mild MR/ID is most frequently diagnosed. However, when mild MR/ID is excluded in analyses, moderate to profound MR/ID continues to be a significant portion of the population, 0.43% in 1996 and 0.33% in 2000 (Karapurkar-Bhasin et al., 2006). Due to the alarming prevalence rates of MR/ID diagnoses, awareness of the disability and its provisions has been heightened. Therefore, a recent terminology change is slowly being incorporated into the literature base.

Terminology Change: Mental Retardation to Intellectual Disability. Culture affects how others view disability and treat persons with disabilities (Gartner, Kerzner-Lipsky, & Turnbull, 1991). Therefore, when society applied negative connotations to a label in the past, it continues to influence present decisions, treatments, and self-concepts. The long-used term mental retardation has acquired an undesirable social stigma in the United States (Baum, 2006; Schalock et al., 2007; Wehmeyer et al., 2008). Because of
this stigma, doctors and health care practitioners are beginning to replace the term “mental retardation” with the term “intellectual disability.” The adoption of the term, intellectual disability, implies an understanding of disabilities consistent with an ecological and multidimensional perspective and requires a societal focus on individual strengths and interventions that emphasize the role of supports to improve human functioning (Wehmeyer et al., 2008). Moreover, the term has fewer negative connotations and stereotypes.

The term replacement has been adopted by many professional organizations from the mid-1990s to the present. The American Association on Intellectual & Developmental Disabilities (AAIDD), an interdisciplinary organization of professionals with a mission to promote progressive policies, sound research, effective practices, and universal rights for people with intellectual disabilities, has been a driving force in the terminology change (Luckasson et al., 2002; Schalock et al., 2007; Wehmeyer et al., 2008). It should be noted that the AAIDD was previously the American Association on Mental Retardation (Luckasson et al., 2002). In February, 2010, an AAIDD committee submitted a draft of the new terminology to the Diagnostic and Statistical Manual of Mental Disorders’ (DSM-V) Developmental Disorders subgroup committee. When the next version of the DSM, (DSM-V) is published, it will utilize the ID terminology (Luckasson & Schalock, 2010). Since the terminology transition is recent and still in progress, the term ‘Mental Retardation /Intellectual Disability’ (MR/ID) will be utilized throughout the current study.

Families with a child with MR/ID. The amount of care and service demands for children with MR/ID greatly impacts all aspects of life, including parental functioning.
Stress occurs as an event or situation, such as a small everyday hassle or pervasive factor, exceeds an individual’s coping ability, resulting in physical and emotional tension which may require some type of change or adaptation (Lessenberry & Rehfeldt, 2004; Neece & Baker, 2008; McCubbin & Patterson, 1983). For example, stressful situations may occur where a medical need (a child who consistently needs to be monitored for safety concerns), a physical need (a child who cannot independently bathroom beyond the age of 4), or a cognitive need (a child who needs academic assistance) is exercised beyond the parents’ capabilities and not mediated by available resources. Parental stress is a particularly salient variable with families that include children who have MR/ID (Dyson, 1997; Hauser-Cram et al., 2001; Baker et al., 2003; Neece & Baker, 2008). Within the United States, prevalence rates of MR/ID are high; indicating a great number of families may be dealing with parental stress specific in families with a child with MR/ID.

Stress is correlated with many negative outcomes, including parent depression (Hastings et al., 2006), less effective parenting, and increased child behavior problems (Baker et al., 2003; Walker, 2000). Research shows consistently appropriate parental functioning or coping can dictate the prevention of stressful events throughout the family as a unit. Also, the improved outcomes of the children with MR/ID, after interventions that result in an improved quality of life, are affected by parents continuing their routines and working though stress (Bowen, 1978). Therefore, it is imperative to identify predictors of parenting stress to adapt interventions aimed at reducing and/or preventing these negative outcomes (Neece & Baker, 2008). Research on parental stress in families with MR/ID can also determine the need for services and assist in the design and implementation of appropriate resources.
Evaluating the levels of stress parents acquire from their families may be complicated due to several affecting components of interactions between the child, parent, and environmental variables. A widely used index of parenting stress is the Short–form of the Questionnaire on Resources and Stress (QRS-F; Friedrich, Greenberg, & Crnic, 1983), which provides a useful conceptualization of stressors as multi-dimensional both in source and kind. However, stress is not a concrete concept; therefore, many researchers often perceive stress according to their own standards. As a result, there has been great variability in how researchers have chosen to operationalize the construct of parenting stress, in some cases making cross-study comparisons difficult. The mixed theoretical approaches of current research contribute to this complexity.

**Theoretical Basis**

Major theoretical influences within family research adaptation models are family theories, typically encompassing family ecological systems theory, family stress theory, and family developmental theory. Each family theory shares structural components and utilizes environmental and interrelationship aspects in explaining families involving children with MR/ID and their family adjustment.

Family ecological systems theory recognizes that within a particular social context or ecology, the family is an open, interactive system with direct and indirect influences that operates according to a generalized set of principles (Bristol & Gallagher, 1986; Turnbull, Summers, & Brotherson, 1986). Therefore, a family is seen as interconnected through various subsystems (marital, parental, sibling, and extended) that work as a whole to maintain homeostasis, while maintaining individuality (Brody, Stoneman, & McCoy, 1994; Head & Abbeduto, 2007; Turnbull et al., 1986). Changes in
one family member affect other family members, resulting in multiple ripple effects over time. So individual characteristics or dynamics within family subsystems can contribute to relationship quality, and individual stress can topple the whole system. Family ecological systems’ perspectives do not address explicitly how stress is then managed.

By conceptualizing the presence of MR/ID as a crisis and stressor within the family system, family stress theory takes an additional step from family ecological systems theory in familial adaptation literature (Hodapp & Dykens, 2003; McCubbin & Patterson, 1983). In general, family stress theories propose that a family’s adaptation to a crisis event, having a child with MR/ID, is explained by multiple factors, including the nature of the crisis event, the internally and externally based resources available, and the meaning ascribed by the family members to the event (McCubbin & Patterson, 1983). Coping resources then have a key role in family paradigms such as the ABCX and Double ABCX models (McCubbin & Patterson, 1983), which emphasize the importance of internal and external support resources in understanding patterns of family coping and adaptation (Hodapp & Dykens, 2003; Xu, 2007). The stressors that families deal with then change and accumulate, affecting each member. However, family stress theory does not provide explanations for environmental stress or age specific stress stages.

Family developmental theories, on the other hand, incorporates both family systems theory and family stress theory for a comprehensive overview of difficulties in potential stresses, crisis points, reactions, and needs of the family (Baum, 2006; Holman & Burr, 1980; Turnbull et al., 1986). Developmental research endorses critical periods of developmental milestones in all children (Baum, 2006; Turnbull et al., 1986; Zimbardo, Weber, & Johnson, 2000). A model within developmental theories, the family life cycle
theory, focuses on the family moving through a series of transitions that create stressors within the family system (Baum, 2006; Turnbull et al., 1986). The most supported stage sequence, when a disability is present, is the 7-stage Family Life Cycle by Olson and colleagues (1984). The sequence follows monumental periods in a family’s life, beginning with two individuals anticipating a family, the couple stage, through the presence of a child and their subsequent life. The stages are couple, childbearing, school age, adolescence, launching, post-parental, and aging (Baum, 2006; Olson et al., 1984; Seligman & Darling, 1989; Turnbull et al., 1986). The cycle follows life events of the parents according to the ages of their children, and as children age, they grow into adults and typically begin their own cycle. The applicability of this model is displayed in its adaptability to family variations, such as the absence of marriage, divorce, multiple children, and the presence of a child with MR/ID.

When a disability is introduced to the family, the entire family stage and its further transitions may be arrested due to the child’s developmental lags (Baum, 2006). How families cope at different stages will depend on what life cycle issues family members face at the time (Baum, 2006). Variations may emphasize more stressful periods of time; for example, families in early stages of a child’s MR/ID diagnosis generally need assistance with developmental and medical issues, which change over time (Haveman et al., 1997). However, previous research has not closely examined the parent stress in shifts or stages occurring throughout childhood.

Within the present study, family developmental approaches provide a salient theoretical base to further current research on parental stress and family functioning with families who have children with MR/ID.
Statement of Purpose

The current study examined the role of adaptive behaviors and parental stress throughout the span of childhood. Participants included parents of children previously diagnosed with MR/ID between 5 and 21 years old. It is important to consider possible implications that different perceptions of parenting stress may have on overall functioning for these families, as well as interventions for these families. Information about the relative impact of family resources and the child's level of developmental impairment on parental stress would not only help in identifying which parents are more at-risk for adverse symptomatology but would also assist in designing more specific intervention strategies to prevent long-term stress effects in families of children with and without disabilities.

Numerous studies have investigated the relationship between child functioning, problematic child behaviors, and parenting stress. However, previous research has not fully examined variables of parental stress and degrees of fluctuations over the lifespan span stages of a child with an MR/ID diagnosis. Therefore, to extend the literature on children with MR/ID and familial impact, the present study examined predictors of parent stress, and the age of specific stress trends by categorizing relevant research into 3 life stage groups in line with developmental family life cycle perspectives. Parents with children previously diagnosed with MR/ID were separated according to the child’s age at the time of participation; parents of children 5 to 7 years old, Preschool; 8 to 12 years old, School Age; and 13 to 21 years of age, Adolescence. In particular, the literature base is lacking within the Adolescence stage. Although a variety of family demographic variables, adaptive behavior skills, and levels of social support were investigated across
age groups, the main focus of the present study is on the Adolescence stage. Specifically, the following research questions were examined.

**Research question 1**

Does the level of perceived parental stress vary across childhood life stages (Preschool, School Age, and Adolescence)?

*Hypothesis 1.* There will be variability in parental stress across childhood life stages.

*Question 1a.* In what stage is the level of parental stress most elevated?

*Hypothesis 1a.* It is theorized that the life stage of Preschool will significantly differ in parental stress from all other stages.

**Research question 2**

Does the level of perceived parental stress differ across child adaptive behavior skills?

*Hypothesis 2.* There will be an inverse relationship between the higher level of perceived parental stress and lower child adaptive behavior ability.

**Research question 3**

Original: Does the relationship between parent stress and child adaptive behavior differ across childhood life stages (Childbearing, School Age, and Adolescence)?

Changed to: In the life stage, Adolescence, is there a relationship between the degree of child adaptive behavior (Social, Conceptual, and Practical) and parental stress?

*Hypothesis 3.* Differences occur between child adaptive behavior and parental stress within Adolescence.

*Question 3a.* How does parent stress interact with adaptive behavior skills (Conceptual, Social, and Practical) and Adolescence?
Hypothesis 3a. It is theorized that lower conceptual and practical adaptive behavior will predict higher stress levels in the Adolescence stage.
Chapter II: LITERATURE REVIEW

Children with Mental Retardation/Intellectual Disability

Mental Retardation/Intellectual Disability (MR/ID) is a complex phenomenon with widely varying levels of functioning and degrees of concomitant emotional, physical, or medical conditions (Hodapp & Dykens, 2003; Luckasson et al., 2002). MR/ID is defined by subnormal intellectual functioning and deficits in adaptive behavior, occurring early in life. The presence of deficits is stable throughout a lifetime, despite the fact that many behaviors or symptoms may improve in degree with intensive interventions. For example, children with MR/ID can learn new skills, but the development of skills is slower than children with average intelligence and adaptive behavior skills (Luckasson et al., 2002). The nature of the disability through the protracted rate of learning implies the gap between the child with MR/ID and his or her peers will widen in terms of intellectual ability throughout life. The effects of MR/ID are broad reaching, presenting obstacles for the child with MR/ID and their family. Often children with MR/ID can recognize their differences. Recognition can have positive or negative implications, depending on perceptions of the disorder from those around them including parents, siblings, and their community.

Background Information

The notion of a person with inferior mental performance and slowness has been recorded for centuries (Hodapp & Dykens, 2003; Wehmeyer et al., 2008). However, past societal views and research focus were far from the progressive standards of mental health currently held. Previous to the 19th century, negative connotations were associated with any form of mental deficiencies. Children with deficits were seen as shameful and
often treated as subhuman; therefore, they were separated from their families and other children. Fortunately, services and beliefs held about people with disabilities began to change over the decades. In the mid 19th century, persons with disabilities were recognized as a distinct group (Gartner et al., 1991). An institutional approach began as residential training schools were established as the accepted way to handle a child with mental deficits. By 1892, most treatment consisted of a multitude of residential facilities (Hodapp & Dykens, 2003).

The awareness, acceptance, and treatment of mental deficits prompted a need for a system to identify and classify individuals with MR/ID. In 1905, Binet and Simon advocated for the measurement of intelligence to achieve identification (Baum, 2006; Urbina, 2004). The test was a series of 30 tasks with varying content and difficulty to assess school learning (Urbina, 2004). Intelligence tests focused on an underlying idea that mental level could be calculated to represent quality of performance. Then, in 1911, William Stern relabeled the scale; the mental age score divided by the chronological age of the subject obtained a mental quotient, which was then multiplied by 100 to produce an Intelligence Quotient (IQ) score (Urbina, 2004). The IQ score was given meaning through standardization, a portion of the population was uniformly administered the tests to provide a base for the appropriate placement of mental age with regards to chronological age. Thus, mental ability was seen as an unchanging function and for the first time could be measured. This innovation was followed by various standardized tests to identify children in school who needed extra help and separate them from the general population (Hodapp & Dykens, 2003).
Around the time of testing developments, Goddard and his colleagues developed a classification system that applied the terms idiot, imbecile, and moron to represent levels of impairment (Hodapp & Dykens, 2003; Schalock et al., 2007; Wehmeyer et al., 2008). At the time, an individual labeled an idiot had development arrested at the level of a 2 year old; an imbecile’s development was considered equivalent to a 2 to 7 year old; and a moron characterized individuals whose mental development were equivalent to a 7 to 12 year old. It was not until the 1930s that the classification term of mental retardation emerged (Luckasson et al., 2002; Wehmeyer et al., 2008).

With an identification and classification system, the institutional approach remained stable until the end of the 1940s. Then, the 1950s marked a change as the definitions of MR/ID began to develop. Parents began to understand the disability more, and as a result, children with disabilities began to stay within the home as a family member. Previously, MR/ID was considered the inability to learn to perform common acts, deficits or delays in social development/competence or a low IQ (Luckasson et al., 2002). A change in emphasis from a genetic or constitutional focus to a function-based definition then occurred. In 1959, the American Association on Mental Deficiency adopted a new definition; "Mental retardation refers to sub-average general intellectual functioning which originates in the developmental period and is associated with impairment in adaptive behavior" (Luckasson et al., 2002). Although this definition included the 3 components of (1) impaired adaptive behavior, (2) less than a standard score of 85 on an IQ test, and (3) origination before age 16, only IQ and age of onset were measurable with the existing psychometric techniques. Therefore, deficits in
adaptive behavior were based generally on subjective interpretations by individual evaluators.

As definitions of MR/ID were evolving, advocacy groups were demanding rights for equal treatment. Legislative mandates throughout the 1970s finally established various protection laws, giving persons with disabilities rights (Gartner et al., 1991; Hodapp & Dykens, 2003; Wehmeyer et al., 2008). Society’s view of MR/ID has become progressively accepting within the 21st century. The legal system now grants equal rights and mandates schools to provide appropriate assessments and necessary treatments to enable adequate functioning (Luckasson et al., 2002). Also, the positive change is reflective in advocacy organizations, as evidenced in the terminology change from mental retardation to intellectual disability. Recent employment of adaptive behavior assessments has allowed access to classification by functionality, in turn providing directed support. However, operational definitions of MR/ID still vary across the criteria from advocacy and supports organizations, such as the DSM-IV-TR, AAIDD, IDEIA, and ICD-10 (American Psychiatric Association [APA], 2004; Luckasson et al., 2002; World Health Organization [WHO], 1996). Currently, there are several different diagnostic criteria for MR/ID, all of which utilize deficits to some degree in intellectual functioning and adaptive behavior. The specifics of each definition are listed below.

The Diagnostic and Statistical Manual (DSM-IV-TR) defines criterion for MR/ID as:

“…significantly sub-average general intellectual functioning (at least 2 standard deviations below the mean on an IQ test) accompanied by significant limitations in adaptive functioning in at least 2 of the following skill areas; communication,
self-care, home living, social/interpersonal skills, use of community resources, self-direction, functional academic skills, work, leisure, health, and safety; … onset before age 18 years; … may be seen as a final common pathway of various pathological processes that affect the functioning of the central nervous system” (APA, p.39, 2004).

The American Association on Intellectual and Developmental Disabilities (AAIDD) criterions for MR/ID are:

“…characterized by significant limitations (at least 2 standard deviations below the mean) both in intellectual functioning and in adaptive behavior as expressed in conceptual, social, and practical adaptive skills…originating before age 18” (Luckasson et al. p.76, 2002).

Individuals with Disabilities Education Improvement Act (IDEIA) defined MR/ID in 2004 as:

“… significantly subaverage general intellectual functioning, existing concurrently with deficits in adaptive behavior and manifested during the developmental period, that adversely affects a child's educational performance.” [34 Code of Federal Regulations §300.8(c)(6)]

The World Health Organization (1996) also includes a definition of diagnostic criterion for MR/ID in its *International Classification of Diseases and Related Health Problems, Tenth Revision* (ICD-10) as:

“… cognitive, language, motor, social, and other adaptive behavior skills used to determine the level of intellectual impairment.” With “noticeable emotional and social immaturity.”
ICD-10 presents IQ levels not as cutoffs but as guides when categorizing individuals with MR/ID. Scores between 50-69 are considered mild, 35-49 moderate, 20-34 severe, and below 20 profound. There is no mention of any standardized cutoffs for adaptive ability. Also, an additional classification of ‘other mental retardation’ is possible when associated physical or sensory impairments make it difficult to establish the degree of impairment (WHO, 1996).

For diagnostic purposes in the United States, the DSM-IV-TR is commonly utilized, although views from each organization above can be incorporated to form a comprehensive understanding of MR/ID. Although each organization’s criterion places greater emphases in different areas, all involve aspects of intellectual functioning and adaptive behavior. The following sections highlight the composition of both of these characteristics with a child with MR/ID.

Intellectual Functioning

Intelligence refers to the general mental capacity to reason, plan, solve problems, think abstractly, comprehend complex ideas, learn quickly, and learn from experience (Luckasson et al., 2002). Intellectual functioning is often measured by intelligence assessments, reflected in a resulting Intelligence Quotient (IQ) score. Given the widespread development of intelligence tests during the past 100 years, many instruments with different theoretical orientations and quality can be employed to diagnose MR/ID. Intelligence tests that the United States government encourages in social security eligibility assessments (Luckasson et al., 2002) are the Bayley Scales of Infant Development (Bayley, 1993), Kaufman Adolescent and Adult Intelligence Test (Kaufman & Kaufman, 1993), Kaufman Assessment Battery for Children (Kaufman &
Kaufman, 1983), Leiter International Performance Scale (Roid & Miller, 1997), Mullen Scales of Early Learning (Mullen, 1995), Stanford-Binet Intelligence Scale (Roid, 2003), Universal Nonverbal Intelligence Test (Bracken & McCallum, 1998), Wechsler Intelligence Scale for Children (Wechsler, 2003), Wechsler Adult Intelligence Scale (Wechsler, 1997), and the Woodcock-Johnson (Woodcock, McGrew, & Mather, 2001).

An IQ score is then attained from a battery of the psychological subtests and calculated into a mental level, which represents quality of performance ability according to chronological age (Urbina, 2004).

Generally, an MR/ID diagnosis is considered if an IQ score is approximately 2 standard deviations below the general population mean, considering calculation of the standard error of measurement for the specific assessment instrument and the instrument’s strengths and limitations (Schalock et al., 2007; Luckasson et al., 2002). This view would approximate MR/ID as a standard IQ score of 70 or below, which is in line with the DSM-IV-TR criteria. However, some flexibility in the application of such cutoffs is necessary and represents standard best practices. The flexibility rationale is applied because a test score is not perfectly reliable; advocating the use of the standard error of measurement (Urbina, 2004). Therefore, IQ standard scores ranging between 70 and 75 are sometimes referred to as a zone of uncertainty (Luckasson et al., 2002).

IQ-based statistical norms can both define the diagnostic group and then further classify those individuals (Urbina, 2004). Generally, research distinguishes between individuals with limited MR/ID and those with more extensive cognitive disabilities (Luckasson et al., 2002). The excepted classification system of MR/ID by the DSM-IV-
TR and ICD-10 denotes levels as mild, moderate, severe, or profound retardation (APA, 2004; Hodapp & Dykens, 2003; WHO, 1996).

*Mild MR/ID.* Individuals with the classification of mild MR/ID possess an IQ between 55 and 70 (APA, 2004). Individuals diagnosed with mild MR/ID tend to appear similar to the general population, can achieve academic skills approximating a sixth-grade level, hold jobs, and form typical interpersonal relationships (Hodapp & Dykens, 2003; Sachs & Barrett, 2000). The mild MR/ID classification constitutes the vast majority of individuals with MR/ID, possibly as many as 90% (Hodapp & Dykens, 2003; Luckasson et al., 2002; Sachs & Barrett, 2000), and is more common in minorities and low-socioeconomic-status backgrounds (Hodapp & Dykens, 2003; WHO, 1996). The World Health Organization attributes higher frequency in low-income areas to poor access to health facilities, under-stimulation, and poor nutrition. However, recent literature speculates that there may be an overrepresentation of MR/ID in this population due to IQ tests that are not culturally sensitive (Hodapp & Dykens, 2003; Sachs & Barrett, 2000).

*Moderate MR/ID.* An IQ standard score between 40 and 55 signifies moderate MR/ID (APA, 2004). Moderate MR/ID is diagnosed within the preschool years (Hodapp & Dykens, 2003). A typical achievement level is often characterized within the second grade level, with general difficulty in abstract concepts (Sachs & Barrett, 2000). Children with moderate MR/ID often require assistance throughout life. Assistance may involve adaptations in learning environments and evaluation of academic performance or the application of psychosocial supports, such as social skills training. In general, individuals
with moderate MR/ID are able to interpret social cues, however, possess difficulty in organizing an appropriate response to social interactions (Sachs & Barrett, 2000).

Severe MR/ID. Severe MR/ID implies an IQ standard score between 25 and 40 (APA, 2004). These individuals often exhibit concurrent ambulatory, respiratory, heart or other medical problems, and very limited language and self-care skills (Hodapp & Dykens, 2003; Sachs & Barrett, 2000). A majority of individuals with severe MR/ID require involved assistance in various daily living activities throughout life (Hodapp & Dykens, 2003).

Profound MR/ID. An IQ standard score below 25 signifies profound MR/ID and considerable impairment (APA, 2004). Generally, children with profound MR/ID learn only the rudiments of communicative skills. For example, they understand the function of indicating need but often lack the skills to appropriately convey need through both verbal and nonverbal means. They require lifelong care and assistance, and intensive training to develop basic skills of eating, grooming, toileting, and dressing behaviors (Hodapp & Dykens, 2003; Sachs & Barrett, 2000).

Difficulty arises in utilizing an IQ based testing model in instances when a child is either very young or determined to be ‘untestable’ or not appropriate for any available tests. A decision may then be made to forgo administration of a particular cognitive assessment test. For example, language-loaded intelligence tests are not appropriate for people who would be disadvantaged due to language limitations, such as children with nonverbal autism. Also, IQ instruments such as the Stanford-Binet (Roid, 2003) and the Wechsler Scales (Wechsler, 1997; 2003) are not designed to test individuals with severe/profound MR/ID (Luckasson et al., 2002). In addition, due to the high floor on the
Wechsler Scales, the publisher recommends that a child obtain a raw score in at least 3 subtests of both the Verbal Scale and the Performance Scale before obtaining a valid Full Scale IQ score (Wechsler, 1997; 2003). Due to all the complications involved in IQ testing for children with severe/profound MR/ID, instead, many obtain a diagnosis through sufficient objective information, parental input, and a developmental assessment of their cognitive domain (Harrison & Oakland, 2003; Luckasson et al., 2002).

In general, identification of a child with MR/ID should be completed through multiple sources of collected data. Instead of an emphasis on disabilities through an IQ derived classification, the AAIDD utilizes an ability based classification system for MR/ID. Ability can be seen as adaptive behavior or real life skills such as grooming, dressing, safety, safe food handling, school rules, ability to work, money management, cleaning, making friends, social skills, and personal responsibility (Luckasson et al., 2002). Adaptive behavior is an important component to the functions and behaviors expressed in an individual with MR/ID.

**Adaptive Behavior**

Successful adaptive functioning involves managing and coping with demands from the everyday environment (Liss et al., 2001). The DSM-IV-TR states that along with an intellectual impairment for an MR/ID diagnosis to occur, there must be at least 2 concurrent adaptive functioning deficits or impairments within communication, self-care, home living, social/interpersonal skills, use of community resources, self-direction, functional academic skills, work, leisure, health, or safety (APA, 2004). However, the AAIDD’s definition of individuals with MR/ID addresses significant limitations in both intellectual functioning and adaptive behavior, which is expressed in 3 broader skill
sections; conceptual, social, and practical adaptive skills (Luckasson et al., 2002). Each domain also reflects a range of complexity and sophistication, which further communicates the increasing expectations for acquiring competencies to meet expanding demands for coping with increasing age (Luckasson et al., 2002). For example, expected competencies in the practical domain vary from eating and toileting to making sound decisions about money and health care needs. Significant limitations of adaptive behavior are determined by a child’s performance of at least 2 standard deviations below the population mean on an adaptive behavior assessment scale, which combines the skill sections (Harrison & Oakland, 2003; Luckasson et al., 2002; Urbina, 2004). The composition of each skill domain is displayed in the following paragraphs.

**Conceptual skills.** The conceptual domain represents competencies that are essential to everyday successful functioning in the community, home, and school. Conceptual skills are characterized by communication, functional academics, and self-direction (Harrison & Oakland, 2003). Communication encompasses both a broad range of expressive and reciprocal behaviors from language acquisition to interaction capabilities. Language acquisition is defined as an interaction of phonological skills, lexicon formation, cognitive abilities, and joint attention (Abbeduto & McDuffie, 2007). Functional academics are skills in which proficiency leads to increased independence and successful daily activities, such as areas of reading, writing, mathematics, and money concepts (Harrison & Oakland, 2003).

Significant limitations in the conceptual domain can lead to serious coping disadvantages and informal recognition of adaptive behavior limitations by others. For example, adolescents who cannot apply literacy skills in everyday situations, such as
comparing prices between different sizes of a commodity, are at a serious disadvantage and show deficits that are readily recognized by peers and adults. Also, difficulties with abstract concepts, anxiety, and compliance issues can interfere with the development of children’s self-direction skills, which is common in MR/ID.

Social skills. Social skills are defined as the behaviors needed by individuals to be considered socially competent by their caregivers and peers (Luckasson et al., 2002). Social skills may include interpersonal relationships, maintaining responsibility, endorsing self-esteem, following rules, obeying laws, and avoiding victimization and gullibility (Harrison & Oakland, 2003). Children typically acquire pro-social skills within their daily routines, interactions, and guidance provided by caregivers and peers. However, children with developmental delays or deficits in this area need additional support and explicit instruction in order to learn appropriate interaction.

Practical skills. The focus of the practical domain is basic maintenance of daily living, a safe environment, and occupation skills (Harrison & Oakland, 2003). Daily living activities include skills related to independent eating, dressing, mobility, and toileting. Instrumental activities such as preparing meals, taking medication, using the telephone, managing money, using transportation, and doing housekeeping activities, also fall in this category. A child with MR/ID may have a wide variety of adaptive behavior deficits. Often, particular deficits are associated with specific syndromes, classifications, and etiologies.

MR/ID Diagnosis and Etiologies

The etiology of most MR/ID is not known, and many diagnoses have resulted from injury, disease, brain abnormality, or genetic condition (Hodapp & Dykens, 2003;
Karapurkar-Bhasin et al., 2006; Luckasson et al., 2002; Sachs & Barrett, 2000). Some of the most common known factors include prenatal genetic disorders, resulting in Downs, Fragile X, or Prader Willi syndromes. Environmental factors, for example, in utero accidents or toxic exposure, in utero exposure to drugs or alcohol, or perinatal insults from serious head injury, stroke, or metabolic conditions, such as meningitis, phenylketonuria, and galactosemia, are also possible etiologies (Hodapp & Dykens, 2003). Regardless of etiology, many children who manifest MR/ID are unavoidably medically involved. Often children with MR/ID need frequent doctor appointments, receive medications that require monitoring, or are at an increased risk for co-morbid disorders and diseases. Therefore, children often rely on their caregivers’ dedication to obtain their children’s diagnoses, assist in their treatments, and manage concomitant complications of everyday life. Families are extremely important in the care of a child with MR/ID.

Families with a Child with MR/ID

Throughout history, societal views have shaped and adapted the nature of a family’s functioning level and interactions with their child with MR/ID. As mentioned previously, centuries ago, societal attitudes towards the disabled were significantly less supportive and encouraging as compared to current positive family research efforts. For example, in the 1850s to the 1940s, America viewed the birth of a child with a disability as a family tragedy, stigmatizing the child, mother, and family. Therefore, children with substantial intellectual deficits were often removed from the home and placed in private and public facilities (Gartner et al., 1991; Hodapp & Dykens, 2003). Throughout this time, mothers of children with MR/ID were often sterilized, and in an extreme case, the
American Psychiatric Association published an editorial that endorsed the legal euthanasia of mentally retarded children and the provision of psychotherapy to parents to relieve them of their guilt (Gartner et al., 1991). Fortunately, euthanasia did not continue for long, and its immediate effect on the public transformed the nature of institutional care.

Although the initial idea of an institution was to train, habilitate, and release persons, it became places where children went to live for a lifetime. Early in this era, institutional care overlooked the actual welfare of the children with MR/ID; rather it was seen as a way of preventing the child from disabling the family. Institutions with higher functioning individuals often trained children and adults with MR to occupy roles of institutional peonage, which is to work on the institution grounds as free labor. Following the Depression in the 1930s and the war in the 1940s, fiscal resources dwindled, and institutions were overcrowded and had fewer trained staff. Children below the age of 5 could not by law be placed in institutions at this time, but by 1943, 32% of beds in institutions were filled by children aged 5 to 10 years (Gartner et al., 1991). Consequently, a great deal of research focused on maternal reactions to the birth of a child with impairment rather than the interaction of the two. Therefore, early research on family functioning was based on a pathological model of adaptation, where maternal psychological reactions were equated to family functioning (Hodapp & Dykens, 2003).

The 1950s then marked a shift in society’s conception of children with MR/ID, as parents increasingly began to advocate on behalf of their children who were disabled. In turn, treatments and interventions began to teach learning skills, and families maintained relationships with their children with MR/ID. Placements in institutions became less
popular (Gartner et al., 1991). At this time, research focused on the child’s or parents’ functional abilities individually but still neglected the relationship of the two. In 1975, the United States government passed public law 94-142, mandating educational services for all children. Also, it allowed for parents to act as decision makers in terms of their children’s education and mandated due process rights (Gartner et al., 1991). With the passing of new laws, advocacy and support organizations became prominent.

A paradigm shift in the 1980s took the present understanding of MR/ID away from an absolute trait expressed solely by an individual to a view emphasizing the interaction between the person with MR/ID and the environment (Luckasson et al., 2002; McCubbin & Patterson, 1983). In recognition of family needs, the Education of Handicapped Act was amended to establish a national network of parent training and information programs. Then, as family based research was popularized in the early 1990s, literature focus changed to family interactions and how a child’s adaptive functioning and behavior interfaced with the interactions in social and academic situations (Head & Abbeduto, 2007; LoBindo-Wood, 2008; Xu, 2007).

Over the last two decades, a great deal of progress has been made on research of parent–child interactions and MR/ID. Presently, families are seen as interconnected; while each individual consists of different functions, roles, and responsibilities, all actions affect the family as a whole (Brody et al., 1994; Head & Abbeduto, 2007; Williams et al., 2002). Interactions of valuable marital, parental, sibling, and extended relationships then determine general family functioning both positive and negative (Lopez, Clifford, & Ouellette-Kuntz, 2008; Haveman et al., 1997; Siklos & Kerns, 2006). Current literature trends on family adaptation recognize the importance of
interacting variables, such as coping processes, supports, diagnosis, behaviors, adaptive behavior, age, and external pressures between children diagnosed with MR/ID and their families (Haveman et al., 1997; Lopez et al., 2008; Neece & Baker, 2008; Siklos & Kerns, 2006). The following sections summarize this research with regards to parent stress and coping.

Family Stress

An individual’s stress can become stress for his or her whole family. Family stress is defined as a state that arises from an actual or perceived imbalance between demand and capability in the family’s functioning (McCubbin & Patterson, 1983). It is possible for stressors to affect all family members in positive and/or negative ways. A stressor is an event or situation exceeding an individual’s coping ability, while a strain is exemplified as the physical and emotional symptoms of a stressful event (Lessenberry & Rehfeldt, 2004). Stress can be caused by small everyday hassles, as well as pervasive, ongoing factors, which may arise from specific events but have long-term ramifications (Lessenberry & Rehfeldt, 2004; Neece & Baker, 2008). When an individual experiences tension, this tension creates stress, which requires some type of change or adaptation (McCubbin & Patterson, 1983). Most people associate stress with pressures, strain, and something that should be avoided. However, stress can be positive. Positive stress heightens awareness, increases mental alertness, and leads to superior cognitive and behavioral performances (Blacher, 1984). The point at which positive stress becomes distress and starts to interfere in daily functioning varies, depending upon an individual’s perception of the stress and his or her resources.
Research has shown parents carry the greatest influence on children’s relationships (Brody et al., 1994). Parental functioning can dictate how each family member behaves within the family. In general, change and trauma also affect the family. Therefore, the manner in which parents adjust and cope with stress produces change and affects all family members’ overall functioning. Major concerns regarding the introduction of a MR/ID diagnosis as an additional familial stressor or traumatic event due to the intense level of service needs, time demands, and subjective burden of care associated with children with MR/ID (Haveman et al., 1997). For example, Haveman and colleagues’ (1997) longitudinal study using stepwise regression examined family-child interactions. A 146 question survey, adapted from empirical tests, such as the Caregiving Burden Scale/Time Demand–Index (Heller & Factor, 1991) and the Inventory for Client and Agency Planning Scale (Bruininks, Woodcock, Weatherman, & Hill, 1986), was completed by 2,573 caregivers for individuals with MR/ID in the Netherlands. Mediating variables were determined by isolating survey sections. These indicator variables were: characteristics of family, educational level, marital status, number of children, presence of disability, characteristics of child, gender, MR level, physical health, adaptive skills, behavior problems, service use, time demands, and subjective burden. Haveman and colleagues’ (1997) main focus was on the demands placed on caregivers over a life cycle and predictors that consume parental time. Regression results indicated significant predictors of time demands on families of a child with MR/ID as; child’s adaptive skills ($R^2=.44 p<.01$), behavior problems ($R^2=.45 p<.01$), physical health ($R^2=.46 p<.01$), parent education level ($R^2=.46 p<.01$), number of children ($R^2=.47 p<.01$), and service use ($R^2=.47 p<.01$).
Although the intent of the study was to measure time demands and burden of care statistics, the results factor into parental stress and family functioning. An increase in care demands, if not appropriately managed, leads to parental stress and family dysfunction.

*Family Stress with a Child with MR/ID*

Parental stress is a particularly salient variable with families that include children who have MR/ID (Dyson, 1997; Hauser-Cram et al., 2001; Baker et al., 2003; Neece & Baker, 2008). Parents encounter stress often when family functioning is not mediated or positive protective factors are not an available resource. Stressful situations occur in instances where a need that requires medical, physical, or cognitive support is exercised in excessive amounts or beyond the parents’ capabilities; for example, a child who consistently needs to be monitored for safety concerns or a child who cannot independently bathroom beyond the age of 4. However, significant variability is reported in the degree of experienced parental stress. Therefore, there are families with MR/ID who do not encounter the major negative stress that others do. Determination of predictors involved in stress can lead to intervention and prevention for families encountering negative stress. The following sections summarize research on negative stress predictors in families with a child with MR/ID.

*Predicting parent stress variables.* Much speculation occurs across family research on factors contributing to the production of substantial portions of preventative and negative influence of stress on family functioning. Smith and colleagues (2001) suggest elevated stress levels that adversely affect family functioning are significantly correlated to the severity level of the child’s diagnosis. Within Smith and colleagues’ (2001) regression models, child functioning significantly increased ($R^2=.039, p<.001$)
overall parental stress. However, the child’s behavior problems were not accounted for, which may confound the study because it is impossible to tell how much behavior contributed to severity.

On the other hand, research indicates that child behavior problems consistently influence parental stress. Behavior problems range from disturbances of feeding, elimination, sleep, or the interaction of factors that exhibit a physical and social impact such as non-compliance to extremes of harm to self or others. Also, problems may occur in children’s ability to manage social situations that are frustrating or demanding. A child’s behavior is complex, and often behaviors are considered a functional response to the situation, a means to reduce internal levels of arousal and stress, or manifestations linked to psychiatric disorders (Hodapp & Dykens, 2003). Despite the presented behavior or its function, parents must find ways to manage their child’s behaviors.

Baker, Blacher, Crnic, and Edelbrock (2002) examined the extent of behavior problems and the relative impact cognitive delays and problem behaviors have on parents. Cognitive or development levels are referred to as the intelligence and behavior typical for the child’s age. A cognitive delay demonstrates the child falling off the developmental path and lagging behind his or her same-aged peers. Parents of 225 children, 3 years of age, with developmental delays or without delays completed the Bayley (Bayley, 1993) and Child Behavior Checklist (CBCL; Achenbach & Rescorla, 2001). To detect the variance in stress attributable to having a child with delays over the actual level of cognitive functioning, a multiple hierarchical regression was utilized. Within mothers, 52% of the variance was explained by the Bayley scores (Bayley, 1993) followed by the presence of a disability. Next, behavior problem scales from the CBCL
were entered, accounting for an additional 40% of variance. Each behavior problem indicator was significant, however, the presence of a disability did not account for any additional variance. Findings from Baker and colleagues (2003) confirm this significance and additionally assume that parent stress may lead to more behavior problems, and more behavior problems lead to more parental stress.

Baker and colleagues (2003) found that once behavior problems were accounted for, the child’s intellectual delay indicated little or no further variance. This contrasted with Smith and colleagues’ (2001) previous research, which did not account for behavior problems but indicated cognitive level or disability severity greatly affect family functioning. This corroborates with past research from Haveman and colleagues’ (1997) increase care demands study, suggesting that the presence of behavioral problems in a child with MR/ID represents a significant stressor to the parents beyond the stress of the child’s actual disability (Baker et al., 2002; Baker et al., 2003; Haveman et al., 1997).

Despite the strong research base, debate exists over how much researchers apply the term behavior problems to actual issues related to severity, diagnoses, age, IQ, or adaptive behavior (Hassall & Rose, 2005; Haveman et al., 1997; Neece & Baker, 2008). Spratt and colleagues (2007) tried to accommodate this debate by addressing factors from diagnosis, severity level, and behavior problems in parents of 227 children ages 4 through 12. Groups consisted of children with combined developmental, behavioral, neurological, and emotional problems, children with intraventricular hemorrhage documented at birth, children with learning and/or attention problems, and children with neural tube defects. However, correlates of parenting stress remained the same. A multiple regression analyses was performed on externalizing and internalizing behavior problems, and
parents’ perceived inadequacy of family resources emerged as consistent stress indicators. Among the categories of child disabilities, parent stress variance was the highest in parents of children with behavior problems only or combined cognitive deficits and behavior problems (Spratt et al., 2007).

An issue with this study, however, is the way severity labels for grouping was obtained. In general, research often does not explicitly define the process in which severity levels are obtained. DSM-IV-TR classification denotes severity labels based solely on IQ scores without regard to the intensity of adaptive behavior deficits. The variations of deficits within conceptual, social, or practical domains of adaptive behavior are based on different criterion than cognitive deficits denoted within an IQ. Consequently, the definition of behavioral problems may coincide with manifestations from adaptive behavior deficits. For example, adaptive behavior deficits in a daily living event, such as toileting can be seen in different ways. The inability to independently toilet may be caused or associated with the disability or with problem behaviors of defiance or frustration manifested as aggression or toilet refusal.

Therefore, the consideration of adaptive behavior could shed new light on Spratt and colleagues’ (2007) study. Similarly, the importance of identifying adaptive behavior can be seen when examining comorbid diagnoses. The diagnosis of MR/ID is often paired with specific developmental disabilities and syndromes, for example, seizure disorders, cerebral palsy vision impairment, hearing loss, Autism Spectrum Disorder, Down syndrome, or Fragile X syndrome. Each additional diagnosis maintains varying adaptive deficits even though their cognitive levels may be the same. For example, a study compared parents’ perceptions of supports required and attained to function with
their child’s disability across autism and Down syndrome (Siklos & Kerns, 2006). Within the study, children were diagnosed with severe forms of autism and Down syndrome, associated with life-long delays in functioning. However, the dissimilarities of the syndromes include a lack of social reciprocity in children with autism that is not present in children with Down syndrome (Rodrigue, Morgan, & Geffken, 1992; Siklos & Kerns, 2006).

Siklos and Kerns (2006) administered a modified version of the Family Needs Questionnaire (Kreutzer, Complair, & Waland, 1988) to a sample of 56 parents of children with autism and 32 parents of children with Down syndrome. The Child Characteristics Questionnaire (Siklos & Kerns, 2006) was administered only to parents in the autism group; no form of adaptive behavior was administered to the Down syndrome group. Although multiple regression analysis found significant group differences from the parents of children with autism, endorsing a slightly greater number of child-centered needs rather than parent-centered F(1, 86) = 4.173, b = 0.195 p < 0.05, a more stringent Bonferroni correction would suggest no fundamental differences exist. While 93% of parents of children with autism reported that they were not receiving adequate support for their child’s therapies, only 63% of parents of children with Down syndrome felt this need was unmet. To validate this research, adaptive behavior clarification is necessary. The autism group may have reported a greater need because each group’s sample had widely varying adaptive abilities. For example, past research has speculated that children with Down syndrome provide their parents with more positive social reinforcement than children with autism (Rodrigue et al., 1992). Specifically, parents who do not receive cues or feedback from their child may experience added stress (Siklos & Kerns, 2006).
Therefore, research that does not specify coexisting diagnoses within their sample introduces an additional confounding variable, as was the case in both Smith and colleagues’ (2001) and Baker and colleagues’ (2003) experiments. However, measurements of adaptive behavior are sensitive to variations in functioning. Therefore, a simple way to avoid introducing error to a study created by diagnosis specific confounding variables is to account for adaptive behavior within the study.

The previous sections reviewing the literature on stress in families of children with MR/ID is an important foundation for the following discussion of coping strategies. Many variables may contribute to the production of stress for parents of children with MR/ID; however, the type of coping strategies parents utilize will impact the amount of increased or reduced stress as mentioned earlier.

*Family Coping and Adjustment with a Child with MR/ID*

Coping is difficult to operationalize because it is a very ambiguous and complex concept, encompassing techniques intended to equip a person with effective ways to deal with life’s challenges. Coping strategies are ways that an individual utilizes available resources for stress reduction (Lessenberry & Rehfeldt, 2004). Research literature consistently advocates appropriate family social and environmental resources, such as support from extended family, friends, and professional help, and access to available leisure time, community programs, and family focused services (Hassal et al., 2005; Hill, 1949; Luckasson et al., 2002; McCubbin & Patterson, 1983; Siklos & Kerns, 2006). Additional resources assist parents in efficiently completing all the extra time and energy required for feeding, toileting, and taking the child to and from doctor appointments. It may become difficult for parents to balance the demands of the child’s and the family’s...
normal life against the demands of the disability. The goals of many family coping strategies are to develop or maintain family-based resources, accommodate new family demands by adjusting the structure, reduce the stressors or negative emotions, and achieve a balance in family functioning (Jacques, 2003; Lessenberry & Rehfeldt, 2004; McCubbin & Patterson, 1983). To accomplish these goals, various mechanisms including problem-solving, reducing negative emotions, or active and passive modes are utilized. Protective factors promoting positive family coping are open communication among family members, supportiveness of each other, meaningful relationships, problem solving skills, outside resources, and appropriate parent-child roles characterized by set boundaries and consistent workable rules (Blacher, 1984).

Research suggests that specific coping strategies do not differ among parents of children with MR/ID and parents of children developing typically. Lopez and colleagues (2008) found that parents of preschoolers with delays (M=49.00; SD=14.45) did not differ in coping strategies compared to parents of children without delays (M=43.47; SD=9.90), (t(44)=-1.394, p=.17). This finding prevailed, despite the fact that parents with children having developmental delays had reported higher stress levels, lower income levels, and more maladaptive behaviors presented within their children. Within this study, parents completed the *Family Stress and Coping Interview* (Nachshen, Woodford, & Minnes, 2003) as a measure of parental stress, and the *Ways of Coping Scale Revised* (McColl & Skinner, 1995) to ascertain parental coping strategies. Although this study brings insight to coping strategies, it may not generalize to the average population due to a small number of variables as possible predictors of stress. The relationship between parental coping and psychological well-being is complex, and our understanding of these
relations has been curtailed by the limitations prevalent in much of the coping research. For example, studies often have assessed the relationship between parental coping and psychological distress and neglected positive emotional states known to play a role in psychological and physical well-being (Pottie & Ingram, 2008).

Hassel and colleagues’ (2005) investigation found that the strong correlation between family support and parenting stress were mediated by parental locus of control. Parent-child interactive stress may arise from a combination of difficult child characteristics and parental cognitions (Hassall et al., 2005).

*Parent adjustment to their child’s MR/ID diagnosis.* Before parents can utilize existing coping strategies to continue balanced family functioning, they must first adjust to the diagnosis. It is theorized that the way that family members will react may depend on the child's age when the diagnosis is made, previous experience and knowledge of the disability, family values and beliefs, family structure, mental and physical health of parents, and other stressors, such as housing and finances (Jacques, 2003).

Several researchers have hypothesized that most parents are apt to follow similar patterns or predictable stages, even though the models differ in terminology. Parents’ adjustment to their child’s diagnosis of MR/ID was summarized in seminal research by Blacher (1984) as a series of stages. First, initial crisis responses occur, and then parents become emotionally disorganized, followed by emotional reorganization, which leads to positive coping. The initial stage may be viewed as a coping process with initial shock that turns into emotional disorganization of feelings of guilt, disappointment, anger, or lowered self-esteem. Emotional adjustment is then hallmarked by adaptation and acceptance. Jacques (2003) indicates similar bereavement reactions of initial numbness
and shock, followed by overt grief, and then the development of coping strategies. The amount of time a parent requires in each stage of acceptance varies according to mediating coping resources. Therefore, each stage can endure for a day or years (Blacher, 1984; Haveman et al., 1997; Jacques, 2003; Lessenberry & Rehfeldt, 2004). Longitudinal research on the stages varies greatly, and specifics of each stage are typically characteristic of each individual study, which is difficult to generalize. However, general theoretical approaches are consistent across each study.

Research on family adaptation with the inclusion of a child with MR/ID typically follow theoretical approaches that consider coping processes, supports, diagnosis, behaviors, adaptive behavior, age, and external pressures. Therefore, the following theoretical models will compartmentalize the adaptation process.

Theoretical Model: Family Theory

The nature and variability in family responses to parenting a child with a disability generally abide to theoretical premises of family theory. Family theory encompasses 3 separate theories, each sharing structural components and utilizing environmental and interrelationship aspects in explaining families involving children with MR/ID and their family adjustment. The main theoretical approaches, which guide most family research, are family ecological system theory, family stress theory, and family developmental theory. In brief, family ecological systems recognize the family as an open, interactive system with direct and indirect influences, operating according to a generalized set of principles (Bristol & Gallagher, 1986; Turnbull et al., 1986). While this theory is typically used in family counseling and therapy, parts of it are extended to prediction models within family stress theory. Family stress theory refers to family
adaptation research models that address a family’s account of crisis, stress, and adaptation. In general, family stress theories propose that a family’s adaptation to a crisis event, such as having a child with MR/ID, is explained by multiple factors, including the nature of the crisis event, the internally and externally based resources available, and the meaning ascribed by the family members to the event (McCubbin & Patterson, 1982). Family developmental approaches aid in the understanding of difficulties of particular families, potential stresses, crisis points, reactions, and needs (Baum, 2006; Holman & Burr, 1980; Turnbull et al., 1986). Also, this theory guides considerations as to why assistance and services are necessary at particular life points. Family developmental approaches will be utilized within the present study, as they provide a salient theoretical base, furthering current research on parental stress and family functioning with families who have children with MR/ID. Therefore, the following sections summarize the development of each approach, outline operational definitions, explain models within each theory, and provide information as to the appropriateness of utilization in the present study.

*Family Ecological Systems Theory*

Family ecological systems theory emphasizes adaptation as an interacting force of all individuals within the family unit. This approach examines how the child’s diagnosis shapes individual family well-being and functioning (Bristol & Gallagher, 1986, Head & Abbeduto, 2007). Contextual variables such as socioeconomic status and access and availability to resources are unique to each family’s functioning. Events that cause stress for one family member in turn affect other family members, resulting in multiple ripple effects over time. This perspective has been pivotal in expanding the focus of
contemporary family research beyond a simplistic assumption of unidirectional effects of specific child characteristics on family or parental adaptation.

Family ecological systems theory originates from the work of individuals like Minuchin (1974), Bowen (1978), and Bronfenbrenner (1979). In the 1960s, Bowen first conceptualized family members as emotionally interdependent and functioning in reciprocal relationships with one another; the functioning of one member cannot be completely understood if taken out of the context of the functioning of the people closely involved with him or her. This view paralleled Minuchin’s (1974) view of a family as an interactive unit, what affects one member affects all members. Throughout the 1970s, family ecological systems theory slowly matured as a descriptive theory from Bowen and Minuchin’s concepts while incorporating seminal work from Bronfenbrenner (1979) on ecological systems. Bronfenbrenner contributed greatly to the formation of a working model that provides a context to understand how various events directly and indirectly influence psychological and behavioral development throughout an individual’s life (Brody et al., 1994; Bronfenbrenner, 1979).

Ecological systems theory. Bronfenbrenner’s ecological systems theory implies that the functioning of individuals depends on how they relate to and influence the overall environment and how they deal with the exerted influence from the overall environment. The model of ecological systems theory conceptualizes development as interacting concentric systems that progressively become more distant environmental relationships; proposing that individuals and families exist not in isolation but in the context of encompassing relationships within society (LoBindo-Wood, 2008).
The basic structure consists of 4 main systems, each layer fitting on the next, while being divided into smaller subsystems (Seligman & Darling, 1989). The center layer or microsystem is the individual interpersonal interactions. For example, a child’s microsystem will include any immediate relationships, such as his or her immediate family and school or daycare. These interactions have an effect on how the child grows, and in turn how the child acts or reacts to these people will affect his or her response treatment. The next system, the mesosystem, includes interrelationships among settings. This describes how the different parts of a child's microsystem work together for the sake of the child. For example, if a child's family takes an active role in a child's treatment, it will help ensure the child's overall growth. In contrast, family conflict and stress will hinder the child's growth. Still broader, the exosystem maintains quality of interrelationships among settings as influenced by forces in which the child engages, including the other people and places that the child may not interact with often but still affect him or her, such as extended family members or the community. Finally, the macrosystem presents broad ideological and organizational social forces; for example, remote sets of people and things, the national government, cultural values, the economy, or war to name a few that indirectly influence the child (Bronfenbrenner, 1979). Figure 1 depicts the ecological systems theory with the star symbol denoting an individual. The individual then interacts with each level to a routine or typical interaction behavior for each. By including outer layers, the ecological system allows the exploration of the effects of services and society.
Theoretical approaches of family ecological systems developed by adjusting the ecological systems model to reference the entire family unit and interactions among environmental systems rather than an individual within a family. Therefore, family ecological systems also recognize the family as an open, interactive system with direct and indirect influences (Bristol & Gallagher, 1986; Turnbull et al., 1986).

*Family ecological systems theory.* In this theory, the family is considered a main system unit divided into subsystems of marital, parental, sibling, or extended family. Each subsystem is engaged on each ecological level, as in the levels previously discussed from Bronfenbrenner (1979). According to Bowen (1978), each member within a family ecological system has an individual role to play and subsystem rules to respect. Within the boundaries of the system, patterns develop as certain family member's behaviors are caused by and in turn influence other family member's behaviors in predictable patterns.
Maintaining the same pattern of behaviors may lead to balance or to dysfunction within the family ecological system. Therefore, family ecological systems theory is a general template of interconnected and interdependent individuals, none of whom can be understood in isolation from the system.

Aspects of the family ecological model can be seen within the family stress theory. Family ecological models do not directly deal with parent stress; they simply exemplify a typical cohesive working family when all stress levels are even. Therefore, minimal empirical research has been conducted on the application of a systems framework on a family with a child with a disability (Head & Abbeduto, 2007; Turnbull et al., 1986). On the other hand, research utilizing family stress theory conceptualizes families of children with MR/ID as in a crisis state and is able to create models including stress from the crisis to extend the familial adaptation literature (Hodapp & Dykens, 2003; McCubbin & Patterson, 1983).

*Family Stress Theory*

The original family stress model was developed by Reuben Hill (1949) after World War II and deemed the ABCX model. Hill’s seminal work was based on family response to war, war separation, and reunions (Hill, 1949; LoBindo-Wood, 2008). After the war, the ABCX model was maintained and frequently utilized for over 30 years. The ABCX model identifies major contributors to family stress, buffers against stress, and agents that cause family crisis (Hill, 1949; McCubbin & Patterson, 1983; Xu, 2007).

*ABCX model.* Within the original model, each letter symbolizes an area, which contributes to the overall interaction of the family’s life. The letter A represents a stressor, which then interacts with B, the available resources or adequacy and inadequacy
of family organization. Both then interact with C, the subjective meaning assigned to a stressor from an individual within the family. All of which combine to produce X, the crisis (Hill, 1949; McCubbin & Patterson, 1982; Xu, 2007). Figure 2 depicts the interaction of the variables in the ABCX model. Family stress and adjustment to crisis is influenced both by the supports in place to deal with the situation and its interpretation. Change came to Hill’s model in the 1980s, as McCubbin and Patterson (1983) revamped the ABCX model and introduced the Double ABCX model.

Figure 2

_Hill’s (1949) ABCX Model_

Double ABCX model. The Double ABCX model of adaptation is an integrated framework emphasizing family strengths, while linking steps of assessment, outcomes, and intervention. Over time, families adapt to altered circumstances and are affected by new stressors, resources, and meanings that have been integrated into the family (LoBindo-Wood, 2008; McCubbin & Patterson, 1983). The Double ABCX model is often utilized in MR/ID family research (Hodapp & Dykens, 2003; Xu, 2007). Adjustments to the original model take into account the frequent occurrences of stressful events over time.
The stressors that families deal with often change and accumulate in a pile-up of stressors and strains over time (LoBindo-Wood, 2008; McCubbin & Patterson, 1983). This version of the model includes a feedback loop, where the outcome of one situation feeds back into the next situation. Therefore, the ‘double’ modification represents the continual reoccurrence of these interactions with the changing of resources and individual perceptions (Xu, 2007). As explained below, the Double ABCX model also adjusted each factor’s reference point.

**Family Demands: Pile-up (aA Factor).** McCubbin and Patterson (1983) relabeled the ‘A’ factor as family demands, aA, rather than a stressor. Family demands were amended to refer to all the hardships that accompany the stressor and the pileups or residuals of family tension (McCubbin & Patterson, 1983).

**Family Adaptive Resources (bB Factor).** Existing, new, and expanded resources that allow the family to adapt and meet demands and needs are labeled as the bB Factor (LoBindo-Wood, 2008). Types of resources considered in the model are self-reliance, family communication patterns, and social support from family members, friends, and community networks (McCubbin & Patterson, 1983). Expanded family resources are strengthened in response to the crisis or as a result of the pile-up of stressors by preventing an event from creating further crisis.

**Family Definition and Meaning (cC Factor).** The family’s perception of the stressor is determined by the significance and meaning that the family member attach to the total situation of the stressor and the pile-up of its results and is labeled as cC Factor. By comprehending the meaning of a stressful situation, the impact can be reduced, and coping and new resources can be facilitated to strengthen the family unit (McCubbin &
Patterson, 1983). Coping then assists in decreasing situational stressors and increasing family movement toward adaptation and adjustment (LoBindo-Wood, 2008).

*Family Adaption Balancing (xX Factor).* The outcome of the Double ABCX model is then xX, adaptation. This representation means that the family has accommodated, compromised, regulated, and given meaning to a crisis, and there is a balance between one of the levels with another (LoBindo-Wood, 2008; McCubbin & Patterson, 1983). Figure 3 depicts the interaction of the Double ABCX model.

Figure 3

*McCubbin & Patterson’s Double ABCX Model*

*Disadvantages of the Double ABCX model.* Although this model seems to account for many adaptation issues, it has yielded conflicting results in determining stress factors; possibly due to differences in population samples, methodology, and statistical analysis. However, one challenge is the lack of consensus on the definition of various components in the model and the resulting use of different instruments as measures of each component (Minnes, Woodford, & Passey, 2007). Another notable limitation is that many research studies select and study specific concepts from the model rather than applying
the whole Double ABCX model. Other studies cannot find reasonable evidence that the adjustments in the Double ABCX model improve prediction outcomes more than the original ABCX model.

In order to contrast the ABCX and the Double ABCX models, Nachshen and Minnes (2005) utilized a structural equation model in family adaptation. Structural equation modeling supported stronger evidence for the ABCX model in both parental stress and control groups. A linear relationship was found in which the parents’ well-being and resources mediated the relationship between the stress of child behavior problems and the outcome of empowerment. Therefore, parental empowerment was adequately explained using the original ABCX model of family functioning (Nachshen & Minnes, 2005). The Double ABCX model had similar fit indices; however, the ABCX model was more parsimonious, indicating it as a better model when interpreting parent stress. Although due to the nature of structural equation modeling, Nachshen and Minnes’ (2005) study may be subject to human error limitations. Within structural equation modeling research a model is chosen based on theory and may not be the only accurate representation of the data. Alternative permutations of the measures and pathways and indicators underlying latent variables may yield a truer or better fit. None the less, this is still valuable research indicating a flow in a newer, more widely used family stress theory.

In addition, most studies utilizing the Double ABCX model have been cross-sectional. Within longitudinal studies, a family has to respond to a complex array of protective and stress variables to fulfill its care-giving functions alongside its other family functions. Family stress theories bring important issues to the literature, but they yield
conflicting results, and though they utilize a feedback loop, they do not account for life stages. Family developmental theories, on the other hand, incorporate both family system theory and family stress theory for a comprehensive overview of difficulties in potential stresses, crisis points, reactions, and needs of the family (Baum, 2006; Holman & Burr, 1980; Turnbull et al., 1986). Also, this theory guides considerations as to why assistance and services are necessary at particular life points, where as family stress theories do not.

**Family Developmental Theory: Family Life Cycle**

The family developmental approach experienced a great deal of growth in the 1960s, forming from Hill’s (1949) initial contributions of family stress (Holman & Burr, 1980). However, during the 1970s, most of the theoretical innovations consisted of a limited conceptual framework, emphasizing life span issues rather than the family processes (Holman & Burr, 1980). For example, most work of this time focused on developmental stages as a checklist of what should happen within a stage, such as Piaget’s cognitive development stages, which are described in depth in an upcoming section. When the family process is examined, all aspects of stage theories are incorporated from individual stages to a collective stage, including the individual family members with addition of the transitions between the stages. Therefore, family developmental theory focuses on the family moving through a series of stages and transitions all of which influence individual stress levels within the family system (Baum, 2006; Turnbull et al., 1986). The main model of family developmental theory is the family life cycle model.

The family life cycle model is a series of developmental stages in which the family engages together while each member conducts his or her own developmental task.
related to the entire family’s stage in the life cycle (Seligman & Darling, 1989). Terms incorporated within the life cycle theory are developmental stages, transitions, and structural, functional, and sociohistorical changes. Each term and its relation to past theories will be examined in the following sections.

*Structural, functional, and sociohistorical changes.* Family life cycle theories incorporate family ecological systems views. For example, this approach is hallmarked by utilization of systematic layers within the family unit from interactions between subsystems to society and environmental layers. These layers influence each developmental stage. The term structural then consists of environmental membership, cultural style, and ideological or coping style, while sociohistorical encompasses cultural, economic, and political trends (Turnbull et al., 1986).

In contrast to family system approaches but similar to family stress theories, family developmental theories incorporate functions as products of family interaction. These family functions represent the ability of each individual family member to engage in an interaction or stressful situation with each other (Turnbull et al., 1986). How families cope with life stressors at different stages will depend on what life cycle issues family members face at the time (Baum, 2006).

*Life cycle developmental stages and transitions.* Developmental stages can be visualized as a series of plateaus. Each stage has different functions and specific developmental tasks (Seligman & Darling, 1989). The entire family may be considered to be in a specific family developmental stage based on the presence and age of the first born child. Various theorists have identified a number of developmental stages to explain a family’s progression through a life span (Seligman & Darling, 1989). The most
supported stage sequence when a disability is present is the 7 stage family life cycle by Olson and colleagues (1984); the stages are couple, childbearing, school age, adolescence, launching, post-parental, and aging (Baum, 2006; Olson et al., 1984; Seligman & Darling, 1989; Turnbull et al., 1986). When a disability is introduced to the family, the entire family stage and its further transitions may be arrested due to the child’s developmental lags (Baum, 2006). A child with MR/ID progresses differently through individual developmental stages from infancy to adolescence, and in turn the developmental stages are mediated by the quality of family relationships and the integrity of family structure. The following paragraph describes each stage and stress that a family with a child with MR/ID may encounter.

The first family life cycle stage, the couple stage, depicts the formation of a family before a child is born; parents begin to form expectations of ideal children. Next, the childbearing stage is characterized by a child entering the family and his or her early childhood. Within the childbearing stage, family stress may result from obtaining a diagnosis, making emotional adjustments, and informing other family members (Turnbull et al., 1986). The third stage, school age, is characterized by the family venturing beyond the boundaries of the family; here, socialization and educational attainment are prioritized. With parents of children with MR/ID, school age depicts difficulties clarifying personal views on educational attainment, dealing with the interaction of the child and his or her peers, and arranging childcare and extracurricular activities (Turnbull et al., 1986). The adolescence stage is next marking a period where children begin to separate from their parents. Here, peer acceptance becomes prominent. Within this stage,
parents are adjusting for the chronicity of the child’s disability, dealing with the child’s sexuality issues, and planning for the child’s vocational future (Turnbull et al., 1986).

The fifth stage, launching, follows as adolescents are beginning to leave home and establish identities and roles outside of the home. Parents of children with MR/ID within the launching stage often acquire stress from decisions on appropriate living arrangements and adjusting to the family’s continuing responsibility (Turnbull et al., 1986). The final two stages of the family life cycle, post-parental and aging, characterize a time of self-enhancement. The family life cycle theory suggests the child leaves the initial cycle during the launching stage to begin the cycle again with his or her own family. Within post parental and aging stages, parents often find stress in reestablishing their own personal space and interact with service providers to determine continual care for their child (Turnbull et al., 1986).

Transitions are normative, anticipated, short-term, adjustment periods between each of the family life cycle stages. Mastering the skills and milestones of each stage allows families to move from one stage of development to the next. However, if skills are not mastered, the family may still move on to the next phase of the cycle, but they are more likely to have relationship difficulty with future transitions. For example, unresolved issues may reoccur throughout the stages. Transitions can upset the homeostasis of the family and be a major source of stress (Baum, 2006; Seligman & Darling, 1989). They often demand change, which may be marked by feelings of uncertainty, anxiety, and a sense of loss of the process of adjustment, reorganization, consolidation, and adaptation, which disturbs previous family behaviors, taxing the families coping abilities.
Ages for appropriate stage development are not stressed in this theory since each
group is individualized and subjective to many extraneous variations, for example, loss
of a job, death, or presence of a disability. To understand a child’s developmental lag and
an appropriate placement across the family life cycle, one must examine typical child
development. Therefore, theories of individual child development, such as Piaget’s
developmental stages, may aid in the understanding of how the presence of a child with
MR/ID shapes the family’s place in family life cycle stages. The following section
describes Piaget’s developmental theory and how it fits within the family life cycle stages
to form a normative view of family life cycle stage progression.

Piaget’s developmental stages of childhood. Piaget’s developmental theory is
based on the premise that for children who develop typically, abilities increase through
the construction of cognitive structures by seeking, selecting, interpreting, and
reorganizing information obtained through environmental interaction (Piaget, 1963;
Zimbardo et al., 2000). These stages can serve as a blueprint of milestones for a child
developing typically. According to this theory, children are viewed as proactive agents in
their learning as they initiate encounters with the environment to gain knowledge. Within
children developing typically, information is organized effectively and adjusted to
accommodate new environmental input (Zimbardo et al., 2000). Piaget (1963) proposed 4
innovative stages of a child’s normal progression and cognitive growth through
childhood.

The first stage of Piaget’s cognitive development coincides with the childbearing
family life cycle stage. The sensorimotor stage begins at birth until the age of 2, and these
children live in the ‘here and now’ and use sensory and motor abilities to form
intelligence. The preoperational stage, also coinciding with the childbearing stage, comes next, between the ages of 2 and 7. In this stage children advance in the mental representation of objects, and their refinement of figurative knowledge and experiences help shape and expand language, mental imagery, and symbolic thought (Zimbardo et al., 2000). With the exception of profound MR/ID, children with MR/ID progress with little lag through these stages (Luckasson et al., 2002).

The next Piagetian stages are increasingly difficult for children with MR/ID, as they enter the school age stage of the family life cycle, where socialization is stressed. The third Piagetian stage, concrete operational, begins between 7 and 12 years of age, as children developing typically begin to reason logically about concrete events. This stage alone requires a great deal of growth and complexity.

The formal operational stage, beyond 12 years of age, is hallmarked by abstract and hypothetical thinking. This stage brings on the independence and maturity known as adolescence in the family life cycle theory. Adolescence is also a period of time when social peer relationships become very important. Individuals with MR/ID are markedly different than their peers in the adolescence stage, and creating and maintaining meaningful positive peer relationships is challenging.

Both the family life cycle and cognitive developmental stages follow similar progression of child development. The main difference in these developmental stage theories is that the family life cycle stage expands beyond the development of the child to factor in external events that occur at each stage and family interaction and functioning through each development and event. Limitations within both stage models are readily apparent when considering individuality, and influential, societal, and cultural beliefs of
parents’ responses. Researchers such as Turnbull and colleagues (1986) and Seligman and Darling (1989) have translated typical family developmental research to accommodate the unique stress factors of families with MR/ID. However, it is nearly impossible to operationalize all variables and follow whole families across multiple life spans. That implies a need within the literature to ameliorate parental stress research within specific developmental areas and their transitions on the level of external supports and parental stress attained across each developmental level.

*Justification of theory use.* To view the entire family as a process that changes over a lifespan is to suggest that an event cannot lead to a crisis as stress theory models propose, but rather there are several interacting factors initiating and controlling stress levels across the family, which lead to positive adaptation. All of the family theories bring perspective to the process of a family stabilizing and adapting, from family systems theory conceptualization of an interacting family unit to stress theory’s role of stress development and coping abilities of the family. The aim of using any model is to move its inherent ideas from testing to practice. Prediction models need to be tested to determine which concepts, in what order, best explain family adaptation. The life cycle framework aids in the understanding of difficulties of particular families, potential stresses, crisis points, reactions, and needs (Baum, 2006). Also, this theory guides considerations as to why assistance and services are necessary at particular life points. Developmental stages justify the division of age into groups for research to replicate similar life experiences for children developing typically.

The following section highlights empirical research of family stress and adaptation. Within the present discussion, family developmental approaches provide a
salient theoretical base, furthering current research on parental stress and family functioning with families who have children with MR/ID.

Demands Across Childhood

The age of the child with MR/ID is an important variable to consider when discussing parental stress. Due to fluctuations of adaptive behavior needs, service needs, time demands, and care demands, parents’ stress levels may fluctuate at different stages of their child’s lifespan (Haveman et al., 1997; Heller, Hesieh, & Rowitz, 1997). For example, the entrance to school and the onset of puberty are monumental adjustments that occur within specific stages of school age and adolescence, respectively. These childhood development and family changes affect children’s functioning and parents’ expectations and actions differently through the various family life cycle stages.

Parents’ expectations and beliefs often begin before their child is born and are modified through interactions with the developing child (Kuhn & Carter, 2006). For many families, recognition of a disability means a sudden and irreversible replacement of present and anticipated images of the child with one of a child with a disability. This replacement image most likely will not represent the child accurately, but it is created from family member’s beliefs and past experiences of individuals with disabilities. The initial turmoil that parents feel can later give way to sadness, a feeling of desolation and isolation, and a longing for a normal baby. A discrepancy between what parents expect of a child’s development and what actually takes place may be devastating (Blacher, 1984). However, people are not static, and eventually relationships build between the parent and child with MR/ID. These disparate feelings revolve in a continuous process throughout the family life cycle.
Children with MR/ID reach developmental milestones in atypical patterns which are often delayed. The continual delayed achievement of each developmental milestone may become a frequent source of heightened stress. Parental expectations and interactions fall generally in line with developmental views and perspectives. Walker (2000) concluded that the presence of a child’s disability and the stress it contributes to the parents are perceived differently across the child’s ages. For example, parental expectations are different when their child is 6 years old as compared to 14 years old; also, the understanding of the disability and the child’s goal attainment is different at various ages for parents. Therefore, the parent’s perceived stress when the child is 6 years old is different than when the child is 14 years old.

Walker (2000) measured parent stress through completion of the Parental Stress Index (PSI; Abidi, 1995) from 136 parents of children who are developing typically or diagnosed with ADHD or Down syndrome. Four separate hierarchical multiple regressions on the PSI domains were conducted to determine whether there were different patterns in the contributors to variation in child-related and parent-related characteristics of stress between mothers and fathers. Although the main goal of this study was contrasting mothers’ and fathers’ parental stress, it included implications of where that stress is derived. For example, the index on the PSI, helpfulness of informal social support, was a significant predictor of parent-related stress for both mothers and fathers. Most importantly results displayed the child’s age as a significant predictor in mothers’ parenting stress and accounted for an additional 11% of the variance beyond that of the child’s disability status. Within Walker’s (2000) survey, parents of younger children reported more stress than at other child ages. However, the pattern of fluctuations of
parental stress across the age of children with MR/ID has not been extensively researched.

Current developmental research endorses critical periods in which a child is theorized to achieve developmental milestones (Baum, 2006; Turnbull et al., 1986; Zimbardo et al., 2000), such as beginning to walk or attending school. However, past research that examined the age of children and parent stress has not always followed developmental perspectives when determining what ages should be grouped together and examined. To exemplify this, consider a study that combines children ages 10 to 16 as one group. In doing this, it is assumed that a parent of a 10 year old faces the same challenges of a 16 year old. Within the minimal parental stress research based on the child’s age, many studies address key points of childhood combined together rather than pinpointing the peaks and valleys that occur across children’s ages. The previously mentioned studies, Haveman and colleagues (1997) and Walker (2000), both used age brackets that do not coincide with family developmental theories to denote stages of life. Haveman and colleagues (1997) analyzed 4 groups of individuals ages 0-9, 10-19, 20-29, and 30+, while Walker (2000) separated groups of children as 0-4 or 5-12 years old. Both studies may benefit from creating groups in line with the family life cycle model. This adjustment would allow an in-depth view without clustering ages containing different developmental views and perspectives.

Previous research has not examined closely the differences in parent stress from shifts that occur throughout the childhood of their child with MR/ID. The following sections examine age specific studies on family adaption by categorizing relevant research into 3 main sections, according to the age of the child with a disability in line
with the family life cycle model of developmental theories. The first discussed stage is Childbearing (referred to as Preschool), which includes research on families of children with disabilities from birth to 7 years old, followed by the School Age stage with children ages 8 to 12, and finally the Adolescence stage with children ages 13 to 21.

Preschool stage: Ages 0-7

Between birth and the age of 7, children develop typically through experiences with sensory and motor abilities, language, mental imagery, and symbolic thought (Piaget, 1963). Throughout the early years of a child with mild to moderate MR/ID, a substantial visible difference between children and their peers is not evident. When children attend school, higher level cognitive demands are placed on the child, making the difference more apparent. Research suggests when the child is young, family stress focuses mainly on parental interactions with each other and locating appropriate services and education for their child.

Initial resources. Haveman and colleagues’ (1997) longitudinal study indicated that families in the early stages of a child’s MR/ID diagnosis generally need assistance with developmental and medical issues, such as how to attain supports, financial assistance, and information regarding the disability and how to interact with their child in order to assist in his or her development. Although the aim of the Quinn, Carr, Carrol, and O’Sullivan (2007) study was to evaluate the effectiveness of the Parents Plus program, they identified key informational skills that parents of children with MR/ID may identify for stress reduction. The Parents Plus program services families of preschool children with developmental disabilities and significant behavioral problems in Ireland. The study surveyed 22 families treated in the program and 19 families with no
treatment from a waiting list. All children in the study were between the ages 4 to 7 and presented with a significant cognitive delay. Parents identified valued skills by rating for relevance and importance on a 5-point scale. Key skills included catching your child being good ($M = 4.43, SD = 0.64$), play skills ($M = 4.46, SD = 0.64$), using praise and encouragement ($M = 4.53, SD = 0.64$), setting consequences ($M = 4.13, SD = 0.64$), active ignoring ($M = 4.27; 0.88$), and using time-out or sanctions ($M = 4.20, SD = 0.77$).

The Parenting Stress Index (PSI; Abidin, 1995) and the Questionnaire on Resources and Stress short form (QRS-F; Freidrich et al., 1983), which measure similar aspects of the stress process, were completed by the parents before and after the intervention. Both measures displayed similar results following the program intervention, indicating a decrease of stress (Quinn et al., 2007).

Parents of children at this early stage may lack information regarding their child’s diagnosis and feel very dependent on professionals (Siklos & Kerns, 2006; Quinn et al., 2007). That is one reason why early interventions are important, and parents can gain empowerment and alleviate their own stress. Services to very young children are often home-based, introducing additional service workers into the home. The presence of home services and the amount of support from these professionals may contribute to stress in a positive or negative way. For example, professionals can become an additional resource, providing positive support for appropriate interactions. Negative stress may occur when families may feel home-based services are an intrusion on their privacy or parents take a subordinate role to the professionals in the care of their child. It is important for professionals to understand a family with a child with MR/ID’s vulnerability at this time. As the Preschool stage resolves, transition to the School Age stage occurs. The focus
shifts away from the importance of home-based support to community support and perceptions.

*School Age Stage: Ages 8-12*

As the child enters the next stage, School Age, the main focus shifts away from home, and children developing typically begin to form social connections in the community. This stage begins at age 8, the age children are required to attend school by the United States government. Entrance to school places new demands for self-regulated behavior and age-appropriate social skills (Neece & Baker, 2008). As children are expected to interact more with their peers, deficits in children with MR/ID become more readily apparent, and the gap of cognitive ability and social acceptance from their same age peers widens. For example, as children develop typically, they are taught at school to reason logically about concrete events (Zimbardo et al., 2000); however, children with MR/ID may find this task difficult (Luckasson et al., 2002). Social skills, learned behaviors that enable a person to interact successfully with peers and adults and to avoid socially unacceptable responses, develops innately with some peers. The difficulty in social situations with children with MR/ID often adds additional stress to parents who are just beginning to bring their child into the community for school or activities.

*Social skills.* Examples of social skills are sharing, helping, requesting help, initiating relationships, and giving compliments (Neece & Baker, 2008). Relative to children without a developmental disability, children with MR/ID exhibit subordinate social skills (Luckasson et al., 2002). Neece and Baker (2008) found social skill deficits in children with MR/ID to be a significant predictor of parental stress. Various parental stress factors and social skill deficits were examined in mothers of children developing
typically (n=115) and children with MR/ID (n=74). Variables were determined, according to parent completed empirical questionnaires. The adaptive behavior variable was obtained through scores from the Vineland Adaptive Behavior Scale (VABS; Sparrow, Balla, & Cicchetti, 1984), the behavior variable from the Child Behavior Checklist (CBCL; Achenbach & Rescorla, 2001), and the parent stress variable from the Family Impact Questionnaire (FIQ; Donenberg & Baker, 1993). Also, demographic information was collected, and a Stanford-Binet Fourth Edition (Thorndike et al., 1986) was administered to all of the children to determine an intellectual status variable. All data was collected twice when each child was both 6 and 8 years old. The variables were then entered into 4 separate hierarchical regressions.

Results indicated that the importance of social skills increases as children mature. Initial analysis at age 6 determined that both children’s social skills and behavior problems accounted for unique variance above and beyond child intellectual status in parenting stress. The second analysis showed the interaction between behavior problems and social skills was also a significant predictor of parenting stress at age 8 but not at age 6. As the children aged, social skill deficits became an even stronger predictor of parental stress, beyond the stress that was caused from child behavior problems (Neece & Baker, 2008). The final analysis supported a bidirectional effect of early social skill increases, predicting decreases in parenting stress over time, while increases in parenting stress predict a depletion of child social skills over time. Therefore, the contribution of deficits in social skills may increase levels of parenting stress as children age.

The impact of social skill impairment for school age children on parental functioning was also seen in DeBildt and colleagues’ (2005) study. They examined
behavior problems on adaptive functioning and the causal relationships between behavior problems, adaptive functioning, and level of education in children with mild learning problems (n=121) and severe learning problems (n=65) in the Netherlands. Adaptive behavior areas compared were derived from scores on the Vineland Adaptive Behavior Scale (VABS; Sparrow et al., 1984), behavior problems from the Child Behavior Checklist (CBCL; Achenbach & Rescorla, 2001), and autistic behavior problems derived from the Autism Behavior Checklist (ABC; Krug, Arick, & Almond, 1980). Children in schools for mild learning problems had higher VABS scores and lower CBCL and ABC scores. The ABC had a significant effect on the total age equivalent of the VABS in schools for severe learning problems and the CBCL in schools for mild learning problems. A direct effect of the ABC and CBCL total scores on the VABS age equivalent was found, together with a direct effect of the VABS age equivalent on level of education. Therefore, autistic and general behavior problems directly influenced the level of adaptive functioning. Adaptive functioning continues to be a stress indicator as children age and begin adolescence around 13 years old.

Adolescence Stage: Ages 13-21

The Adolescence stage has been deemed as one of the most critical phases in the lives of individuals with MR/ID and their families (Silverberg & Steinberg, 1990; Todd & Jones, 2005). Once adolescence occurs, young adults developing typically can form abstract concepts (Zimbardo et al., 2000); however, this is a continual struggle for young adults with MR/ID. At this age, an awareness of the self as disabled and different becomes more apparent. Despite monumental transitions, often current research overlooks parental adjustment and stress when the child is in adolescence. Most parent
stress research for this age group is qualitative in nature, perhaps due to the cut off age of 12 on the PSI, the most frequently utilized stress measure. Although an adolescent version, the Stress Index for Parents of Adolescents (SIPA; Sheras, Abidin, & Konold, 1998) was published in 1998, the measure has not yet been adopted within research literature due to its lengthy administration and weak correlation with the PSI. However, the Short-Form of the Questionnaire on Resources and Stress (QRS-F; Friedrich et al., 1983) is normed to include this population but is utilized by few studies including adolescents.

Adolescence is often paralleled by and embedded within the mid-life phase for parents (Todd & Jones, 2005). Thus, during the middle years of parenting, parents may face the dual management of their child’s and their own life transitions. Todd and Jones (2005) found family transitions to be interrelated between mothers dealing with mid-life transitions and their children with MR/ID reaching adolescence. Although the study was descriptive in nature, Todd and Jones (2005) implicated that parents experience difficult emotional, physical, and social changes. Also, they determined that at this stage families rely less on the assistance of professionals. However, the limited sample size (n=22) and the opportunistic and qualitative nature of the study limits its generalizing ability.

Within typical adolescence, studies have revealed that the onset and progression of puberty is associated with higher levels of parent/child distance, young adult assertiveness, and influence on family decision making (Silverberg & Steinberg, 1990). Major stress issues may occur around increased hormone production spanning into adolescence. In general, adolescence marks a time where an individual gains greater choice and autonomy as they become independent. Transition planning is when parents...
prepare for greater independence with young adults with MR/ID when moving from traditional schooling to a trade or secondary school.

A major concern for families with young adults with MR/ID is the future. Rapanaro, Bartu, and Lee (2008) investigated the perceived benefits and negative impact associated with demands encountered by 119 parents of young adults with MR/ID. The study was qualitative; parents answered open-ended questions to recount stressful events associated with their child’s transition into adulthood. Among the items eliciting the most stress were transition out of a secondary school system, a lack of access to post-school services, problematic interactions with service providers, issues relating to their child’s independence or dependence, sexuality and behavioral problems, and their child’s vulnerability and wellbeing (Rapanaro et al., 2008). Similar challenges were reported by Turnbull and colleagues (1986) and Todd and Jones (2005).

McIntyre, Blacher, and Baker (2002) utilized similar stress variables in an empirical study to determine if maladaptive behavior has an impact on parental stress and on decisions about residential placement. McIntyre and colleagues (2002) interviewed 103 mothers of adolescents, ages 16 to 25, with severe MR/ID to assess their child’s adaptive functioning, maladaptive behavior, mental health problems, and negative impact on the family, as well as their own thoughts on out-of-home placement. Problem behaviors were assessed by the Scales of Independent Behavior-Revised Problem Behavior Scale (Bruininks et al., 1996), and the Reiss Screen (Reiss, 1994) assessed mental disorder. These measures were highly correlated (r = 0.64) and significantly predicted the mothers’ perceived negative impact of the adolescent on the family.
Researchers conducted a hierarchical linear regression analysis with adolescent demographics entered first, and then both mental health and maladaptive behavior scores entered together. After gender, age, the presence of Down syndrome, and school status accounted for 15% of variance, behavior/mental health problems accounted for an additional 27% of variance in negative impact on the family. Therefore, perceived negative impact was highest in families where the young adult with MR/ID was male and had greater behavior/mental health problems. The definition McIntyre and colleagues (2002) gave to serious maladaptive behavior, for example, failure in community living arrangements, social isolation, frequent moves, and reduced employment prospects, parallels AAIDD’s definition of adaptive behavior.

Additionally, when a family was seeking out-of-home placement, it did not predict further parental stress after accounting for the adolescent’s health and the mother’s higher educational attainment. While only 27% of families had made steps toward placing or launching their young adult into alternative living arrangements, most that were in good health were more likely to be considered for placement (McIntyre et al., 2002). This study implies that higher stress levels in parents indicate a greater chance of parents deciding to continue at home care for their child as they become an adult.

Summary

Every family experiences stress or an actual or perceived imbalance between demand and capability in the family’s functioning throughout the span of raising a child (McCubbin & Patterson, 1983). Previous research has not fully examined variables of parental stress and degrees of fluctuations over the span of a child with MR/ID’s childhood. Despite the fact that many behaviors or symptoms may improve in degree
with intensive interventions, development of skills will be slower than children with average intelligence and adaptive skills (Luckasson et al., 2002). The United States has improved progressively in the conceptualization of MR/ID from negative, shameful connotations and subhuman treatment before the 19th century to the equal rights and treatment of the 21st century (Gartner et al., 1991; Hodapp & Dykens, 2003). Similarly, family research of a child with MR/ID has adapted with societal views. Past pathological models of adaptation equated maternal psychological reactions to family functioning (Hodapp & Dykens, 2003). Current literature trends now recognize the importance of interacting variables between children diagnosed with MR/ID and their families (Haveman et al., 1997; Lopez et al., 2008; Neece & Baker, 2008; Siklos & Kerns, 2006).

Parents encounter stress when family functioning is not mediated or positive protective factors are not an available resource. Significant variability is reported in the degree of experienced parent stress, implying that determination of predictors involved in stress can lead to intervention and prevention for families encountering negative stress. Although there is speculation across family research of factors contributing to the production of substantial portions and influence of parental stress, some variations can be attributed from unaccounted conflicting variables (Dyson 1997; Hauser-Cram et al., 2001; Baker et al., 2003; Neece & Baker, 2008). Contributions to research inconsistency may be due to sample composition, child age and ability variation, and measurement style and labeling terms, for example, intellectual functioning rather than adaptive behavior.

Generally, MR/ID diagnosis involves aspects of intellectual functioning and adaptive behavior. However, difficulty arises in utilizing an IQ based testing model in
instances when the majority of the sample has similar IQs but varying functioning levels. When assessment emphasis is placed on adaptive behavior or real life skills such as grooming, dressing, safety, safe food handling, school rules, ability to work, money management, cleaning, making friends, social skills, and personal responsibility, a more accurate portrayal of functioning can discriminate among children with severe and profound MR/ID (Luckasson et al., 2002). Adaptive behavior can be expressed by a range of complex conceptual, social, and practical skills (Luckasson et al., 2002), which fluctuate across a lifespan (Haveman et al., 1997; Heller et al., 1997).

Although developmental research endorses critical periods of developmental milestones (Baum, 2006; Turnbull et al., 1986; Zimbardo et al., 2000), previous research has not closely examined the shifts in parent stress occurring throughout childhood. The variations may emphasize more stressful periods of time; for example, families of a child with MR/ID generally need assistance with developmental and medical issues at the early stages of life because of their lack of previous knowledge. Information about the disability and any medically involved comorbid diagnoses, attaining treatments, supports, and financial assistance are major concerns for families when children are young (Haveman et al., 1997). However, need changes overtime, and both DeBildt and colleagues (2005) and Neece and Baker (2008) found that the interaction of social skills with parental stress increases in importance as children mature through the school age years. Another parental concern shifts focus for families as the child with MR/ID becomes an adolescent, and new independence issues and stress over future planning comes into play. With transition out of a secondary school system, parents face a wealth of new stressors when dealing with a lack of access to post-school services, problematic
issues relating to their child’s independence or dependence, sexuality and behavioral
problems, and their child’s vulnerability and well being (Rapanaro et al., 2008; Turnbull
et al., 1986; Todd & Jones, 2005). Despite its importance, current research on adolescents
with MR/ID often overlooks parental adjustment.

Family research abides generally to theoretical influences of family theory
ecompassing family ecological system theory, family stress theory, and family
developmental theory. Each theory shares structural components and utilizes
environmental and interrelationship aspects in explaining families involving children
with MR/ID and their family adjustment. The family life cycle theory best integrates key
aspects of each theory and then focuses on the family moving through a series of
transitions that create stressors within the family system (Baum, 2006; Turnbull et al.,
1986). Within the present study, family developmental approaches provide salient
theoretical base to examine the role of adaptive behaviors in parental stress throughout
age specific trends by categorizing 3 age-driven life stage groups in line with family
developmental perspectives for children 0 to 21 years old previously diagnosed with
MR/ID.
Chapter III: Method

This study investigated parental stress differences among children’s adaptive behavior and childhood life stages, according to the family life cycle theory. More specifically, the differences in mean parental stress scores, as determined by the QRS-F, were compared between child characteristics of the 3 groups of adaptive behavior scores, as determined by the domain scores of the ABAS-II, and the childhood life stages of Preschool, School Age, and Adolescence, as determined by the demographic questionnaire. Due to unequal groups and the lack of research in the Adolescence life stage the primary analysis for this study was a t-test of adaptive levels Social vs No Elevation and parent stress and follow-up regression tests. For supplemental material, a qualitative content analysis was conducted on a subset of the sample. The following chapter identifies the participants, measures, and analysis.

Participants

Participants consisted of parents of male (n=33) and female (n=35) children previously diagnosed with MR/ID and enrolled in 3 special education approved private schools in southwestern Pennsylvania. Participation in the study was open to all parents of children who are between the ages of 5 and 21 years old. No exclusion criteria were based on race, ethnicity, or gender. Informed consent was obtained from each parent before completing the provided materials.

A statistical power analysis, using G*Power version 3.0.10 (Budner, Erdfelder, Faul, & Lang, 1997), determined that a minimum sample size of 30 is necessary to detect a statistically significant difference between parental stress in adolescence and the 3 levels of adaptive behavior skills. This analysis was conducted for a 1x3 one-way
ANOVA with repeated measures (within). An established significance level of .05 and an effect size for the analysis was set at a moderate level, \( f = .25 \). Power was set at .95; as such a level is indicative of adequate power for a statistical test or an adequate level from which the null hypothesis would be accurately rejected if in fact a difference exists between the groups (Budner et al., 1997; Stevens, 2002). A target population of 216 families was distributed surveys, however, a total of 72 participants responded indicating a low return rate of 32%. It is theorized that the response was low because the targeted population has many time demands and elevated stress. After statistical data was cleaned, the subsequent final sample size was \( n = 68 \). Due to the low response rate, the data analysis and research questions were adapted.

Measures

**Demographic Information**

Parents completed a demographic questionnaire, including the age and gender of their children, diagnostic information, their own age, ethnicity, education level, relationship to the child with a disability, and the number of siblings that live in the home. The demographic page consisted of 11 multiple choice and fill in the blank questions; no identifying information was included, see Appendix 1.

**Adaptive Behavior Assessment System-II**

Adaptive skills are particularly important for children whose independent living and self-care is limited (Liss, et al., 2001). Therefore, significant limitations in areas of adaptive behavior impact many aspects of a person’s daily life and his or her abilities to respond to situations and environments (Luckasson et al., 2008). Assessment of adaptive functioning allows one to ascertain more directly how well individuals function in their

The ABAS-II is a common assessment tool that generates norm-referenced scores for 9 skill areas and 3 broad domains. All scores are presented as standard scores, age-based percentile ranks, and age equivalents. Norms, based on ratings of more than 3,200 individuals in 31 age groups, are stratified by sex, race/ethnicity, and level of education (Harrison & Oakland, 2003). Each scale provides a General Adaptive Composite (GAC) score derived from 3 domain scores (Conceptual, Social, and Practical) and an assessment of the 9 adaptive skill areas specified by the Diagnostic and Statistical Manual of Mental Disorders—Fourth Edition—Text Revision (DSM-IV-TR; APA, 2004). These skill areas fall in line with the suggested adaptive behavior criteria from the American Association on Intellectual Developmental Disabilities. Each skill area contains at least 20 items on a 4 point Likert scale. The participants circled the answer that best described their child completing a task. The scale included: 0= is not able, 1= never or almost never when needed, 2= sometimes when needed, 3= always or almost always when needed. The skill area raw scores were added to create scaled scores with a mean of 10 and standard deviation of 3. The scaled scores were then added to calculate the domain scores with a mean of 100 and standard deviation of 15.

Reliability and Validity for ABAS-II. The ABAS-II provides extensive reliability and validity evidence. Scores can be used with confidence as coefficients for the GAC exceeded 0.90, and the domain scores were also near, at, or exceeded 0.90 (Harrison & Oakland, 2003). The inter-rater reliability coefficients on the GAC scores were between
0.83 and 0.85. However, some variance in coefficients occurred for the individual skill areas. In the parent form, the inter-rater reliability coefficients for the skill areas were in the 0.70s. Even though these coefficients are generally considered low, inter-rater reliability coefficients exceed similar estimates with other scales (Burns, 2004). Harrison and Oakland (2003) estimated test-retest reliability using Pearson’s product-moment correlation coefficient. All standardized sample reliability coefficients were mostly in the 0.90s. In addition, 50% to 82% of the individuals with MR/ID sampled scored < 2 standard deviations below the mean on the GAC. Significant differences were displayed between mean GAC scores of the individuals with mild and moderate MR/ID.

The content validity of the ABAS-II was adequately assessed through expert ratings of items; consistent with AAMR and DSM-IV-TR definitions (Burns, 2004; Harrison & Oakland, 2003). Relatively high correlations, 0.82, of convergent validity were reported in relationships between the ABAS-II (Harrison & Oakland, 2003) and the Vineland Adaptive Behavior Scale (Sparrow et al., 1984). The structure of the ABAS-II would suggest that skill areas are somewhat independent of each other, but it averaged 0.40s to 0.50s intercorrelations with high correlation averaging around 0.70 with its respective domain. Therefore, caution should be taken in interpreting the skill areas independently (Burns, 2004).

*Short-Form of the Questionnaire on Resources and Stress*

The Short-Form of the Questionnaire on Resources and Stress (QRS-F; Friedrich et al., 1983) is a 52-item instrument measuring 4 broad categories of Parent and Family Problems, Pessimism, Child Characteristics, and Physical Incapacitation in families with children with a disability. For all items, true or false response formats were used, which
were scored 0 or 1. Parents were asked to indicate whether the items were true or false. A total category score was derived by summing the number of negatively endorsed items, and positively worded items were reverse scored.

In order to create these subscales, Friedrich and colleagues (1983) completed a principal components factor analysis, rotated using the VARIMAX method, then loadings of +0.40 or greater were accepted as a factor. Among subscales, many researchers have utilized the Parent and Family Problems sub-scale only to isolate parent stress (Glidden & Floyd, 1997; Loyd & Hastings, 2007; Hastings & Johnston, 2001; Honey, Hastings, & McConachie, 2005; Quinn et al., 2007). Items loading on to this subscale are between 0.40 and 0.68 (Friedrich et al., 1983).

The Parent and Family Problems sub-scale of the QRS-F contains 20 items assessing the impact on the parent and family (Friedrich et al., 1983). For example, ‘Other members of the family have to do without things because of the child, and the child is able to fit into the family social group.’ A complete list of the Parent and Family Problems sub-scale questions of the QRS-F is attached as Appendix 2.

Although the Parent and Family Problems subscale is a common stress measure, Glidden and Floyd (1997) specifically examined the subscale for depression tendencies. They identified a further 5 item subscale within the QRS–F that seemed to be a robust measure of parental depression. Because of the presence of a short depression measure from items on the Parent and Family Problems subscale from Glidden and Floyd (1997), some subsequent research removed these items from their study.

Honey and colleagues (2005) conducted a study of 120 parents of young children with autism using a portion of the QRS–F. The excerpt compiled the Parent and Family
Problems subscale and the Pessimism subscale with Glidden and Floyd’s (1997) suggested 5 item removals, resulting in 31 items. This study had intended to establish psychometric properties of the subscales for parents of children 2-6 years of age with autism. A principal components factor analysis, regardless of the extracted number of factors or rotation method, failed to identify the previous two-factor structure with the removed items. The majority of the items loaded significantly onto the first factor extracted. Therefore, removal of the 5 items affected the reliability of the subscale factors, although the test still seemed reliable with Kuder–Richardson-20 coefficients (KR-20) of 0.85. Although reliable, the KR-20 is not the most parsimonious test to utilize as defined in the reliability section below. Also, the analyses between QRS–F scores and the Judson adaptation scale (Judson & Burden, 1980) were significantly correlated with maternal stress ($r (54) = −0.70, p < 0.001$) and paternal stress ($r (43) = −0.46, p < 0.01$). Those with a more positive adaptation to their child reported less stress.

Reliability and Validity for QRS-F. The QRS-F and its subscales were normed on 289 parents with children in the MR/ID range between the ages of 5 and 18. The measure has acceptable internal consistency reliability coefficients above 0.70 (Friedrich et al., 1983). The KR-20 reliability coefficient for internal consistency is 0.95 (Friedrich et al., 1983), similar to Honey and colleagues’ (2005) findings of 0.93. Although the KR-20 is seen as a derivative of the Cronbach alpha formula for dichotomous variables, it is not a preferred method. The nature of the test is dichotomous, but answers are not right or wrong as a KR-20 coefficient measures. A Cronbach alpha would be a better fit to the data; however, due to the mathematical nature of both reliability coefficients, similar results will be yielded. Therefore, the QRS-F is considered reliable.
To determine the concurrent validity of the QRS-F, Friedrich and colleagues (1983) completed a second study on 40 mothers. In this study, the parents completed additional measures, the Beck Depression Inventory (Beck, Ward, Mendelson, Mock, & Erbaugh, 1961) and the Marlowe-Crowne Social Desirability Scale (Crowne & Marlowe, 1960). Again, the KR-20 reliability coefficient was high 0.93, and the parent and family problem subscale was correlated significantly with both tests.

Research Design

In the current study, the main analysis was a non-experimental ex post facto, quantitative design describing the differences of parental perceived stress across childhood age categories and adaptive behavior levels. Independent-samples t-test evaluated the variability of stress in the School Age and Adolescence life stages. A one-way analyses of variance (ANOVA) was conducted to determine the effects of the 4 levels of adaptive behavior elevation, Conceptual, Social, Practical or no elevation (all domains fall within the same standard deviation) on parental stress (QRS-F). Follow-up qualitative information was also analyzed to supplement the research questions. In the Adolescence life stage individual t-tests with stress and the levels of elevated social domain and no elevation followed by a multiple regression analyses to evaluate how well the domains scores from the ABAS-II measured predicted parental stress levels.

Independent & Dependent Variables

The independent variables for this study consisted of the child with MR/ID’s age and domain subtests from the ABAS-II. Parents of children with MR/ID were divided into 3 separate categories, according to the family life cycle model: Preschool, ages 5-7; School Age, ages 8-12; and Adolescence, ages 13-21. Additionally, the ABAS-II skill
scores from the Social, Practical, and Conceptual domains were examined and adaptive behavior elevation levels, Conceptual, Social, Practical or no elevation (all domains fall within the same standard deviation).

To assess all hypotheses, regarding differences in the reported level of parenting stress between the 3 groups and within the 3 groups, the Parent and Family Problems subscale of the QRS-F was the dependent measure. This measure provided a quantitative total score of parent perceived stress.

Procedures

Within southwestern Pennsylvania, special education approved private schools were contacted. A packet consisting of a cover letter, procedural safeguards, consent form, demographics, ABAS-II, QRS-F, and a stamped addressed envelope was sent home in folders of all children attending the schools. All items in each packet, except the consent form, were void of all identifiable information other than a numerical code to correlate each measure as completed by the same person. The consent form is attached as Appendix 3.

Upon the schools’ receipt of the completed packets, they were forwarded to the school psychologist or school secretary who then separated the consent form from the data to assure animosity. For incentive to participate, parents who returned the forms were entered in a $50 gift card drawing for a local store (Giant Eagle). A consent form was randomly chosen after all packets were received, and the school awarded 1 parent the gift card purchased by the researcher. Upon the primary researcher’s receipt of the materials, the data was entered into a Statistical Package for the Social Sciences 15.0 (SPSS, 2006) for analysis.
Due to the True and False nature of the QRS-F survey, the data needed to be reverse scaled to be entered into the database. After entered, data was examined across all questions and a total QRS-F score was calculated for each participant. This total score was then entered into the main database.

Data Analysis

The study investigated the relationship of stress in parents with children diagnosed with MR/ID across age groups. Descriptive and inferential analyses were first applied to the data set to describe the sample and address the research questions and hypotheses. Missing data was examined and addressed according to type and frequency. Within the QRS-F, a listwise deletion discarded 2 cases, due to a few missing variables found randomly distributed across all observations. Cases discarded were less than 5% of the data. Additionally, 1 case was discarded for not including a QRS-F survey and 1 for missing a portion of the ABAS material. These deletions resulted in the sample size of 68.

It is important to adjust for the assumptions because the nature of response to a survey study results typically in uneven ns within the groups. The nature of an independent group design assures some variability in participants equally volunteering from each group. In the current study, major disparity existed among the age of the participants’ children. There were only 5 parents with children between the ages of 0-7, 19 participants with children between the ages 8-12, and 45 participants between the ages of 13-21. Although the best way to correct for errors with unequal cell sizes is an unweighted-means analysis, the disparity among the samples and omission of scores for missing data made this analysis inappropriate (Weiss, 2006). The research of this field
indicated limited quantitative data within adolescence. To correct for the unequal cell sizes and previous research, the examiner created a separate data base on respondents with children who are in the adolescence group and focused the main analysis on it.

Next, assumptions were determined for this database. The primary assumptions examined were linearity, normality, and homogeneity of variance (Tabachnick & Fidell, 2007). The assumption of linearity states that the relationships between the independent variables and the dependent variable should be linear. The assumption of normality states that each variable and linear combination of variables should be normally distributed. In addition, homogeneity of variance was checked through a Levene’s test equality of variances to assure that the error variance of the dependant variable was equal across groups. A description of adjustments for assumptions is found in the preliminary analysis section of Chapter IV, Results.

Finally, a pearson correlation was conducted on continuous background variables, including age of parent, education level of parent, and number of children in the home, in order to determine if there were any significant differences between the 3 groups prior to analyzing the dependent variables. Results of this analysis can also be found in the preliminary analysis section of Chapter IV, Results. After these assumptions were justified, the primary analysis began. The following research questions were examined:

**Research question 1**

Does the level of perceived parental stress vary across (Preschool, School Age, and Adolescence)?

*Hypothesis 1.* There will be variability in parental stress across childhood life stages.
Computation: Initially, the frequencies and percentages of levels of stress for all life stage groups were examined. Due to an insufficient response rate and unequal groups, the Preschool life stage of this research question could not be statistically addressed. However, an independent-samples t-test evaluated the variability of stress in the School Age and Adolescence life stages.

Research question 2

Does the level of perceived parental stress differ across child adaptive behavior?

Hypothesis 2. There will be an inverse relationship between higher levels of perceived parental stress and lower child adaptive behavior ability.

Computation: To test the hypothesis frequencies were examined and an ANOVA was conducted.

Research question 3

Does parent stress in the childhood life stage Adolescence differ across child adaptive behavior (Social, Conceptual, and Practical)?

Changed to: In the life stage Adolescence, is there a relationship between the degree of child adaptive behavior (Social, Conceptual, and Practical) and parental stress?

Hypothesis 3. Differences occur between child adaptive behavior and parental stress within Adolescence.

Computation: Further preliminary statistics were performed and followed by individual t-tests with the levels elevated social domain and no elevation

Question 3a. How does parent stress interact with child factors; adaptive behavior skills (Conceptual, Social, and Practical) and the Adolescence life stage?
Hypothesis 3a. It is theorized that lower child practical skill levels will predict higher stress levels in the Adolescence stage.

Computation: A follow-up multiple regression analyses was conducted to evaluate how well the domains scores from the ABAS measured predicted parental stress levels.
Chapter IV: Results

The current study examines parental stress trends and adaptive behavior capabilities with children with low-incidence disabilities. The results section is organized in the following manner: an examination and description of the participant sample, data pre-analyses, each research question’s tests of statistical assumptions, and the main analyses results.

Participants/Demographics

All participants (parents) have a child who attends one of the three special education approved private schools in southwestern Pennsylvania and are between the ages of 5 and 21. Although a total of 72 participants responded, after cleaning the main body of statistical data, the subsequent sample size is 68. A typical participant is a Caucasian female 46 years of age or older with a college degree and more than one child. The following demographics describe the participants and their children with a low-incidence disability.

Most participants in the sample, 86.8%, are the mothers of a low incidence child. Fathers compile 8.8% of the sample, while only 1.5% is legal guardians, and 2.9% identify themselves as other. As for ethnicity, the majority of the sample, 92.6%, indicate they are Caucasian. The ethnicity for the rest of the sample is as follows: 2.9% African American, 2.9% Hispanic, and 1.5% Asian. The most defining characteristics of the parent demographics are an age of 46 years or older (51.5%), education beyond high school (82.4%), and 2 or more children, including the special needs child living in the home (71%). Child statistics are similar across gender; 48.5% of the subjects’ children are male and 51.5% are female. Most parents indicate that their child is in the severe
disability range and has been identified prior to age 8. Diagnoses that parents indicate as their child’s primary disability include: Cognitive, Physical, or Visual impairments, Autism, or a Syndrome disorder, for example, Angelmans, Phelem McDermit, and Fragile-X.

Initially, the study intended to examine adaptive behavior, according to the life stage sequence. However, the participants resulted in uneven groups. The largest group to participate is 45 parents with a child in the Adolescence life stage, ages 13-21. The life stages School age, ages 8-12, \((n=18)\), and Preschool, ages 0-7, \((n=5)\), has a significantly lower response rate. The disproportionate responses indicate a need for adaptations within two of the research questions. The main analysis focuses on the largest group, the Adolescent life stage. The limited amount of quantitative research in the adolescence literature base indicates the adjustment is appropriate.

Preliminary Statistical Analysis

Before conducting the main analyses, the data is examined for missing data, outliers, and statistical assumptions. The methods section describes the procedures for the adjustment of missing data. Two databases, the total sample, and a subset database of parents in the Adolescence life stage are examined. In both databases, outliers are examined by transforming scores into z-scores and box-plots. Outlying data points may affect the results and the probability of committing a type I or II error. Within a normal distribution, assume that 99% of the z-scores will be within the range 3 to -3 (Mertler & Vannatta, 2005). For the database that includes all the participants, stress variables (QRS-F) consist of z-scores between 2.0 and -1.9, therefore no outliers are detected. Similarly all adaptive behavior (ABAS-II GAC z-scores) are within acceptable ranges, 2.9 to -0.64.
For the Adolescence database stress variables (QRS-F) consist of z-scores between 2.0 and -1.77, therefore no outliers are detected. However, there is a large portion, greater than 5%, of subjects with extreme adaptive behavior values. Of these values, only one case is considered an outlier with a z-score of 3.09. Examination of box-plots indicates this score is not extreme enough to be considered an outlier, therefore, none are removed.

Next, the assumption of linearity is examined to determine if there is a straight line relationship between two variables. Normality is examined to determine the extent in which all observations in the sample for a given variable distribute normally. In an inspection of bivariate scatterplots, if variables normally distribute and linearly relate, the shape of the scatter plot will be elliptical (Mertler & Vannatta, 2005). A visual inspection of the relationship between QRS-F and ABAS-II scores indicate both databases are neither normal nor linear. Also, significant Kolmogorov-Smirnoff test of normality indicate significant deviance from normality for each variable (Stevens, 2002). Upon further inspection, all ABAS-II variables skew negatively, indicating a greater frequency of lower scores on all variables.

Furthermore, the scores obtained on the ABAS-II for these participants also truncate towards the lower end of the possible score range. This indicates that the participants in this sample display generally low levels of adaptive skills. On the other hand, the QRS-F presents a moderately positive skew. In an attempt to remedy the lack of normality and linearity in the independent variables, transformations are conducted on each variable as shown in the main analyses section. The following sections address the main analysis for each research question.
Assumptions and Main Analyses

Research question 1

Does the level of perceived parental stress vary across (Preschool, School Age, and Adolescence)?

Hypothesis 1. There will be variability in parental stress across the childhood life stages.

Computation. Initially, the frequencies and percentages of levels of stress for all life stage groups are examined. Due to an insufficient response rate and unequal groups, the Preschool life stage of this research question cannot be statistically addressed. However, an independent-samples t-test evaluates the variability of stress in the School Age and Adolescence life stages.

Frequencies. Table 1 displays the frequencies of parent stress levels across the child life stage groups. Within the Preschool life stage group, the 5 participants who respond endorse high levels of stress on the QRS-F survey. The School Age group presents an even amount of stress levels ranging between low, middle, and high. The largest group is the Adolescence life stage group with 45 participants. Within the Adolescence group, 48.9% of participants endorse high levels of stress.
Table 1

Frequencies of parent stress levels across life stage groups

<table>
<thead>
<tr>
<th>Parent Stress (QRS-F)</th>
<th>Life Stage</th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Preschool (0-7)</td>
<td>School Age (8-12)</td>
<td>Adolescence (13-21)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Stress Levels</td>
<td>Count</td>
<td>%</td>
<td>Count</td>
<td>%</td>
<td>Count</td>
</tr>
<tr>
<td>Low</td>
<td>0</td>
<td>0</td>
<td>5</td>
<td>27.8</td>
<td>13</td>
</tr>
<tr>
<td>Middle</td>
<td>0</td>
<td>0</td>
<td>5</td>
<td>27.8</td>
<td>10</td>
</tr>
<tr>
<td>High</td>
<td>5</td>
<td>100</td>
<td>8</td>
<td>44.4</td>
<td>22</td>
</tr>
<tr>
<td>Total</td>
<td>5</td>
<td>100</td>
<td>18</td>
<td>100</td>
<td>45</td>
</tr>
</tbody>
</table>

Despite the percentage differences, the QRS-F means for each group, Preschool, School Age, and Adolescence are similar, as the bar chart on Figure 4 depicts. QRS-F group means are high for the Preschool and Adolescence group and within the middle range for the School Age group. However, the disparity of the group sizes indicates extreme caution should be taken when interpreting these frequencies.
Figure 4. Stress levels group means across child life stage groups. This figure illustrates the means from the QRS-F survey for each life stage group.

An independent-samples t-test evaluates the hypothesis that parent stress varies with children with a low-incidence disability in the School Age and Adolescence life stages. The test is not significant, \( t(38.24) = -0.457, p = .650 \), counter to the research hypothesis. Participants in the School Age group (\( M = 31.17, SD = 3.01 \)) on average do not have as spread out stress levels as the Adolescence group (\( M = 31.58, SD = 3.70 \)). Figure 5 shows the mean distributions for the two groups.
Further preliminary analysis assures that any potential third variables that significantly associate with the primary dependent and independent variables are to be identified prior to running the main analysis (Tabachnick & Fidell, 2001). Therefore, the total numbers of parents’ demographics are examined in order to identify possible correlations. The examined demographic variables are: child disability (Cognitive, Physical, Vision/Hearing impairment, Traumatic Brain Injury, Autism, or a Syndrome disorder), child impairment level (mild, moderate, or severe), parent age (18-25, 26-35, 36-45, or 46+), parent ethnicity (African American, Caucasian, Hispanic, or Asian), parent education (grade school, high school, some advanced training, college, masters, or doctorate), number of children living in the home, and parent stress (QRS-F). Because the
demographic information is continuous, a Pearson Correlation analysis is used. Table 2 presents the results. There is one significant correlation at the p< 0.05 level. Parent ethnicity correlates to parent education level.

Table 2

*Pearson Correlations of demographics*

<table>
<thead>
<tr>
<th>Demographics</th>
<th>Child Disability</th>
<th>Child Impairment</th>
<th>Parent Ethnicity</th>
<th>Parent Age</th>
<th>Parent Education</th>
<th>Children in Home</th>
<th>Parent Stress</th>
</tr>
</thead>
<tbody>
<tr>
<td>Child</td>
<td>1</td>
<td>-.228</td>
<td>.224</td>
<td>-.031</td>
<td>-.110</td>
<td>-.108</td>
<td>.145</td>
</tr>
<tr>
<td>Disability</td>
<td>1</td>
<td>.001</td>
<td>.016</td>
<td>.040</td>
<td>.044</td>
<td>-.188</td>
<td></td>
</tr>
<tr>
<td>Impairment</td>
<td>1</td>
<td>.007</td>
<td>-.246*</td>
<td>.062</td>
<td>-.099</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Parent</td>
<td>1</td>
<td>.007</td>
<td>-.246*</td>
<td>.062</td>
<td>-.099</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ethnicity</td>
<td>1</td>
<td>.007</td>
<td>-.246*</td>
<td>.062</td>
<td>-.099</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Parent Age</td>
<td>1</td>
<td>.137</td>
<td>-.086</td>
<td>.025</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Parent</td>
<td>1</td>
<td>.014</td>
<td>-.060</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Education</td>
<td>1</td>
<td>.178</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Children in</td>
<td>1</td>
<td>.178</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Home</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Parent Stress</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Note: * Significant at the p< 0.05 level (2-tailed). Sample size, n=68

**Research question 2**

Does the level of perceived parental stress differ across child adaptive behavior?
Hypothesis 2. There will be an inverse relationship between higher levels of perceived parental stress and lower child adaptive behavior ability.

Computation. To test the hypothesis, frequencies are examined and an ANOVA is conducted.

Frequencies. Table 3 displays frequencies of the adaptive measure (ABAS-II) and a count and percentage of each ABAS-II domain (Conceptual, Social, and Practical) according to how the standard score falls into the standard deviation descriptive categories: Extremely Low, Borderline, Below Average, and Average (Harrison & Oakland, 2003). No scores fall in the Above Average, Superior, or Very Superior range; therefore, these descriptive categories are not in the table. The scores separate by domain across child life stage groups, Preschool, School Age, and Adolescence.

Table 3

ABAS-II domain count for each adaptive descriptive level, separated by life stage groups

<table>
<thead>
<tr>
<th>ABAS-II Descriptive Levels</th>
<th>Life Stage Groups</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Preschool (0-7)</td>
</tr>
<tr>
<td>Extremely Low</td>
<td>3</td>
</tr>
<tr>
<td>Borderline</td>
<td>0</td>
</tr>
<tr>
<td>Low Average</td>
<td>1</td>
</tr>
<tr>
<td>Average</td>
<td>1</td>
</tr>
</tbody>
</table>

Note: Con. represents Conceptual, Soc. represents Social, Prac. represents Practical
Table 4 displays the total count and percentage of each descriptive level for the ABAS-II domains across the total sample, \( n=68 \).

Table 4

*Total count and percentage of descriptive levels for each adaptive domain*

<table>
<thead>
<tr>
<th>Descriptive level</th>
<th>Conceptual</th>
<th></th>
<th>Social</th>
<th></th>
<th>Practical</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Count</td>
<td>%</td>
<td>Count</td>
<td>%</td>
<td>Count</td>
</tr>
<tr>
<td>Extremely Low</td>
<td>59</td>
<td>86.8%</td>
<td>52</td>
<td>76.5%</td>
<td>60</td>
</tr>
<tr>
<td>Borderline</td>
<td>5</td>
<td>7.4%</td>
<td>4</td>
<td>5.9%</td>
<td>1</td>
</tr>
<tr>
<td>Low Average</td>
<td>2</td>
<td>2.9%</td>
<td>6</td>
<td>8.8%</td>
<td>4</td>
</tr>
<tr>
<td>Average</td>
<td>2</td>
<td>2.9%</td>
<td>6</td>
<td>8.8%</td>
<td>3</td>
</tr>
<tr>
<td>Totals</td>
<td>68</td>
<td>100%</td>
<td>68</td>
<td>100%</td>
<td>68</td>
</tr>
</tbody>
</table>

*Note: All life stages included, \( n=68 \)*

An examination of frequencies shows that parents indicate children’s adaptive behavior within the Extremely Low range most frequently in all domains across life stage groups. Relatively, the Social domain presents the most variability across the ABAS-II’s descriptive level categories. The percentage of participants that indicate their children have Extremely Low adaptive skills in each domain are Conceptual domain 86.8%, Social domain 76.5%, and Practical domain 88.2%.

A variable is created to categorize ABAS-II elevation levels into: elevated Conceptual, Social, Practical, or no elevation. Based on the elevated domain, each participant’s ABAS-II standard domain scores that are elevated more than one standard deviation above the others are separated into assigned numbers from 1 to 3. Scores,
where all domains fall in the same standard deviation are labeled as 4 or no elevation. An ANOVA evaluates the effects of the 4 levels of adaptive behavior elevation, Conceptual, Social, Practical or no elevation (all domains fall within the same standard deviation) on parental stress (QRS-F), as Table 5 displays. Results are not significant, \( F (3.64)= 0.810, \ p= 0.493 \). The significance level for this analysis of variance is set at \( \alpha = .05 \). Additionally, the assumption of homogeneity of variance is met for the ANOVA. The Levene’s test of equality of variances statistic is 0.089 with a \( p \) value of 0.966.

**Table 5**

*Tests of Between-Subjects Effects of adaptive behavior levels, Conceptual, Social, Practical, or no elevation on parental stress*

<table>
<thead>
<tr>
<th></th>
<th>df</th>
<th>Mean Square</th>
<th>( F )</th>
<th>Significance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Corrected Model</td>
<td>3</td>
<td>9.914</td>
<td>.810</td>
<td>.493</td>
</tr>
<tr>
<td>Intercept</td>
<td>1</td>
<td>26357.022</td>
<td>2153.024</td>
<td>.000</td>
</tr>
<tr>
<td>ABAS elevation levels</td>
<td>3</td>
<td>9.914</td>
<td>.810</td>
<td>.493</td>
</tr>
<tr>
<td>Error</td>
<td>64</td>
<td>12.242</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>68</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*Note:* The dependent variable is QRS-F. The ANOVA computes using an alpha equal to .05, with R Squared = .037, and Adjusted R Squared = -.009.

Post hoc tests reveal similar non-significant tests. Table 6 displays the descriptive statistics for the above ANOVA. Descriptive statistics indicate 3 parents have children with an elevated Conceptual domain, 11 have children with an elevated Social domain, and 6 have children with an elevated Practical domain. Most parents have children whose adaptive scores are equal across adaptive behavior domains. With parent stress as a
dependant variable, the mean stress level and standard deviation is displayed for each group.

Table 6

*Adaptive behavior (ABAS-II) elevation levels descriptive statistics*

<table>
<thead>
<tr>
<th>Elevation Levels</th>
<th>Mean</th>
<th>Standard Deviation</th>
<th>Number of Participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>Conceptual</td>
<td>32.00</td>
<td>4.359</td>
<td>3</td>
</tr>
<tr>
<td>Social</td>
<td>33.00</td>
<td>3.688</td>
<td>11</td>
</tr>
<tr>
<td>Practical</td>
<td>30.50</td>
<td>3.391</td>
<td>6</td>
</tr>
<tr>
<td>No elevation</td>
<td>31.48</td>
<td>3.427</td>
<td>48</td>
</tr>
<tr>
<td>Total</td>
<td>31.66</td>
<td>3.484</td>
<td>68</td>
</tr>
</tbody>
</table>

*Research question 3*

In the life stage Adolescence, is there a relationship between the degree of child adaptive behavior (Social, Practical, and Conceptual) and parental stress?

*Hypothesis 3.* Within the Adolescence life stage, differences occur between child adaptive behavior and parental stress.

*Computation.* Further preliminary statistics are performed and followed by individual t-tests. Descriptive statistics indicate out of the 45 participants with children in the Adolescence life stage, there is 1 with an elevated Conceptual domain, 10 with an elevated Social domain, 1 with an elevated Practical domain, and 33 participants with no elevation among the domains that is at least a standard deviation above the other domain
scores. Therefore, t-tests are conducted with the levels elevated social domain and no elevation.

Prior to the t-tests, the violations of the assumptions of normality are addressed. All ABAS-II variables skew negatively and truncate towards the lower end of the possible score range. This indicates that the participants in this sample display generally low levels of adaptive skills. On the other hand, the QRS-F presents a moderately positive skew. In an attempt to remedy the lack of normality in the independent variables, transformations are conducted on each variable. The purpose of transformations is to improve normality. However, the transformations (QRS-F-square root and ABAS-II GAC- inverse transformations) do not marginally decrease the skew and hence fail to improve normality. The analysis is conducted despite these problems. The violations in assumptions shown in the current data set result in an under estimation of the strength of the results found (Tabachnick & Fidell, 2007).

Additional preliminary analysis is needed to assure that any potential third variables that are significantly associated with primary dependent and independent variables are identified prior to running the main analysis (Tabachnick & Fidell, 2001). Since the Adolescence life stage data displays the most spread distributions of stress and is the focus of the main analysis, the Adolescent life stage data is examined in order to identify possible correlations with demographic variables. The following are the demographic variables: child disability (Cognitive, Physical, Vision/Hearing impairment, Traumatic Brain Injury, Autism, or a Syndrome disorder), child impairment level (mild, moderate, or severe), parent age (18-25, 26-35, 36-45, or 46+), parent ethnicity (African American, Caucasian, Hispanic, or Asian), parental education (grade school, high school,
some advanced training, college, masters, or doctorate), number of children living in the home, and parent stress (QRS-F). Because the demographic information is continuous, a Pearson Correlation analysis is used. Table 7 presents the results.

Table 7

*Pearson Correlations of demographics for the Adolescence Life Stage group*

<table>
<thead>
<tr>
<th>Demographic</th>
<th>Child Disability</th>
<th>Child Impairment</th>
<th>Parent Ethnicity</th>
<th>Parent Age</th>
<th>Parent Education</th>
<th>Children in Home</th>
<th>Parent Stress</th>
</tr>
</thead>
<tbody>
<tr>
<td>Child</td>
<td>1</td>
<td>-.221</td>
<td>.031</td>
<td>.110</td>
<td>-.086</td>
<td>-.039</td>
<td>.180</td>
</tr>
<tr>
<td>Disability</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Child</td>
<td>1</td>
<td>.182</td>
<td>.075</td>
<td>.032</td>
<td>-.075</td>
<td>-.200</td>
<td></td>
</tr>
<tr>
<td>Impairment</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Parent Age</td>
<td>1</td>
<td>-.086</td>
<td>-.262</td>
<td>.196</td>
<td>-.067</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Parent</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Education</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Children in</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>.160</td>
</tr>
<tr>
<td>Home</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Parent Stress</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>1</td>
</tr>
</tbody>
</table>

*Note:* * Significant at the p< 0.05 level (2-tailed). Sample size, n=45, A square root transformation of QRS is used as a parent stress measure
There is one significant correlation at the p< 0.05 level. Parent age correlates to the number of children living in the home. This correlation logically makes sense because older parents have more opportunities to have more children.

**Main Analyses.** Independent-samples t-tests are conducted for the ABAS-II levels Social vs no elevation. Due to group size, there is no examination of Conceptual and Practical domains. The test is not significant, \( t(13.754) = 1.190, \ p = .254 \). Participants whose child have an elevated Social domain (\( M=32.90, SD= 3.872 \)) on average do not have as spread out stress levels as those with no elevation across ABAS-II domains (\( M=31.27, SD = 3.494 \)).

Follow-up tests include multiple regression analyses to evaluate how well the domains scores from the ABAS measures predicted parental stress levels. The linear combination of adaptive behavior significantly relates to the parent stress measure, \( R^2 = .132, \) adjusted \( R^2 = .112, \ F(1,43) = 6.552, \ p < .05 \). Table 8 displays the means and standard deviations of the adaptive behavior means. The regression equation for predicting the overall parental stress index is: \( Predicted \ overall \ parent \ stress \ (QRS-F) = .64 \ Conceptual + .062 \ Social - .397 \ Practical - 25.119. \)

Table 8

*Descriptive statistics of adaptive behavior domains*

<table>
<thead>
<tr>
<th>ABAS-II</th>
<th>Mean</th>
<th>Std. Deviation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Conceptual Domain</td>
<td>54.20</td>
<td>11.277</td>
</tr>
<tr>
<td>Social Domain</td>
<td>65.11</td>
<td>15.204</td>
</tr>
<tr>
<td>Practical Domain</td>
<td>45.93</td>
<td>13.451</td>
</tr>
</tbody>
</table>
To determine which ABAS-II level is the most important or which beta weights most heavily on parental stress, the QRS-F in the Adolescence life stage correlations and variances are examined. In Table 9, presented indices indicate the relative strength of the individual predictors. The Conceptual domain, $p<.01$, and the Social domain, $p<.05$, are both correlated to parental stress. The Practical domain does not appear to impact stress as much as the other domains.

Table 9

*The Bivariate and Partial Correlations of the Predictors with Parental Stress*

<table>
<thead>
<tr>
<th>ABAS-II Predictors</th>
<th>Correlation between each predictor and stress</th>
<th>Correlation between each predictor and stress controlling for all other predictors</th>
</tr>
</thead>
<tbody>
<tr>
<td>Conceptual Domain</td>
<td>.364**</td>
<td>.364</td>
</tr>
<tr>
<td>Social Domain</td>
<td>.303*</td>
<td>.043</td>
</tr>
<tr>
<td>Practical Domain</td>
<td>.231</td>
<td>-.202</td>
</tr>
</tbody>
</table>

Note: A * indicates significance as $p<.05$, ** indicates $p<.01$

Descriptive Analysis

The following data is a qualitative design derived from a case interview question. This supplemental information reflects how individuals make sense of stress and the experience of raising a child with a disability. Some participants answer an open-ended optional question on the demographic sheet: “Describe what it is like living with a child with a disability and its impact on stress in your day to day life?” The case interview question provides perception of parental stress in the moment. A content analysis of the statements was then conducted and expressed in common themes based on the answers.
However, this information should be interpreted with caution because there is no cuing of responses. This implies that participants may endorse themes that they did not include in their open-ended responses.

The open-ended question allows parents an avenue to express their own interpretation of stress and its causes. Sixty-three percent of the sample responded to this question, more specifically 10.5% of the Preschool life stage, 38.5% of the School Age life stage, and 63.6% of the Adolescence life stage. Many parents filled an entire page with editorials; some even typed multiple pages of responses.

Preliminary Statistics: Coding

In order to appropriately analyze this data, 2 researchers coded the responses. In order to decide how many concepts to code, the first researcher reads the open-ended questions and creates a list of all presented topics. Then the researcher narrows the list by comparing similar topics found in literature and creates a matrix of codes for existence of a concept. For example, similar theoretical or pragmatic concepts, such as any specific examples of limitations or mention of a desire to attend more activities, are placed in the ‘limits activities the family can attend’ theme. Both researchers then read and code the essays independently using a matrix of themes and create rules for coding each theme, such as existence of ‘religious faith /belief’ and must include the wording that indicates assistance or relief from some type of faith related activity, such as prayers, congregation, or belief. The researchers read each response, condense the statements, and write onto note cards, separating them into concepts. Irrelevant information is categorized as additional information.
The researchers’ note cards are compared to insure inter-rater reliability of the themes. To determine the number of times the judges agree and disagree, the number of agreements is divided by the number of agreements and disagreements \((125/125+17) = 88\). Inter-rater reliability is 88%. For coding disagreements, each researcher compares the note cards. Then the researchers reread the essays in question and make an agreement for each of the 17 disagreements.

Common statements within the open-ended response consist of parents indicating the following coded categories:

1. The family adjusts to change the same as if their child did not have a disability
   
   (Rule: a comparison is made to other, typical, families)

2. Religious faith and/or belief assisting in family functioning
   
   (Rule: a reference to assistance or strength from religion, a parish, or prayer)

3. The interaction and experience is personally rewarding
   
   (Rule: recognition of positive attributes in life because of their child with a disability)

4. Stress is a result of concerns over the child with a disability’s future
   
   (Rule: consists of any concerns for the future, who will care for the child long-term)

5. A feeling of constant exhaustion and being tired or overwhelmed
   
   (Rule: mentions feelings of being run down or overwhelmed)

6. Stress is a result of their child requiring extra assistance and engaging in time consuming activities (Rule: reference to additional time needed for doctor appointments, therapy, planning)
7. The child’s disability limits the activities that the family is able to attend
   (Rule: mentions cannot attend certain events or take child to different places)

8. Feels the child is given unfair disadvantages or situations
   (Rule: mentions a sense of loss or unfair attitude towards child’s situation)

9. Care for their child has caused financial stress
   (Rule: child has acquired or requires an excess amount of financial resources that
   puts a strain on the family budget)

10. Receives sufficient assistance and support from family members and friends
    (Rule: mentions assistance from extended family, friends, or community)

11. Stress is affected by the absence of sufficient help and support
    (Rule: mentions lack of assistance with childcare activities)

12. Issues related to the disability significantly added to marital conflict between spouses
    (Rule: indicates that arguments over child care has caused a strain on marriage)

13. Concern over the effects that interactions have with their siblings
    (Rule: expresses concerns over how the sibling has adjusted or feels towards their
    brother/sister)

14. Siblings assist in care giving tasks
    (Rule: mentions sibling assists or presents an example of a routine care task the
    sibling performs)

15. Partake in relaxation or activities he or she enjoys
    (Rule: mentions takes breaks for self or describes relaxing activities that are done
    on a regular basis not related to childcare)

16. Additional irrelevant information is included
(Rule: includes irrelevant information such as telephone number, information about other family members, or detailed descriptions of child’s past medical history)

17. Parent thank researcher for interest in topic

18. Positive child attributes

(Rule: describes any positive attribute of their child with a disability, for example, states he or she is fun to be around or has a wonderful smile)

19. Statements made that allude to taking one day at a time

(Rule: mentions the phrase takes one day at a time or a derivative of the phrase, for example, we take it day-by-day)

20. Expresses stress and concerns caused by child’s involved medical condition

(Rule: specifically describes medical condition as a source of stress)

To further understand the distribution of codes across life stages, Table 10 displays a count of item code frequency. The last column of the graph displays the percent of times each code appears in the total qualitative sample, n=41.

Table 10

*Count of themes coded within the open-ended response for each child life stage*

<table>
<thead>
<tr>
<th>Item response code</th>
<th>Child Life Stage</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Preschool</td>
</tr>
<tr>
<td></td>
<td>Count</td>
</tr>
<tr>
<td>Personally rewarding</td>
<td>1</td>
</tr>
<tr>
<td>Family adjusts</td>
<td>1</td>
</tr>
<tr>
<td>Religious</td>
<td>0</td>
</tr>
<tr>
<td>Concerns over child's future</td>
<td>0</td>
</tr>
</tbody>
</table>
Constantly exhausted  1   5   5    26.8
Time consuming activities  0   4   10   34.1
Feels child unfair  1   1   2    9.8
Financial stress  0   0   3    7.3
Receives assistance  0   2   2    9.8
Does not receive help  0   2   4    14.6
Causes marital conflict  0   0   4    9.8
Worried about sibling  0   1   5    14.6
Sibling assists in care  0   3   3    14.6
Self activities/relaxation  0   0   3    7.3
Positive child attributes  2   3   7    29.3
Goes day by day  1   2   5    19.5
Medical concerns  0   1   4    12.2

Note: Number of participants who provide a qualitative response, Preschool=2, School Age=11, Adolescence=28

Descriptive Analysis

An exploratory factor analysis is used to determine underlying constructs observed within the intercorrelations of the responses from the case interview question. Then the dimensionality of the 18 coded response items from the open-ended response measure is analyzed using maximum likelihood exploratory factor analysis. For the purpose of interpretability, the codes, Additional/irrelevant information and Thanking the researcher, are not included in the factor analysis. The factors are rotated using an
oblique rotation procedure. This rotation will minimize cross products of loadings (Mertler & Vannatta, 2005). The rotated solution, as Table 11 shows, yields 7 interpretable factors: 1. Perspective, 2. External Stressors, 3. Day by Day, 4. Overwhelmed and Overworked, 5. Receives and Requires Assistance, 6. Adjustment Difficulties, and 7. Worries and Conflicts. Items with absolute value loading under .257 are suppressed. Within Table 11, the numbers in parentheses are above the suppressed cut-off but not included in a factor because each loads higher on to a different factor.

One response code (Self activities /relaxation) loads on multiple factors, Perspective and Receives and Requires Assistance. Due to logical interpretability it is placed on the Receives and Requires Assistance factor. Two items did not load onto any factor, the Child is at a disadvantage and Religious attributes. This is not surprising due to the low amounts of parents who endorse these items.

Table 11

Rotated component factor loadings of the coded open-ended responses

<table>
<thead>
<tr>
<th>Loading</th>
</tr>
</thead>
<tbody>
<tr>
<td>Positive child attribute</td>
</tr>
<tr>
<td>Medical concerns</td>
</tr>
<tr>
<td>Financial stress</td>
</tr>
<tr>
<td>Sibling assists in care</td>
</tr>
<tr>
<td>Takes one day at a time</td>
</tr>
</tbody>
</table>
Component 4: Overworked and Overwhelmed
Does not receive help .965
Constantly exhausted .624

Component 5: Receives and Requires Assistance
Receives help from others .777
Time consuming activities .624
Self activities/relaxation .309

Component 6: Adjustment Difficulty
 Limits activities .646
Family adjusts -.562
Personally rewarding experience -.257

Component 7: Worries and Conflicts
Causes marital conflict .796
Worried about effects on siblings .439
Concerns over child's future .422

Note: The extraction method is Maximum likelihood and Oblimin rotation with Kaiser Normalization. The rotation converges in 25 iterations.

Caution must be taken with interpretation. The Eigenvalue criteria are questionable since the number of variables is less than 30, and all communalities are less than 0.7. The Perspective factor accounts for 15.18% of the variance, External Stressors accounts for 11.90% of the variance, Day by Day accounts for 9.66%, Overwhelmed and
Overworked accounts for 8.8%, Receives and Requires assistance accounts for 8.17%, Adjustment Difficulties accounts for 7.11 %, and Worries and Conflicts accounts for 6.87% of the variance. Few items loaded negatively, Positive attributes, Personally rewarding experience, and the Family adjusts. The negative loading slightly complicates factor interpretation.

Furthermore, the structure coefficients show that some items correlate with multiple factors and items in component 6 are all below .7. Chi square fit indices indicate the model is over-identified, $\chi^2(48) =21.039, p <.001$. The Bartlett’s test of Sphericity indicates $(153) =.350$. Additionally, Stevens (2002) recommends not including factors with only one significant Loading, as displayed in two components. Therefore, interpretation of Factor 1 and Factor 3 includes surrounding factors. The represented factors are not reliable.

Correlations. Additionally, a Pearson correlation determines the participants’ stress levels as indicated on the QRS-F in relation to the factors of open-ended themes. The correlation coefficient ranges from $-1$ to 1. A value of 0 implies that there is no linear correlation between the variables. Table 12 displays the correlation matrix.

There is a significant negative correlation at the .01 level between Parent stress and the factors, Adjusts to circumstances and Worries and conflicts. This implies, when participants did not mention items within these two factors, their stress scores elevate more. Additionally, the number of children living in the home positively correlates to the external stressors factor. Participants stress scores reach higher levels when more children live in the home.
Table 12

Pearson Correlation of open-ended response factors, parent stress, and demographics

<table>
<thead>
<tr>
<th>Factors</th>
<th>Parent stress (QRS-F)</th>
<th>Child age</th>
<th>Child gender</th>
<th>Number of children in the home</th>
<th>Adaptive behavior (ABAS-II GAC)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>-.297</td>
<td>.302</td>
<td>.219</td>
<td>-.086</td>
<td>.008</td>
</tr>
<tr>
<td>2</td>
<td>.022</td>
<td>.025</td>
<td>.083</td>
<td>.341*</td>
<td>.174</td>
</tr>
<tr>
<td>3</td>
<td>.045</td>
<td>-.118</td>
<td>-.016</td>
<td>-.004</td>
<td>-.048</td>
</tr>
<tr>
<td>4</td>
<td>-.047</td>
<td>-.113</td>
<td>-.083</td>
<td>.220</td>
<td>-.084</td>
</tr>
<tr>
<td>5</td>
<td>-.007</td>
<td>.000</td>
<td>-.239</td>
<td>.042</td>
<td>-.178</td>
</tr>
<tr>
<td>6</td>
<td>-.361*</td>
<td>-.273</td>
<td>.088</td>
<td>.032</td>
<td>-.172</td>
</tr>
<tr>
<td>7</td>
<td>-.340*</td>
<td>.191</td>
<td>.077</td>
<td>.069</td>
<td>-.083</td>
</tr>
</tbody>
</table>

*Note: A * indicates the correlation is significant at the 0.05 level (2-tailed). The number of participants (n) is 41.

To determine if there is a pattern between the demographics of participants who answered the open-ended question, independent t-tests are conducted. Table 13 displays the results of the t-tests. There is no significant pattern.
Table 13

*Independent t-tests of demographics for participants’ response to the open-ended question*

<table>
<thead>
<tr>
<th>Independent Samples Test</th>
<th>T</th>
<th>df</th>
<th>Sig. (2-tailed)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Equal variances not assumed</td>
<td>---</td>
<td>---</td>
<td>---</td>
</tr>
<tr>
<td>child age</td>
<td>.779</td>
<td>51.733</td>
<td>.440</td>
</tr>
<tr>
<td>parent age</td>
<td>.348</td>
<td>55.579</td>
<td>.729</td>
</tr>
<tr>
<td>parent education level</td>
<td>1.570</td>
<td>57.671</td>
<td>.122</td>
</tr>
<tr>
<td>parent children</td>
<td>.167</td>
<td>55.911</td>
<td>.868</td>
</tr>
<tr>
<td>QRS</td>
<td>-.529</td>
<td>60.343</td>
<td>.599</td>
</tr>
<tr>
<td>ABAS-II GAC</td>
<td>-.804</td>
<td>41.583</td>
<td>.426</td>
</tr>
<tr>
<td>Equal variances assumed</td>
<td>---</td>
<td>---</td>
<td>---</td>
</tr>
<tr>
<td>child gender</td>
<td>.200</td>
<td>66</td>
<td>.842</td>
</tr>
</tbody>
</table>

In summary, the qualitative data consists of responses to an optional open-ended question on the participants’ demographic questionnaire. Sixty-three percent of the sample provides many elaborate supplemental responses. No significant patterns exist between the demographics of the participants in the sample who provided an open-ended response and the demographics of the participants in the sample who did not.

Finally, there is a significant negative correlation at the .01 level between Parent stress and the factors, Adjusts to circumstances and Worries and conflicts. This implies, when participants did not mention items within these two factors, there is an elevation in their stress scores. Additionally, the number of children living in the home positively correlates to the external stressors factor. Participants stress scores reached higher levels when more children live in the home. Chapter 5, Discussion, demonstrates examples of the qualitative data.
Chapter V: Discussion

Summary

Previous research established that parents of children with intellectual disabilities often experience stress, resulting from the worries and demands related to their child’s special needs (Lopez et al., 2008; Minnes, 1998). Within past research, the child’s behavioral differences (problem behaviors) were often examined rather than adaptive skills. Deficits in adaptive behavior may underlie the etiology of problem behaviors in individuals with MR/ID and are therefore a primary training target in the treatment of problem behaviors (Cipani & Spooner, 1997). Although numerous studies have investigated the relationship between problematic child behaviors and parenting stress, the variables of parental stress and differences in the lifespan stages of a child with an MR/ID diagnosis have not been fully examined. More specifically the literature base is lacking within the Adolescence life stage. Existing research examines parent stress with qualitative methodology (Todd & Jones, 2005; Rapanaro et al., 2008). For example, Rapanaro and colleagues (2008) examined stress from providing open-ended questions to parents. Additionally, there is limited research on scales capable of measuring stress during adolescence. The most commonly used parent stress scale only goes up to age 12. Therefore, the area is in need of further exploration.

To extend the literature base on children with MR/ID and parental stress, the present study examined predictors of parent stress in line with developmental family life cycle perspectives. The purpose of the present study was to evaluate the relationship between parent stress and the adaptive skills of their children with MR/ID across life span stages. Participants included parents of children previously diagnosed with MR/ID
between 5 and 21 years of age. Parents were separated according to the child’s age at the
time of participation; Preschool, children 0 to 7 years old; School Age, 8 to 12 years old;
and Adolescence, 13 to 21 years old. Although a low response rate limited the study of
the Preschool life stage, many parental stress factors were described. In addition, the
examination of the Adolescence life stage extended the limited research base. The
following sections examine the results of this study, discuss the limitations the researcher
encountered, and suggest applications for practical use and future research in this area.

Research Findings/Interpretation

The participants’ demographics reflected the general population of students
attending the schools that were approached. Previous research conducted on children and
young adults with a MR/ID diagnosis showed the mother as the primary caregiver.
Therefore, it was not a surprise that most participants of the present study were mothers.
A typical participant was a Caucasian mother, over 46 years old, with an education
beyond the high school level and 2 or more children living in the home, including the
child with special needs. Participants indicated equal amounts of sons and daughters with
diagnoses that included: Autism, Cognitive, Physical or Visual Impairments, or a
Syndrome disorder, for example, Angelmans, Phelem McDermit, or Fragile-X.

The majority of participants were parents of children ages 13 to 21. The
Adolescence life stage group consisted of over half, 66.2%, of the 68 participants. The
life stage group differences could be due to several factors. First, a greater number of
students, ages 13 to 21, attended the schools than students in the Preschool and School
Age life stage groups. Secondly, in the Adolescence life stage, parents have accumulated
more experiences to share. Finally, the researcher had a previous relationship with a classroom in this life stage. Most of the parents of children in this classroom responded.

*Parent Stress vs Adaptive Behavior.* The current study hypothesized that levels of perceived parent stress were higher when their child had limited adaptive behavior ability. Contrary to the hypothesis, ANOVA results showed no specific trend to relate stress and adaptive behavior. Previous research suggested that the presence of behavioral problems in a child with MR/ID represents a significant stressor to the parents beyond the stress of the child’s actual disability (Baker et al., 2002; Baker et al., 2003; Haveman et al., 1997). Although behavioral problems are related to adaptive behavior, research has not examined adaptive behavior in this fashion. The current study’s results added to the research base by suggesting that parent stress and adaptive behavior may not be related in this specific population.

However, the results may be due to the composition of the current study’s sample. Generally, parents rated their children’s adaptive behavior within the Extremely Low range in all domain areas (Conceptual, Social, Practical) and across life stages (Preschool, School Age, Adolescence). This may have indicated that the adaptive measure (ABAS-II) was not sensitive enough to detect differences within the population. Low ratings were not surprising, considering the composition of the schools within the study.

On average, children with severe functioning problems attended these schools. In both schools, many classrooms included a teacher, a teaching assistant, and a variable amount of personal care aides. One parent commented that despite the fact that she answered 0 on many adaptive behavior questions on the survey, her child was capable of
many things but not in the manner asked in the question. Many of the parents had children who were non-verbal but communicated in a variety of ways not detected in the adaptive measure. The typical use of the adaptive measure (ABAS-II) is for diagnosis of MR/ID, which may explain the lack of accommodating adaptations in various areas.

Within the present study, the Social domain presented some variability in parents’ ratings across ABAS-II descriptive category ranges. The Social domain includes interpersonal relationships, maintaining responsibility, endorsing self-esteem, following rules, obeying laws, avoiding victimization and gullibility, and partaking in leisure activities (Harrison & Oakland, 2003). In comparison with the other domains, 11 parents had children with an elevated Social domain, 3 parents had children with an elevated Conceptual domain, and 6 with an elevated Practical domain. The remaining participants showed no elevation between domains, generally because all of their domains fell in the Extremely Low range. Typically in this population, children want to interact with others but often need explicit instruction on how to interact. The majority of participants was in the Adolescence life stage and had received intense social instruction for a longer period of time; therefore, it was not surprising that the Social domain displayed higher adaptive scores than any other adaptive domain or age group. Similar to the total sample in just the Adolescence life stage, 1 parent indicated higher Conceptual scores, 10 parents indicated higher Social scores, 1 parent indicated higher Practical scores, and 32 parents reported similar scores across domains. However, parents whose children had an elevated Social domain, on average, had similar stress levels mostly in the High range as compared to varying stress levels for those with no elevation across adaptive behavior domains.
Differences in Adolescence. The final hypothesis indicated that differences occurred between child adaptive behavior and parental stress within the adolescence life stage. Of the 45 participants in the Adolescence life stage, almost half endorsed high levels of stress. Further testing indicated that the Conceptual domain was most significantly related to parent stress in the Adolescence life stage. The Conceptual domain was characterized by communication (expressive and reciprocal language acquisition and interaction capabilities), functional academics (proficiency in areas of reading, writing, mathematics, and money concepts), and self-direction (self-independence) (Harrison & Oakland, 2003). Significant limitations in the Conceptual domain during the Adolescence life stage could lead to difficulties with abstract concepts, anxiety, and compliance issues that interfere with the self-direction skills. In the Adolescence life stage, as parents are anticipating their child transitioning to secondary schools or work programs, stress increased when their child had not developed functional work related skills or self-independence. At this point many parents consider their own capabilities or options for long-term care agencies.

Past research identifies child age as a major predictor in parents’ adjustment and stress. Parents’ adjustment to their child’s diagnosis of MR/ID was summarized in seminal research by Blacher (1984) as a series of stages. First, initial crisis responses occur, and then parents become emotionally disorganized, followed by emotional reorganization, which leads to positive coping, interaction, and functioning through development. Both DeBildt and colleagues (2005) and Neece and Baker (2008) found that the interaction of social skills with parental stress increases in importance as children mature through the school age years. For example, Neece and Baker (2008) determined
that the interaction between behavior problems and social skills was a significant predictor of parenting stress at age 8 and not age 6. The present study added to this research by examining the interaction in the Adolescence life stage. Although social skills contributed to stress, it was not the main predictor for reported parent stress in the Adolescence life stage. Combining previous and present research may imply that parent stress is heightened by a child’s lack of social skills during the School Age life stage, but when the child is younger or older, it is not as important.

Interestingly a regression determined that the Practical domain did not contribute to parent reported stress scores. The Practical domain is associated with self-care, health and safety, community use, and home life.

Descriptive Analysis. While the results of the research questions were limited, the importance of stress and adaptive behaviors in the field of MR/ID is too profound to only be investigated in one manner. Therefore, a case interview question was examined to provide perceptions of parental stress in the moment. Sixty-three percent of parents in the sample wrote a response to this question. Many parents filled an entire page with editorials; some even typed multiple pages of responses. It appeared that many participants enjoyed the chance to express their opinions without limitations or felt that their experience of stress was being acknowledged. Several responses included comments of gratitude, “Thank you for listening” or phone numbers with responses to call for further information. No significant patterns existed between the parents who provided an open-ended response and those who did not.

A content analysis of the statements was then conducted and expressed in common themes based on the answers. However, this information should be interpreted
with caution because there was no cuing of responses. This implies that participants may endorse themes that they did not include in their open-ended responses. Responses were coded as possessing the following themes: The family adjusts to change the same as if their child did not have a disability; Religious faith and/or belief assisting in family functioning; The interaction and experience is personally rewarding; Stress is a result of concerns over the child with a disability’s future; A feeling of constant exhaustion and being tired or overwhelmed; Stress is a result of their child requiring extra assistance and engaging in time consuming activities; The child’s disability limits the activities that the family is able to attend; Feels the child is given unfair disadvantages or situations; Care for their child has caused financial stress; Receives sufficient assistance and support from family members and friends; Stress is affected by the absence of sufficient help and support; Issues related to the disability significantly added to marital conflict between spouses; Concern over the effects that interactions have with their siblings; Siblings assist in care giving tasks; Partake in relaxation or activities he or she enjoys; Inclusion of additional irrelevant information; Thanking the researcher for interest in topic; Describing any positive attribute of their child with a disability; Statements made that allude to taking one day at a time; Expresses stress and concerns caused by child’s involved medical condition. Many identified concerns were similar to past qualitative research, for example, Rapanaro and colleagues (2008) identified major concerns over providing future care, lack of access resources, and issues relating to their child’s independence or dependence.

For descriptive purposes, a factor analysis was conducted to place the themes into factors. The following 7 interpretable factors were formed: 1. Perspective, 2. External
Stressors, 3. Day by Day, 4. Overwhelmed and Overworked, 5. Receives and Requires Assistance, 6. Adjustment Difficulties, and 7. Worries and Conflicts. A description of the factors and their affects on parent stress and adaptation are described in the following paragraphs. Some factors are described together because they cannot be reliably interpreted alone.

Adaptation. Current literature trends on family adaptation recognize the importance of interacting variables, such as coping processes, supports, diagnosis, behaviors, adaptive behavior, age, and external pressures between children diagnosed with MR/ID and their families (Haveman et al., 1997; Lopez et al., 2008; Neece & Baker, 2008; Siklos & Kerns, 2006). The family systems approach suggested that there were several interacting factors initiating and controlling parent stress levels, which led to adaptation.

In the current study, the subjective experiences of these families expressed in the open-ended response often emerged in the factors, Day by Day and Receives and Requires Assistance. Day by Day refers to parents who live and deal with stress by taking one day at a time. This accounted for 9.66% of parents. Receives and Requires assistance explained 8.17% of parents. This factor entails parents receiving help from others in their family and community, engaging in time consuming child care activities, and taking time for relaxation and enjoyable activities. The following quotes were examples of some responses that fell in these factors.

‘We do the normal family activities just adjusted slightly. The day to day things are sometimes difficult. If I need to go to the grocery store and my husband is working, then I have to manage a cart and a wheelchair at the store. I think it’s
something you just adapt to and eventually don’t even think about doing it. --- is a
blessing to our family and we will work and do work around any obstacles.’

‘Being a parent of a special needs child is no different than being a parent
to a child who plays baseball, football, or one that plays in the band from an early
age- they network and communicate and so do we, the parents of children with
special needs. It was necessary and still is at times to adjust our schedules, but
again it is no different than any other family that is trying to balance multiple
children going in multiple directions all at the same time. Our family has learned
to adjust, go on with life, and when you hit a bump, pick yourself up, dust off, and
move on.’

The majority of parent responses implied or directly stated that every second of
their day is devoted to their family. Many parents submersed themselves in this rule and
forgot or did not leave time for themselves. However, 2 participants stated that taking
time for themselves helped them provide care for their family. For example, “We (mother
speaking of herself and husband) have also realized that the only way you can care well
for a handicapped child is to take care of yourself first. In some sense, one must be a little
selfish and always remember to take time to do something for yourself. You are then able
to better care for your child.” Both parents that endorsed taking time for themselves fell
within the Adolescence life stage group and displayed relatively low stress scores on the
QRS-F.

Two participants noted that they received some kind of comfort or solace from
their faith community. One parent wrote of the close knit special needs community and
the relationships formed from support groups. However, a consistent trend seemed to appear that while some participants noted that friends, neighbors, family members, and coworkers understood their situation and were able to support them emotionally, many participants struggled finding instrumental support, such as a flexible work schedule or child care. For example, one parent stated, “I have to be home for him to get off the bus. It’s not a job where I can call a neighbor or have my older son help him off…. I would like to go back to work, but my options will be limited as I will have to get home before him, guaranteed.” This observation changed over the child life stages. Within the School Age life stage, grandparents played an instrumental role in supervising the child and supporting the parent. Within the Adolescence stage, grandparents were not mentioned as providing this support, and parents struggled to find reliable childcare.

Negative adaptations. Negative adaptations were frequent within the responses. Family stress is defined as a state that arises from an actual or perceived imbalance between demand and capability in the family’s functioning (McCubbin & Patterson, 1983). Therefore, it is important to reflect on how a parent interprets their situation. However, in current research, significant variability is reported in the degree of experienced parental stress. In the current study, the Perspective factor explained most (15.8%) responses, and it accounted for those who did not mention a positive attribute about their child. Additionally, the Adjustment Difficulties factor accounted for 7.11 %. This factor represented limited activities the family is able to attend, a lack of personally rewarding experiences, and a lack of statements that depict the family simply adjusting. The factor Overwhelmed and Overworked accounted for 8.8% and also depicted negative adjustments.
Some parents indicated their families’ lives have changed by limiting their ability to attend recreational activities, including shopping, dining out, and family vacations. This pervasive effect of having a child with a disability has been noted in other research (Dyson, 1997; Spratt et al., 2007). One parent noted, “So much to deal with and take care of: doctors, hospitals, therapists, insurance companies, in home caregivers, school, the MH/MR system, state, school districts, etc. Not to mention my daughter, and no family support near me. If something happened to me, there’s no one to care for her.”

Many mothers reported that much of the responsibility for child rearing fell to them, (only females completed the open-ended question), and this perceived inequality contributed to stress. When parents did not mention items within this factor, there was an elevation in their stress scores. The necessity of schedules became more burdensome with these families, “Living with --- is by no means easy, but we love her. Spontaneity is not a word that is used a lot to describe our family activities. Nothing can happen without careful planning!” However, some parents reported that this constant planning did not always pay off.

‘I feel guilty when I’m not spending time with my son, since he does absolutely nothing then. But even when I do spend time directly with him, it doesn’t seem to make much difference. Sometimes I think I’m driving myself crazy for no reason because he seems bored but not happy. I think that when people spend a lot of time doing something, they want to see results, and with a child like this, there are really no tangible results or at most, very few. You have to just let go of expectations and enjoy the moment in time with them, otherwise you might go crazy.’
Adaption Aspects. The External Stressors factor included financial concerns, medical needs, and requiring siblings to assist in child-care. It accounted for 11.90% of responses. Taking a demographic stance, the only major characteristic that was associated with the External Stressors factor was the number of children living in the home. Therefore, parents stress scores reached higher levels when more children lived in the home. This was a logical similarity because the addition of each child, with a disability or not, brings further financial strain and medical care.

Worries and Conflicts accounted for 6.87%. Some participants were coping with a sense of loss or concern for the future. A parent stated, “The firsts that she will never experience like getting married, holding her first newborn in her arms, going to her prom, and her first boyfriend are probably the hardest things for me.” When parents did not mention items within this factor, there was an elevation in their stress scores. This inverse relationship may be due to how well adjusted the parent is according to Blacher’s stages. If a parent is having trouble excepting the present situation, he or she has not moved on to have concerns over the future.

Life Span Perspective. Previous research had not closely examined the differences in parent stress throughout the life stages of their child with MR/ID. Parents’ expectations and beliefs begin often before their child is born and are modified through interactions with the developing child (Kuhn & Carter, 2006). One parent stated, “She is 21 now. If you asked me about stress when she was younger, I would have a different answer, since all younger children come with their own set of stressors.” Another parent noted the
commitment they have made as they grow older. “We bought a house with a basement that can be converted to an apartment so --- can stay near us.”

Research suggested that stress can be a reflection of how an individual perceives the situation he or she is in. The following quote was a reflection from a caring parent.

‘So much time has passed since he was born. About the best I can do is comparing my life as it is to what I think it would have been like without him. Certainly, I know without a doubt, I am a better parent and person because of having him. I am more patient, more loving, more accepting of other people, and have a much better understanding of life.’

Another parent described behavioral issues of her daughter to explain her view on being a parent. ‘She was dealing with her disability the best way she could--- most children want to please their parents and try their hardest to do so –she was very different- she was doing her best… I would rather have and take care of her knowing what her issues are and that they were beyond her/our control. It’s my job to help her be the best she can be – I accept that. It’s part of being a parent.”

Another parent summed up her experience by stating, “The best way I can describe having a child with a disability is a roller coaster ride. Sometimes it’s calm and emotions are at bay and you’re having fun, then it gets overwhelming, and you feel it’s not possible to do another minute.” In all, parents interpret their situations through many factors from support and demands to the degree of their child’s ability to function in various situations. Parent stress is caused by the impact in which each parent believes that these factors contribute to their lives at any given time over a lifespan.
Limitations

The main limitation of this study was the response rate and final sample size. Initially, the researcher had intended to conduct a 3x3 two-way ANOVA with child life stages (Preschool vs. School Age vs. Adolescence) as a between subjects factor and adaptive behavior (Social vs. Practical vs. Conceptual) as within subjects. However, as determined by a statistical power analysis using G*Power version 3.0.10 (Budner, Erdfelder, Faul, & Lang, 1997), a minimum sample size of 108 was necessary to detect a statistical significance, with a significance level of .05, a moderate effect size (f = .25), and power set at .95. Despite the 223 distributed surveys, only 72 participants responded, indicating a low return rate of 32%. This return rate limited data analysis significantly. Additionally, most of the received data did not display variability within the adaptive measure (ABAS-II). Data collected within the skills section often received a scaled score of 1, the lowest score available.

Several factors may have contributed to low participation rates. First, a majority of the surveys were distributed at the end of the school year, a busy time for many families. Second, the targeted population had many time demands and elevated stress due to the nature of their child’s disabilities. These stressed families may not have had the time to complete the surveys.

The results of the present study may have been limited because of the restricted range of adaptive skills observed in the present sample. A majority of the researcher’s present data was scored as the lowest ABAS-II standard score addressed in the manual. Many participants had children with very limited adaptive abilities, which caused little variability within the ABAS-II’s subdomains. The full range of possible standard scores...
on the ABAS-II GAC is 40 to 150. Generally, individuals with the MR/ID diagnosis have standard adaptive scores from 40 to 75. However, scores in this sample ranged from 40 to 93, and the GAC mean score was 49.51. Of the Adolescence life stage group, 22 participants rated GAC skills as the lowest standard score, 40. Thus, the range of scores in this sample was restricted when compared to the possible range of scores on the ABAS-II, including those with MR/ID. The low adaptive scores in turn caused a negative skew of the data. This information can be interpreted as a limitation of the ABAS-II.

While the ABAS-II is one of the most widely used instruments for the assessment of adaptive skills, it may not adequately assess the adaptive skills of lower functioning individuals.

Based on this observation of the data, it seems possible that the choice of selection of participants from 2 private special needs schools was limiting. Often, individuals attend private schools due to their limited abilities to function independently within public schools. Therefore, the participants in this study already represent a population that engages in limited adaptive behavior. Perhaps the use of a sample of individuals with MR/ID attending both private and public schools would have provided a wider range of adaptive behaviors and therefore may have increased the likelihood of finding a stronger relationship. The present study, however, can be viewed as providing valuable information for individuals with lower functioning and more severe deficits in adaptive skills.

The measures chosen limited the ability of statistical tests to find significance. The stress measure (QRS-F) was a self-report questionnaire, which is subject to response bias. The use of self-reports may have limited the findings concerning helpfulness of
coping strategies and the type of child’s disability. Additionally, the research base on stress measures for parents of children with special needs is limited, which affects the measures reliability.

Another shortcoming of the study was that the majority of responses were from Caucasian mothers. Mothers’ and fathers’ ratings were not collected separately on the same child. Mothers’ and fathers’ ratings of their children’s abilities have been shown to have both a shared component and an individual view component, suggesting that parents may experience their child’s behavior problems differently (Rowe & Kandel, 1997). Previous research has shown that father’s stress is also affected by the child’s behavior problems (Baker et al., 2003), but the contribution of children’s social skills to fathers’ parenting stress has yet to be determined. Future research should be done on additional and larger populations for a more diverse sample.

Implications

It is important to consider the implications that perceptions of parenting stress may have on overall functioning for these families, as well as interventions. Information about the relative impact of family resources and the child's level of developmental impairment on parental stress would not only help in identifying which parents are more at-risk for adverse symptomatology but would also assist in designing more specific intervention strategies to prevent long-term stress effects in families of children with and without disabilities. Individuals with MR/ID and problem behaviors are known to display deficits in adaptive skills, but these deficits are inherent in the definition of MR/ID (APA, 2004; Luckasson et al., 2002) Adaptive skills are the first step to independent living and therefore of critical importance.
In adolescence, as parents are anticipating their child transitioning to secondary schools or work programs, stress increases when their child had not developed functional work related skills or self-independence. In addition to promoting independence, adaptive behavior deficits may lead to the skill void being replaced with the problem behaviors of aggression, self-injury, and stereotypy (Cipani & Spooner, 1997). The primary method used for the assessment and treatment of problem behaviors is based on function that the maladaptive behavior serves for an individual. This methodology is based on the theory that an individual with MR/ID who engages in problem behaviors lacks more appropriate adaptive behaviors. Therefore, if an adaptive behavior is taught to replace the maladaptive one, the individual may engage in lower rates of the problem behavior. The results of the present study have both theoretical and practical value within the field of parental stress and MR/ID. Adolescence programs should target teaching expressive and reciprocal language acquisition, work trade skills, and self-independence. Another important point that programs can address is teaching parents how to teach these skills, especially aspects of vulnerability and gullibility. Parent stress in the Adolescence life stage can improve by parents seeking out support networks and for schools to provide resources readily available to deal with additional stressors.

A practical application of this would be for school districts to have an understanding of stress within the home and to assist with interventions and flexibility as often as possible. Many parents do not have an outlet for stress and embrace the chance to express their opinions without limitations. When providing treatments to the child, parent limitations must be considered. A systems approach is very important with this
cliental, and to help the child, clinicians must be sensitive to and listen to the stressors parents encounter.

The final implication involves the use of the adaptive measure ABAS-II. Traditionally, the main use of the adaptive measure ABAS-II is for diagnosis, an appropriate application, however, a trend in research indicates its use for progress monitoring as well. An implication of the present study may be for psychologists to be aware that the adaptive measure (ABAS-II) may not be sensitive enough to detect differences within children with severe functioning problems or non-verbal.

Future Research Recommendations

Further research is needed in the field. The conclusions from the present study indicated a limited relationship between parental stress and specific adaptive skills in individuals with MR/ID. This portion of the study highlighted the need to expand research to include a wider range of individuals with varying levels of functioning, personality style, and coping strategies. Future research could explore how the child’s disability affects other family members, such as siblings and the extended family, and the possibility of family enmeshment. Personal interviews could be conducted to strengthen and support the information received on the questionnaires. Also, it is encouraged that future researchers examine adaptive behavior across a life cycle. With a larger number of participants, a trend may be evident.

Concluding Thoughts

To conclude, stressors are evident across a lifespan, and family adjustment, style, resources, and perception determine the impact on parents. Every family experiences stress or an actual or perceived imbalance between demand and capability throughout the
life span of raising a child (McCubbin & Patterson, 1983). Children with MR/ID reach developmental milestones in atypical patterns which are often delayed. The continual delayed achievement of each developmental milestone may become a source of heightened stress at different periods of a child’s life. Without proper support, awareness, and assistance, parent stress levels can remain high throughout their child’s lifespan. The teaching of adaptive behaviors to children with MR/ID may positively impact the child’s functioning and the parents health in improving stress levels.
REFERENCES


http://www.psycho.uni-duesseldorf.de/aap/projects/gpower/

Harrison, Patti L., Oakland, Thomas. Mental Measurements Yearbook, 16.


Appendix 1: DEMOGRAPHICS

Please circle each answer that best describes your child diagnosed with a disability.

1. What is the age of your child? _______ years old

2. What is the gender of your child with a disability? Male Female

3. How would you describe your child’s disability? Please circle all that apply.
   Cognitive Disability Vision/Hearing Impairment Autism
   Physical Disability Traumatic Brain Injury Syndrome Disorder

4. How would you describe your child’s impairment? Mild/Moderate Severe

5. At what age was your child diagnosed with a disability? 0-6 7-11 12-21

Please circle the responses that best describe you or fill in the blank with appropriate responses.

1. What is your relationship to the child with a disability that you are rating?
   Father Mother Legal Guardian Other (Please specify) _______

2. Which ethnicity group(s) do you consider yourself to be a member of?
   Caucasian African-American Hispanic Asian Other

3. What is your age? 18-25 26-35 36-45 46+

4. What best describes your education level?
   Grade school High school diploma Some advanced training
   College degree Masters level degree Doctoral level degree

5. How many children live with the family? _______

6. Please indicate all additional children’s gender, age, and disability (if present).
   Male Female Age:_______ Disability __________________________
   Male Female Age:_______ Disability __________________________
   Male Female Age:_______ Disability __________________________
(Optional) Describe what it is like living with a child with a disability and its impact on stress in your day to day life?

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
Appendix 2

A SHORT-FORM OF THE QUESTIONNAIRE ON RESOURCES AND STRESS (Friedrich, Greenberg, & Crnic, 1983)

This questionnaire deals with your feelings about a child in your family. As you look at the questionnaire, imagine the child’s name filled in on each blank. Give your honest feelings and opinions. Please answer all of the questions, even if they do not seem to apply. If it is difficult to decide True (T) or False (F), answer in terms of what you or your family feel or do most of the time. Remember to answer all of the questions.

1. Other members of the family have to do without things because of ______. T F
2. Our family agrees on important matters. T F
3. The constant demands for care for ______ limit growth and development of Someone else in our family. T F
4. I have given up things I have really wanted to do in order to care for ______. T F
5. ______ is able to fit into the family social group. T F
6. In the future, our family’s social life will suffer because of increased Responsibilities and financial stress. T F
7. I can go visit with friends whenever I want. T F
8. Taking ______ on vacation spoils pleasure for the whole family. T F
9. The family does as many things together now as we ever did. T F
10. I get upset with the way my life is going. T F
11. There are many places where we can enjoy ourselves as a family when ____ comes along. T F
12. It is easy for me to relax. T F
13. I get almost too tired to enjoy myself. T F
14. There is a lot of anger and resentment in our family. T F
15. The constant demands to care for ______ limit my growth and development. T F
16. I feel sad when I think of ______. T F
17. Caring for ______ puts a strain on me. T F
18. Members of our family get to do the same kinds of things other families do. T F
19. I rarely feel blue. T F
20. I am worried much of the time. T F
Appendix 3

COVER LETTER

May, 2009

Dear Parents,

My name is Wendy HuWalt, and I have been working at The Day School at the Children’s Institute as an intern for the past year under Dr. Mary Denison. Currently, I am a doctoral candidate completing my dissertation in School Psychology at Duquesne University in Pittsburgh, PA. I am involved in research investigating several aspects of parenthood that may be related to perceptions of parental stress. I am collecting information from parents of children with Mental Retardation/ Intellectual Disabilities between the ages of 0 and 21.

Enclosed is a questionnaire that includes statements of parental stress and child adaptive behavior, in addition to brief demographic information regarding family characteristics. It is my hope that the data obtained will be useful to other families and individuals who will work with families who have children with special needs. Your participation is entirely voluntary, and your answers will be kept anonymous. There is no place for your name or address on the questionnaire. All information will be kept anonymous, and the data collected will remain anonymous through the use of code numbers and be analyzed in aggregate form only.

Your name will be entered into a drawing for a $50.00 gift certificate after the school receives the completed questionnaire. Also, parents may request a copy of the results of this study when they receive their packet. If you choose to participate, your total time commitment will be approximately twenty minutes. I would be extremely grateful if you could help me by completing the attached questionnaire and returning it in the enclosed addressed, stamped envelope by mail or sending it back in your child’s book bag by June 5, 2009.

If you have any questions, please feel free to call my research advisor, Dr. Mary Denison, at (412) 420-2318 or myself, Wendy HuWalt at (412) 965-2086.

Thank you for your time!

Wendy HuWalt, M.S.Ed.
CONSENT FORM

DUQUESNE UNIVERSITY

600 FORBES AVENUE ♦ PITTSBURGH, PA 15282

CONSENT TO PARTICIPATE IN A RESEARCH STUDY

TITLE: Children with Mental Retardation / Intellectual Disability: The Function of Adaptive Behavior and Parental Stress Across Childhood

INVESTIGATOR: Wendy (HuWalt) Westwood, M.S. Ed.
Duquesne University
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(412)-965-2086 huwaltw@duq.edu

ADVISOR: Kara McGoey, Ph.D., NCSP
Duquesne University
Department of Counseling, Psychology, & Special Education
209A Canevin Hall, Pittsburgh, PA 15282
(412) 396-4105 mcgoeyk@duq.edu

SOURCE OF SUPPORT: This study is being performed as partial fulfillment of the requirements for the doctoral degree in School Psychology at Duquesne University

PURPOSE: You are being asked to participate in a research project that seeks to investigate parental stress differences among children’s adaptive behavior and childhood life stages. In participating in this study, you will be asked to respond to questions and complete rating scales related to your stress levels and your child with a disability’s adaptive behavior skills. These are the only requests that will be made of you.

RISKS AND BENEFITS: There are no risks greater than those encountered in
everyday life. This research should provide valuable information about the variables impacting stress in parents in efforts to provide preventative support.

COMPENSATION: There is to be no monetary compensation for participation. However, participants will be entered into a drawing for a $50 gift card. Participation in the project will require no monetary cost to you. A stamped envelope is provided for return of your response to the school.

CONFIDENTIALITY: Your name will never appear on any survey or research instruments. No identity will be made in the data analysis. All consent forms will be maintained by the school your child attends. Your response(s) will only appear in statistical data summaries. All materials will be destroyed at the completion of the research.

RIGHT TO WITHDRAW: You are under no obligation to participate in this study. You are free to withdraw your consent to participate at any time, and should you choose to withdraw at any time during the study, you may request that any information already collected will be destroyed.

SUMMARY OF RESULTS: A summary of the results of this research will be supplied to you, at no cost, upon request.

VOLUNTARY CONSENT: I have read the above statements and understand what is being requested of me. I also understand that my participation is voluntary and that I am free to withdraw my consent at any time, for any reason. On these terms, I certify that I am willing to participate in this research project.

I understand that should I have any further questions about my participation in this study, I may call Wendy (HuWalt) Westwood, Principal Investigator 412-965-2086, Dr. Kara McGoey, Advisor 412-396-4105, or Dr. Paul Richer, Chair of the Duquesne University Institutional Review Board 412-396-6326.

Participant's (Parent) Signature Date

Researcher's Signature Date