EXPLORING RESILIENCE AMONG LOW-INCOME AFRICAN AMERICAN FAMILIES WITH A YOUNG ADULT MEMBER WITH MILD MENTAL RETARDATION

By

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To my incredible family
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EXPLORING RESILIENCE AMONG LOW-INCOME AFRICAN AMERICAN FAMILIES WITH A YOUNG ADULT MEMBER WITH MILD MENTAL RETARDATION

By

Mary Catherine McCue

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To reduce the negative stigma of caring for a child with a developmentally disabled family member, researchers have begun to look with a more positive lens at families’ experiences of living with a child with a disability. Although positive impacts have been reported among white middle class populations, culturally diverse populations living in poverty have not been studied. The purpose of this study was to develop a theory describing the lived experiences and resiliency of low-income African American families having a young adult member with mild mental retardation. By gaining a greater understanding of the unique strengths possessed by these families, professionals can more effectively intervene with and advocate for them.

Two low-income African American families caring for a young adult with mild mental retardation were interviewed for this study. A series of twelve individual and four family group interviews were conducted and the data were analyzed using grounded theory methodology. From this analysis, a theory about the resilience of these families was developed depicting an intricate process by which the participating families created shared beliefs, communications styles and constructed meanings about the adversities
they experienced. This theory was composed of three major dimensions: overarching beliefs, collaborative communication, and positive meaning making.

The theory that emerged from this study expands on existing family resilience theory by depicting the distinctive beliefs, communication patterns and efforts to reframing adversity that characterize the strengths of these low income African American families. The results of this study affirm the need for professionals to learn about the unique resources possessed by low-income African American families caring for a young adult with mild mental retardation and to use those resources in planning a course of treatment.
CHAPTER 1
INTRODUCTION

Social scientists view families having a member with a developmental disability as living under an umbrella of "stressful circumstances." Most research on such families is marked by the longstanding and pervasive belief that the birth of a child with a developmental disability is a tragedy encompassing lifelong struggles for their families. For example, several studies have reported that there is a greater risk of high stress levels and depression among parents of children with developmental disabilities as compared to parents of non-disabled children (Eisenhower, Blacher, & Baker, 2005; McIntyre, Blacher, & Baker, 2002; Baxter, Cummins, & Yiolitis, 2000; Cummins, 2001). Additionally, these parents have reported increased feelings of isolation and stress in addition to a decreased ability to cope when discussing their child’s transition into adulthood (Whitman, 2008). Moreover, a study conducted by Risdal and Singer (2004) reported the negative impacts of disabilities on parents and families, including destructive influences on marital relationships.

Although there is little dispute that caring for a family member with a developmental disability adds additional stressors to individual and familial life, during the 1980’s several researchers began to look with a more positive lens at families’ experiences of living with a child with a disability. Questioning why children with a disability were seen so negatively, these researchers began to shift from a deficit orientation to investigating factors that promoted health, well-being, quality of life, protective factors, resilience and empowerment in these families. Using this new perspective, questions began to be asked and new measures developed to explore the
positive adaptation, quality of life, and benefit to families of having a family member with a disability (Risdal & Singer, 2004).

Few studies have used this positive lens to study the experience of low-income culturally diverse families caring for a young adult with a developmental disability. Instead the samples used have overwhelmingly been comprised of White middle class mothers caring for children with developmental disabilities. Yet while persons from diverse cultures with a disability and their families are under-represented in current research, they are overrepresented in this diagnostic category. Because low-income culturally diverse populations caring for a young adult family member with a disability are severely underrepresented in the research literature, their experiences and lives need further examination.

**Scope of the Problem**

The majority of research on families with a developmentally disabled member is deficit based. Researchers have consistently reported that there is a greater risk for high stress levels and depression in parents of children with disabilities (Blacher & Baker, 2002; Glidden, 1989). The majority of disability research has focused on the mother’s adaptation to a child with a disability. In a study conducted by Bristol, Schopler, and Gallagher (1998), the researchers found that “mothers of developmentally disabled children carry a disproportionately heavy burden” (p. 449) and these parents “report significantly more marital difficulties than their peers with nondisabled children” (p. 449). In addition Hassall, Rose, and McDonald (2005) found that mothers of children with developmental delays experienced significantly elevated stress levels.
Current literature does not provide an ample understanding of the strengths families possess or the unique qualities that families bring to the experience of having a member with a developmental disability. Researchers Hassall, Rose, and McDonald (2005) recommended that future research “examine the potential buffering effects of positive experiences of caring for a disabled child on the parents’ emotional state” (p. 415).

In addition, there is little understanding of how families function either as individuals or as a whole unit. Current research is focused on individual family member’s views such as mothers’ and siblings’ experiences of caring for an individual with a disability. Hastings, Kovshoff, Ward, degli Espinosa, Brown, and Remington (2005) suggested that “a more dynamic and more comprehensive systematic analysis of family functioning is needed to help develop successful interventions for families of children with disabilities” (p. 643). Research that focuses on the families’ collective views and how this shapes their understanding of the experience and adaptation is currently unavailable.

Moreover, impoverished African American families caring for a family member with a developmental disability are a neglected population. These families have several social and cultural factors to contend with yet they continue to survive. Yet most of the current research lacks sensitivity to the community and cultural factors that influence how resilience is defined by different populations and manifested in everyday practices (Ungar, 2008).

Instead the majority of resilience research is focused on mainstream populations and their definitions of healthy functioning. According Young, Green, and Rogers
a problem with current resilience literature is that it does not account for socially and culturally constructed definitions of resilience, nor does it depict what resilience means to marginalized groups. According to Seccombe (2002), resilience needs to be understood as a quality of the environment as much as the individual: “The widely held view of resiliency as an individual disposition, family trait, or community phenomenon is insufficient…resiliency cannot be understood or improved in significant ways by merely focusing on these individual-level factors. Instead careful attention must be paid to the structural deficiencies in our society and to the social policies that families need in order to become stronger, more competent, and better functioning in adverse situations” (p.385).

Hence, there is a need for an inquiry into what resilience means in different cultures and contexts. Looking at the strengths and resources of culturally diverse families can assist people in formulating appropriate intervention and prevention strategies. Hence determining what it means to be resilient in a low-income African American family with a young adult with mild mental retardation needs further exploration.

Low Income Families with an Intellectually Disabled Child

There is not a consistent definition of poverty in the current literature. Instead, there have been multiple ways used to classify poverty. Researchers have relied upon personal reports, data bases, national averages, or study delineations when accounting for socioeconomic status (SES). Even so, researchers have found that there are more children in poverty with a disability than without a disability. There appears to be a significant link between disability and poverty. Emerson (2004) reported that, “children with intellectual disabilities are at a greater risk of experiencing poverty than non-
intellectually disabled children” (p. 324) and “the experience of poverty is likely to have a negative impact on the health and well-being of mothers of children and upon family functioning” (p. 324). Fujiura and Yamaki (2002) reported among “children with disabilities aged 3 to 21 in the United States, 28% are living in poor families” while “children without disabilities in the same age range, only 16% are living in poverty.” However the researchers judged this to be a modest difference.

Families living in poverty who have a member with a disability are at an even greater risk for developing negative consequences in relation to their quality of life. These families are often categorized and misunderstood. Throughout childhood, children may experience risk factors that may threaten their social and emotional development, such as poverty, divorce, death, family discord or disability. Children and families often respond to these stressors with symptomatic behaviors, whether expressed externally (aggression) or internally (depression). These symptomatic behaviors for children and families living in poverty are often heightened by the narrow and negative climate in which they are viewed. Observation, identification, and labeling may occur for these families (Lamb-Parker, LeBuffe, Powell, & Halpern, 2008).

These families contend with the stress surrounding the family member with a disability as well as stressors that accompany low income such as financial stress, limited supports, and segregation. Park, Turnbull, and Turnbull (2002) found that “low-income adults are more likely to suffer from stress and mental health problems due to difficult life events such as not being able to pay their bills, being evicted, losing their jobs, moving frequently and worrying about money” (p. 157). Researchers have found that not only is having a member with a disability a stressor, but living in poverty is also
a family stressor. The combination of the two stressors often increases the amount of
strain and discomfort a family feels.

In a study conducted by Emerson, Hatton, Liewellyn, Blacher, and Graham (2006),
the researchers “suggest that failure to address SEP (socio-economic position or socio-
economic status) is likely to reinforce an overly ‘pathological’ orientation in which
children with ID’s (intellectual disabilities a.k.a. mental retardation) are implicitly
assumed to be a ‘burden’ and a punitive cause of maternal stress” (p. 869).

These families need to be appropriately assessed and understood from a strength-
based perspective rather than the persistent deficit based perspective. There needs to
be a shift from the negative lens focused on poverty and disability to a strength-based
focused on resilience lens. This is a neglected population whose voices need to be
heard. There needs to be an understanding of families having a young adult member
with a disability and the context in which they live, including socioeconomic and ethnicity
factors. There are low-income families living with a young adult with a disability who are
surviving their experiences. There is little doubt that these families face multiple
challenges, yet it is important to view positive experiences and strengths forged through
adversity.

Rather than continuing to build upon the seemingly hopeless situations of these
families, understanding how they survive, maintain, grow, and adjust may be paramount
to creating appropriate supports, identifying needed resources, enhancing self-
sufficiency, and acquiring a richer understanding of their lives. According to Robinson
and Rathbone (1999), “factors such as poverty, racial and ethnic discrimination, and a
lack of culturally competent service systems continue to interfere with the delivery of needed…services” (p. 334).

**Transition to Adulthood**

The dominant focus in the current body of disability research is on the impact on families of children with disabilities. This is reasonable as the majority of children with developmental disabilities reside in the family home. However, a considerable percentage of adults with developmental disabilities also reside in the family home (Braddock, Emerson, Felce, & Stancliffe, 2001). Among young adults with mental retardation approximately sixty percent live in the family home (Braddock, 1999). Moreover, families of individuals with developmental disabilities have reported challenges during young adulthood (Timmons, Whitney-Thomas, McIntyre, Butterworth, & Allen, 2004). The transition to adulthood has been reported by these families as a time of “increased isolation and stress with decreased ability to cope” (Whitman, 2008, p. 460).

Additional stressors are seen when low income families caring for a member with a developmental disability face challenges at various life stages. One of the most significant life stages occurs when the child with a developmental disability transitions to adulthood. Research has found that there are multiple factors to contend with when faced with the transition to adulthood for an individual with a disability. In a study conducted by Timmons, Whitney-Thomas, McIntyre, Butterworth, and Allen (2004) investigating the transition experiences of parents of young adults with disabilities, the researchers found that parents face significant and at times overwhelming challenges.

These families of young adults with developmental disabilities receive little guidance from formal services and no school resources. This is in part due to the
individual with a developmental disability no longer meeting criteria used for determining service eligibility (Tymchuk, Lakin, & Luckasson, 2001). Because of discontinuities between school and post school life these individuals are at risk for exploitation, neglect and abuse.

As a result, the families’ role must change as the caregivers must now advocate for and locate services that had previously been available through school resources. This can cause additional stressors as the family is responsible for finding services and resources for the family member with a disability which they previously did not have to do. Of additional concern is that researchers have found that individuals living in poverty are less likely to have access to services and resources in the community (Robinson & Rathbone, 1999). For these families they have a new responsibility that they are not prepared for and may not have the knowledge, skills or resources to face this new responsibility.

For many individuals with mild mental retardation, the transition from school to adult life is met with failure due to poor to no preparation, limited family support, and monetary constraints (Tymchuk et al., 2001). Much of this failure can be attributed to the lack of transition services available to individuals and their families (Ludlow, Turnbull, & Luckasson, 1988). Up until the individual with a disability is 22 years of age they are inundated with services generally offered through the school system. Once an individual turns 22 years of age there is a drastic and significant decline in available resources.

There has been a dearth of research focused on studying low-income families with a young adult with a developmental disability during the transition to young adulthood. This limited attention on this population has “placed these individuals in an increasingly
vulnerable position within society” (Tymchuk et al., 2001, pg. 22). Current literature does not adequately describe low-income families with a member with a disability during the transition to adulthood.

**African-American Families**

Culturally diverse families and individuals are not highlighted in the disability research. The majority of research focusing on African American individuals focuses on the disproportionate number of African American students represented in special education programs in school. Parrish (2002) reported that African American students are the most overrepresented group in special education programs in nearly every state. There is a disproportionate representation of African Americans labeled with mental retardation and emotional disturbance with African American students being 2.88 times more likely than European American students to be labeled as mentally retarded and 1.92 times more likely to be identified as emotionally disturbed.

Researchers suggest that culturally diverse students, especially African Americans, are overrepresented in more restrictive educational environments and underrepresented in less restrictive environments (Skiba, Poloni-Staudinger, Gallini, Simmons, & Feggins-Azziz, 2006). Additionally, Serwatka, Deering, and Grant (1995) found that across disability types, African American students are more readily placed in segregated settings than European American. African American students may receive unequal access to the opportunity to be educated with nondisabled peers in general education settings.

Although there is a substantial body of research examining African American children’s overrepresentation in the diagnosis of mental retardation, most of this research does not examine African American children after the age of 22, when these
students labeled with mental retardation transition out of the school system. While African Americans are overrepresented in the category of mental retardation from ages 4 -21, they are underrepresented in studies after the age of 22.

**Conclusion**

Culturally diverse families living in poverty with individual family members with developmental disabilities demand research attention. Fujiura and Yamaki (1997) found that “minority status is closely interwoven with the myriad of conditions related to the status of developmental disability: poverty, access to social institutions and systems of care, and general circumstances of health and well-being” (p. 289). Emerson, Hatton, Llewellyn, Blacher, and Graham (2006) also observed in relation to families in poverty caring for a child with a disability that there is a “systematic failure of previous research to employ representative samples of children and families or to investigate the impact of the broader social context within which families operate” (p. 863). Very limited research has been conducted on the experiences of low-income African American families caring for a family member with a disability during the transition to adulthood. There is little known about their experiences or their point of view. This is a group of people whose voices have not been heard.

**Theoretical Framework**

The majority of society still holds a deficit-based lens concerning individuals or families residing in poverty and those living with a disability. However some researchers have begun to depict resilience and adaptation of these families. This theoretical perspective of psychological resilience “is based on the conviction that both individual and relational strength can be forged through collaborative efforts to deal with sudden
crisis or prolonged adversity" (Walsh, 2006, p. 4). As stated by Bonanno (2004), “resilience reflects the ability to maintain a stable equilibrium” (p. 20).

Resiliency was initially conceptualized in terms of individual adaptation. Individual adaptation is the way that individuals acclimate to change, circumstances, and/or life events, characterized as positive or negative. However, family theorists expanded this view of individual adaptation and conceptualized it in terms of broader transactional processes in families and social contexts (Walsh, 2006). As a result, Rutter (1987) suggested the need to “attend to the interplay between occurrences within families and the political, economic, social, and racial climates in which individuals and their families perish or thrive” (p. 92).

Family resilience has mainly been conceptualized either as an interaction of risk and protective factors (Rutter, 1987) or as a flexible process demonstrating the family’s strength at various points during the life cycle of the family and within different circumstances (Walsh, 2003). In this study the latter conceptualization is favored. Froma Walsh (1998) describes family resilience as the ability to recover from adversity stronger and more resourceful. Walsh (2002) expanded the notion of family resilience by observing that it involves more than just being able to manage and survive a stressful event, instead adversity is used to forge transformative personal and relational growth. From this perspective, resilience is not an achieved outcome or incident-specific response, but a lifelong way of being (Walsh 2002, 2003).

Walsh (1998, 2002, 2006) identified three domains that are paramount to family resilience: (a) the family’s belief systems, (b) organizational patterns, and (c) communication processes. Each of these domains has sub-domains. The family’s belief
systems are comprised of sub-domains; making meaning of adversity; positive outlook; and transcendence and spirituality. Making meaning of adversity involves viewing resilience as relationally based and normalizing adversity by viewing of adversity as a challenge and as manageable. Positive outlook involves feelings of hope and optimism in addition to exhibiting strengths such as courage and the ability to seize opportunities and master the possible. The final sub-domain in belief systems is transcendence and spirituality. This requires the acknowledgement of a larger purpose, faith, inspiration and transformation.

The second domain, organizational patterns, is comprised of flexibility; connectedness; and social and economic resources. Flexibility is the ability to rebound and adapt to challenges, find stability and leadership though disruption. The next sub-domain, connectedness, requires members to provide support, collaboration, dependability, respect and reconnection to each other. The final sub-domain of organizational patterns is social and economic resources. This requires that social, familial, and community connections are available as well as financial security.

The third domain, communication processes, is comprised of communication clarity; open emotional expression; and collaborative problem solving. The first sub-domain, clarity, entails clear, consistent, explicit communication. Emotional expression involves the ability to share and take responsibility for a variety of emotions and empathize with other family members’ views. The final sub-domain in communication process is collaborative problem-solving. Shared decision making, brainstorming, goal focusing, and a proactive stance are characteristics of the communication process sub-domain. This model of family resilience “goes beyond problem solving to problem
prevention; it not only repairs families, but also prepares them to meet future challenges” (Walsh, 2006, p. 25).

The concepts of resilience has often been misinterpreted by many theorists who “have often underestimated and misunderstood resilience, viewing it either as a pathological state or as something seen only in rare and exceptionally healthy individuals” (Bonanno, 2004, p. 20). In addition, Young, Green, and Rogers (2008) found that “one of the problems with much resilience literature is that it fails to acknowledge the socially and culturally constructed nature of the outcome definitions of resilience (e.g. academic success as normative social good)” (p. 45). Moreover, resilience has not been examined with cultural sensitivity and diversity as to its meaning.

Resilience and Disability

It has been extensively documented that stress is often experienced by a family when there is a member with a developmental disability. Because of this constant focus on the disadvantages of having a family member with a disability, the attributes, strengths and benefits of having a family member with a disability are often overlooked. There needs to be an understanding of the strengths and resources that families bring to caring for their member with a disability: “Family supports and services should be targeted on ameliorating negative and strengthening positive impacts” (Summers, Poston, Turnbull, Marquis, Hoffman, Mannan, & Wang, 2005, p. 778).

A number of models, such as family stress theory, family resilience theory, and Rolland’s Family Systems-Illness model, have been utilized to conceptualize the factors that contribute to family adaptation when there is major illness or disability (Patterson, 2002; Rolland, 1994; Walsh, 1998). The strength-oriented models focus on possibilities
for resilience and growth. They help families and service professionals to identify individual and family resources and strengths that make adverse life events manageable.

With a shift from a deficit-based orientation to a strength-based orientation families experience a change from what they are generally bombarded with, questions regarding their difficulties with having a child with a disability. Hartshorne (2002), when discussing stress and coping models, noted, “such treatments aimed at addressing primary deficits may, in fact, increase feelings of inadequacy and discouragement in families who are trying to develop the courage to raise this child” (p. 272).

A key issue for professionals working with families caring for a member with a disability is to identify family strengths and to build on them, with the aim of empowering the family. According to Hulme (1990), “families who perceive themselves as competent and able to manage their everyday life without constant support probably will experience increased opportunities for positive family functioning” (Ylven, Bjorck-Akesson, & Granlund, 2006, p. 253).

**Resilience Among African Americans**

Culture consists of shared characteristics that provide the foundation for perceiving, believing, evaluating, communicating, and acting (Triandis, 1996). According to Sue and Sue (1999), worldview is the orientation that determines what people think and how they behave, make decisions, and define events. Researchers have suggested ways in which African Americans construe reality and experience the world through their cultural orientation and worldview (Grills, 2002; Jones, 2003; Nobles, 2004). These views are found in cultural values grounded in a strong religious belief system, a collective social orientation, strong family and kinship bonds, emotional self-
expression, and present time orientation (Grills, 2002; Jones, 2003; Nobles, 2004; Taylor, Chatters, & Levin, 2004).

These values provide strength-based resources for African American families. These resources are spiritually based coping, extensive social support networks, flexible family roles, strong kinship bonds, positive ethnic group identity, and a high level of psychological and emotional hardiness (Harvey & Hill, 2004; Mattis, 2004; Miller, 1999; Miller & Maclntosh, 1999; Nobles, 2004). Bowman (1990) found that extended family systems, strong spiritual beliefs, and ethnic pride served as a resource for African Americans dealing with adversity.

Although an interest in resilience research is growing, additional attention must be given to culturally diverse populations living in poverty and the manner in which resilience develops. The majority of research on African American families continues to focus of deficits. Lynch and Hanson (1998) recognized that the deficit based models “must be replaced by an awareness that African American families live their unique culture in a traditional manner that allows them to carry out their responsibilities to one another and to society in a way that has meaning for them” (p. 180). The strengths and approaches used by culturally diverse populations to positively adapt to pervasive environmental stressors is an area rich in useful data for researchers and program providers (Miller & Maclntosh, 1999).

There is increasing evidence that families with a member with a disability demonstrate a great degree of strength and that family members often report that there are positive contributions of disability to their family’s life and well-being (Bayat, 2007). Additionally research suggests resilience factors among African American families.
Researchers have found that family communication, availability of economic resources, and social supports are resilience factors for low-income families (Orthner, Jones-Sanpei, & Williamson, 2004). However, more research needs to be conducted that explores how resilience is understood and constructed by the families of young African American adults with disabilities.

**Need for the Study**

It is well documented that stress is experienced by a family when there is a family member with a developmental disability. Historically, researchers have focused on the negative impacts of having a child with a disability; other developmental life stages of the individual with a disability are often over looked. In contrast, the attributes and benefits of having a young adult family member with a disability and the strengths and resiliency of the family are often overlooked. By shifting focus to strengths and resilience, families with a member with a disability have an opportunity to describe their successes and ultimate power. Although family resilience and positive adaptation is beginning to be discussed, the majority of disability literature continues to have a deficit focus.

In addition, few studies employ low income culturally diverse families. The majority of the research has utilized study participants who are White, middle class mothers who have a child with a developmental disability. Few studies focus on the “family”; instead the focus is either on one member or the marital dyad. Yet family may no longer be mom, dad and two children. “Family” is a complex and changing definition, which can only be defined by individual families and their members. According to Poston et al. (2003) “It is critically important in family research to ensure a closer match between the researcher’s own definition of family and the family’s own definition” (p. 319). Thus in
this study a family will be defined as including the people who think of themselves as part of the family, whether related by blood or marriage or not, and who support and care for each other on a regular basis.

Moreover, it is imperative to understand how families make meaning about their lives with a disabled member. Current research is lacking in that little is known about the meaning of disability in the context of family life (King, Zwaigenbaum, King, Baxter, Rosenbaum, & Bates, 2006). There needs to be an understanding of how diverse families describe disability and make meaning of the disability within the context of their family life as well as across developmental stages in order to appropriately assess needs and service implementation.

In addition to limited understanding of the meaning of disability in families there is also confusion when defining disability in disability research. Studies typically involve families of children with a range of disabilities, including syndromes, hearing and visual impairments, developmental delay, muscular dystrophy and autism (King et al., 2006). Current research often employs pooled samples; mental retardation, cerebral palsy, Attention Deficit Disorder, Alzheimer’s, among others into one study and makes generalities regarding acute, chronic and developmental disabilities. This practice does not lend itself to an accurate understanding of disabilities as each disability comes with its own distinctive characteristics as well as the individual characteristics. Hence, there is a strong need to focus on one type of disability that is bounded by well-defined inclusion criteria.

**Purpose of the Study**

The purpose of this study is to describe the experiences of low-income African American families having a young adult with mild mental retardation and to explore
resiliency within these families. More specifically, family members’ thoughts, feelings, and perceptions related to resiliency will be explored.

**Research Questions**

1. What factors promote resilience among low-income African American families with a young adult with mild mental retardation?

2. What influences positive adaptation in low-income African American families?

3. What experiences typify low-income African American families who are caring for a young adult with mild mental retardation?

4. What helps such families achieve positive adaptation over long periods of time?

**Definition of Terms**

**Adaptation:** According to a literature review conducted by Ylven, Bjorck, and Granlund (2006) examining positive functioning in families with children with a disability, “there is no consensus in the reviewed articles of how the concept of adaptation is defined” (p. 266). However, for the purposes of the current study, adaptation is defined as the way that individuals and/or family members acclimate to change, circumstances, and/or life events, characterized as positive (e.g., healthy communication, family cohesion) and negative (e.g., dysfunctional communication, secondary stressors).

**Developmental Disability:** Is a broad term that refers to a range of conditions that hinder a person's ability to function in everyday activities. Chapter 393, Florida Statutes, defines developmental disabilities as spina bifida, autism, cerebral palsy, Prader-Willi syndrome and mental retardation.

**Family:** Two or more individuals who are related by blood, marriage, or adoption. In this study family will be defined by whom the members choose to include in their definition of family.
Low-Income: Refers to families who are receiving Florida Medicaid and whose family member with a disability is currently receiving Florida Medicaid Waiver services.

Mild Mental Retardation: Described by the DSM-IV-TR; Mild Mental Retardation is determined by an IQ level 50-55 to approximately 70. This group constitutes about 85% of the entire population of people with Mental Retardation (DSM-IV-TR, 2000).

Mental Retardation: The American Association on Intellectual and Developmental Disabilities (name changed from American Association on Mental Retardation in January 2007) defines MR on three key criteria: low general functioning as measured by IQ scores, difficulties in adaptive behavior, and the conditions manifesting before the age of 18.

Positive Coping: Is defined as the individual’s efforts to meet the demands in a problematic situation and to manage the conflicts arising from it.

Resilience: Refers to the ability to recuperate after experiencing a crisis or challenge, strengthened and more resourceful.

Young Adult: In this study, a young adult is categorized as being 18-24 years of age.
CHAPTER 2
REVIEW OF LITERATURE

Practitioners treating individuals with intellectual disabilities have traditionally viewed such disabilities from a deficit based, problem-laden perspective. This perspective is one that is attentive to the shortfalls, inadequacies, problems, and pathologies of an individual with an intellectual disability and the effect on the individual’s family. However, an increasing number of current researchers have begun to examine how such individuals and their families overcome adversities associated with the disability and display positive adaptation and resilience. This study will explore the resilience of low income African American families of young adults with mild mental retardation.

In this chapter, literature is reviewed examining the characteristics of individuals with mild mental retardation, the families’ experiences of adaptation/coping with a child with such a disability, the cultural and historical issues impacting African American families, the impact of poverty on families, theories of family resilience, and the application of family resilience theory to families with a disabled member. In addition, limitations of previous research and directions for new research will be addressed.

Characteristics of Individuals with Mild Mental Retardation

The American Association on Intellectual and Developmental Disabilities (2008), previously American Association on Mental Retardation, defines MR on three key criteria: low general functioning as measured by intelligence quotient (IQ) score, difficulties in adaptive behavior, and the conditions manifesting before the age of 18.

The Diagnostic and Statistical Manual of Mental Disorders (DSM-IV-TR) relies heavily on IQ when defining mental retardation. The manual has incorporated adaptive
skills into the general definition; however intellectual impairments are based mainly on IQ scores. As defined by the DSM-IV-TR, mental retardation’s general features include: “subaverage general intellectual functioning that is accompanied by significant limitations in adaptive functioning in at least two 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” (p. 41).

According to the International Statistical Classification of Diseases and Related Health Problems (ICD-10), in addition to IQ scores, which fall into similar ranges as in the DSM-IV-TR, a diagnosis of mental retardation includes categories to identify the extent of impairment of behavior, which dictates the type of supports needed (World Health Organization, WHO, 2007). Mental retardation is not something that is easily defined, as there are a variety of perspectives surrounding the classification of characteristics. There is currently no universal definition for mental retardation.

Along with varied definitions/classifications of mental retardation, there are also a variety of names used when referring to this developmental disability. Mental retardation is also known as general learning disorder, mental handicap, learning disability, intellectual handicap and intellectual disability (Leonard & Wen, 2002, p. 117). This leads to confusion when understanding the characteristics and occurrence of this developmental disability.

Studies have shown that somewhere between 1% and 3% of Americans have been diagnosed with mental retardation. According to The ARC of the United States (2008) based on IQ score alone, the percentages would be closer to 3%, approximately.
6 million people (Table 2-1). And yet the President’s Committee for People with Intellectual Disabilities estimates seven to eight million Americans of all ages experience intellectual disability (2009).

Intellectual disabilities affect about one in ten families in the United States (American Association on Intellectual and Developmental Disabilities, AAIDD, 2009). Leonard and Wen (2002) reported that males were 1.6 to 1.7 times more likely than females to be identified as having mental retardation. The DSM-IV-TR reports the “male to female ratio at approximately 1.5:1” (p. 46) (Table 2-2). In addition, the DSM-IV-TR finds that individuals from lower socioeconomic classes are overrepresented in the diagnosis of mental retardation.

There is a strong need for research which focuses on refining the classification and identification of mental retardation. Each degree of mental retardation (i.e., mild, moderate, severe, and profound) comes with its own unique features and characteristics. The individual characteristics cannot be combined into one loosely defined category.

Mild Mental Retardation

Individuals having an IQ level of 50-55 to approximately 70 are classified as having mild mental retardation. Mild mental retardation comprises approximately 85-90% of individuals diagnosed with mental retardation (American Psychiatric Association, 2000; Smart, 2001). Individuals with mild mental retardation typically develops social and communication skills during their preschool years (0-5), have minimal impairment in sensorimotor areas, and often are not distinguishable from children without mental retardation until a later age (American Psychiatric Association, 2000). In general,
individuals with this degree of mental retardation attain intellectual functioning up to a sixth grade level.

According to Elias, Vermeer, and Hart (2005) children with mild intellectual disabilities are “prone to experience failure and consequently they do not regularly experience feelings of competence” (p. 288) due to their cognitive limitations. These researchers believed that perception (familial and individual) has direct consequences for the child’s well-being. They further stated that this is a neglected population that is in need, as there is a lack of research conducted on individuals with mild intellectual disabilities.

**African American Families and Mental Retardation**

The prevalence rate of mental retardation is difficult to determine; a difficulty which Leonard and Wen (2002) believe is “attributable to the variations in major classification systems and the diversity in study operational definitions and methodologies” (p. 121). It is also “influenced by social, economic, cultural, racial/ethnic and other environmental factors” (Leonard & Wen, 2002, p. 124). For example, “a child from minority cultures are …more likely to be labeled as having MR (mental retardation) as a result of cultural differences including socially different behaviors and culturally inappropriate IQ tests” (Leonard & Wen, 2002, p. 124).

There is generally a higher prevalence of mental retardation among African-American children as compared with children of other racial groups (Leonard & Wen, 2002). More than 2.2 million children from culturally diverse backgrounds are receiving special education services across the United States (U.S. Department of Education, 2000). According to Duren Green (2005), “African American students in U.S. schools are overrepresented in 10 out of 13 disability categories; the greatest disparities are in
soft categories (more subjectively determined categories) such as mild or moderate mental retardation (34%), emotional disturbance (28%), and specific learning disability (18.8%)”. Similarly, the National Research Council (2002) found that African American students are overrepresented in the categories of mental retardation (MR), emotional disturbance (ED), and multiple disabilities when compared to European Americans.

In virtually every state African American students are the most overrepresented group in special education programs, falling mainly in the categories of mental retardation and emotional disturbance (Parrish, 2002). According to the National Research Council, more than 14% of African American students are in special education, in contrast with 13% of American Indian students, 12% of White students, 11% of Hispanic students, and 5% of Asian American students (Paolino, 2003). Additionally, African American students are almost three times as likely as White students to be identified as mentally retarded, two times as likely to be labeled emotionally disturbed, and 1.3 times as likely to be labeled as having a learning disability (Council for Exceptional Children, 2002). Once identified, African American students are at higher risk for being segregated from their non-disabled peers, frequently receiving inferior instruction in separate settings (The Civil Rights Project, 2002; U.S. Department of Education, 2002).

Generally the problem with overrepresentation among culturally diverse populations has been viewed through a deficit-based lens which attributes the discrepancies to genetic deficiencies, the influence of poverty, and cultural deficits (Garcia & Guerra, 2004; Valencia & Solorazano, 1997). However, others believe that there is a cultural divide between the schools and the home environments that may
account for overrepresentation and educational differences (Boykin, 2001; Gay, 2000; Brody, Yi-Fu, Murry, Simons, Xiaojia, Gibbons, Gerrard, & Curtona, 2006).

In a qualitative study utilizing an interpretive approach, Petersen (2006) sought to describe the lived experience of a single African-American woman labeled as having a learning disability. The purpose of the study was to “seek a detailed and nuanced understanding of this young woman’s schooling experiences” (Petersen, 2006, p. 722). The researcher found that the initial labeling of learning disabled was “likely a consequence of her unfamiliarity with the predominantly white, middle class school culture. The lackluster instructional methods and materials she received thereafter continued to render her learning disabled” (p. 727). Petersen (2006) noted that a student’s success in school relies largely on their success with hidden expectations which are described as the three Rs: rules, regulations and routines. Delpit (1995) argued that many students from diverse backgrounds struggle in attempting to negotiate, learn, and conform to these hidden expectations.

The success of students identified as having a disability translates to young adulthood and employment after high school. Among high school students with disabilities, 75% of African American students were not employed 2 years after graduating from school. Furthermore, 54% of African American young adults were not employed 5 years after graduating (Losen & Orfield, 2002).

Disabilities occur in all cultural groups. Studies indicate that persons of diverse cultures with a developmental disability, and their families, are under-represented in current research yet overrepresented is diagnosis. Inadequate attention has been paid to families from diverse cultures caring for family members with developmental
disabilities. Fujiura and Yamaki (1997) found that “minority status is closely interwoven with the myriad of conditions related to the status of developmental disability: poverty, access to social institutions and systems of care, and general circumstances of health and well-being” (p. 289). The increase of ethnic minorities, poverty, and children identified with developmental disabilities forces researchers to change focus and attention to a neglected population.

Views of disability are socially constructed; disabilities have many meanings depending upon factors such as sex, income, and culture (Groce & Zola, 1993). It has not been well researched to determine if minority cultures caregiving experiences are similar or different from other families or families in the majority culture. In an attempt to bridge this gap in research McCallion, Janicki, and Grant-Griffin (1997) conducted a study using focus groups composed of culturally diverse families caring for a family member with a developmental disability. A description of what constituted a developmental disability was not provided. The researchers sought to “gain an understanding of the uniqueness of the caregiving experiences of specific cultural groups, reasons for lower service use and the extent of cross-cutting concerns around aging, disability, caregiving and future planning” (McCallion et al., 1997, p. 347). The researchers contended that aspects of culture had not been examined and that “understanding the concerns of caregiving families drawn from diverse cultures and successfully addressing those concerns requires a systematic consideration of these issues” (p. 349).

The focus group was comprised of family members involved in caring for an adult or child with a developmental disability, staff or administrators of community based
services and cultural organizations, and leaders of the cultural community. Participants were from African American, Chinese American, Haitian American, Hispanic-Latino American, Korean American, and select Native American communities. The family participants were both male and female, with females making up two-thirds of the family participants. The age range of family members was from 40-85 years. Information about the actual proportion of participants within each cultural group was not provided.

A grounded theory method utilizing the constant comparative approach to analysis was applied. The researchers identified eleven themes: (1) how the disability is perceived, (2) who is the family, (3) who provides care, (4) how the family makes decisions, (5) what family members expect of each other, (6) what support families receive from friends and community, (7) why the family moved, (8) cultural values important to family members, (9) families’ willingness to accept services from outside the family, (10) the family’s primary language, and (11) families’ concerns about service providers (McCallion et al., 1997).

The researchers reported the following findings: (1) How the disability is perceived; families reported that they struggled with their own beliefs regarding disability as well as the perception others have relating to the disability and of caregivers of individuals with a disability. (2) Who is the family; the participants asserted that extended and non-traditional family members should neither be assumed nor ignored. Yet, finding out about family members and understanding their roles will require effort. (3) Who provides care; generally the mothers were identified as the primary caregiver however family participants noted that the focus of care should not be exclusively assumed to be on one or two members. (4) How the family makes decisions; varies from family to family.
(5) What family members expect of each other; all focus group members valued family support and expected families to help with caring, however the reality for individual families is quite different. (6) What support families receive from friends and community; varies widely by cultural group and individual families. (7) Why the family moved; either from another country to the United States, small town or rural area to large cities, and urban areas to suburbs or rural areas. (8) Cultural values important to family members; participants felt that there needed to be an understanding of the key values about the disability and care giving common to the culture with which the family identified. The importance of values and traditions should never be assumed for any family or family member. (9) Families’ willingness to accept services from outside the family: a desire for the services to be within their own community. (10) The family’s primary language: a large barrier with accessing services. (11) Families’ concerns about service providers: if they would be provided the services needed, forced into services and concern that the family member with a developmental disability would be removed from their care (McCallion et al., 1997).

The current study concluded by stating the need for “further exploration with other groups and in other locations. Also, other research approaches may provide more fruitful in gathering information on this topic and may also help determine if there were other cultural topics and that were not fully discussed because of the focus group make-up” (p. 355).

In a study exploring the transition into young adulthood of individuals with mild mental retardation Mitchell-Kernan and Tucker (1984) found that the African American individual’s transition went more smoothly than their Caucasian counterparts. Even
though these African American individuals with mild mental retardation lived in deteriorated, high-crime neighborhoods their success rate was significantly higher. It was reported that the African American individuals had more marriages, closer family relationships, and more friends. Additionally they displayed fewer antisocial behaviors and exhibited better job performance. Most noteworthy was the fact that few of these individuals received social services, and almost all had strong support from networks of kin and friends.

Similar studies are far and few between. Few researchers have focused on factors such as culture, ethnicity and gender that play a role in the transition from school to adulthood for low-income African American individuals diagnosed as having mild mental retardation. Very little has been articulated in research about the experiences of African-American families and disability. There is little known about the experiences of African American families caring for a family member with a disability. There is particularly little research and writing from their point of view. Moreover, given the dearth of research on the experiences of African American families caring for a member with a disability, there has subsequently been little in the way of theorizing on how gender and disability intersects with race (Petersen, 2006; Thomas, 1999). Collins (2000a) also agreed that there is a serious need to examine the experiences of individuals within various cultures and disabilities. The meanings we attribute to difference depend largely on the culture in which we live, as well as our place within that culture (Ore, 2000).

**History of Treatment of Individuals with Mild Mental Retardation**

Individuals with developmental disabilities have had a history of institutionalization, sterilization, and demoralization. Prior to the mid 1880’s most families caring for a child with a disability provided care in the family home. Out of home placement was generally
not an option because of the cost and physical location of these institutions. Individuals with an intellectual disability were viewed as “unfortunates” or “innocents” requiring charitable considerations (Scheerenberger, 1983). During the 1880’s this benign view began to change as a result of Darwin and the open door immigration policy (Cummins, 2001). Much of the change in treatment of individuals with intellectual disabilities was strongly influenced by Charles Darwin’s theory of Natural Selection. Darwin posited that to avoid future incidence or “spreading” of intellectual deterioration or disabilities, society needed to focus on reproducing only the fittest families rather than the unfit. Hence, institutionalization along with sterilization became the primary strategy for avoiding contamination or the spreading of disabilities.

Around the same time the government devised, “the 1891 amendment to the USA Immigration Act excluding all people seen by the authorities as undesirable” (Cummins, 2001, p. 84). The intent of this legislation was to prevent people who were deemed morally or mentally defective from entering and residing in the United States. During this same time period, individuals with disabilities who were identified in society were removed and placed in institutions, asylum, and almshouses: “Between 1880 and 1910 the number of people with an intellectual disability housed in special residential facilities quadrupled” (Cummins, 2001, p. 84). At this time the advantages of institutionalization was to one, prevent reproducing, as these individuals were segregated, sterilized, or both and two, remove these individuals from society so their existence could be ignored. The number of individuals with disabilities who were institutionalized reached a peak in 1969 of 214,000, the majority of whom were under 25 years of age (Cummins, 2001).
During the 1950’s, the mass institutionalization of individuals with disabilities began to be questioned. However, it was not until the 1970’s that there was a strong shift toward deinstitutionalization. This was for both humanitarian and economic reasons. The main proponents for this change were Nirje (1970, 1976) and Wolfensberger (1972). They focused on “normalization” and “least restrictive environments” for individuals with disabilities (Cummins, 2001, p. 85). As the twentieth century ended, families were once again expected to care for their family member with a disability.

**Families with Intellectually Disabled Children**

Historically, research examining the impact on families of caring for a family member with an intellectual disability took one of several directions. One direction was to study the stress, depression or sense of burden of individuals giving care to a disabled child. The results of such research revealed that family members experience strain and negative consequences from having a child with a disability. Moreover, researchers reported that there was a greater risk of high stress levels and depression in parents of children with disabilities (Blacher & Baker, 2002; Glidden, 1989).

This research tradition was characterized by a longstanding and pervasive belief that the birth of a child with a developmental disability is a tragedy encompassing lifelong struggles for families. In 1948, Alfred Deutsch, an advocate for better institutional care for people with mental retardation wrote, “one of the most heartbreaking situations in American life arises in families burdened with the care of low-grade mental defectives at home because they can’t get them placed in proper institutions” (Deutsch as cited in Trent, 1994, p. 241 from Risdal 2004). The feelings experienced by such parents were categorized as: grief, despair, strain, and stress.
This research direction reflected the pervasive view that parents suffered greatly from the presence of a child with mental retardation and that out-of-home placement was preferred (Wolfensberger, 1967 from Risdal, 2004).

For example, in a 2001 review, Cummins analyzed qualitative and quantitative research on the consequences for people caring for a family member with a disability. In his review of 12 studies, caregiver stress was evident and led to adverse reactions, as Cummins (2001) found, “that children with disability, across disability types, have a higher risk than normal for carer (i.e., caretaker) abuse” (p. 89). The family members are so overwhelmed by caring for the family member with a disability that abuse of the disabled person may occur.

A second research direction was to focus on the impact of a child with a disability on their family’s functioning. Researchers typically reported the negative impact on parents and families, including destructive impacts on marital relationships resulting from having a child with a developmental disability (Risdal, 2004). The direction of much of this research continued to examine only the negative impacts of having a family member with an intellectual disability and parental stress. Many researchers use a variety of stress and coping models when studying families with a member with a developmental disability.

The overall impact to the family when caring for individuals with disabilities has received substantial attention. Cummins (2001) argued “the assumption that people with severe disability are better off living within their families than elsewhere needs to be tested” (p.97). Cummins contends that stress endured by families caring for a member with a disability far exceeds the abilities of these families. The majority of this research
focused on mother’s adaptation to a child with a disability. Because the mother was seen as the primary caregiver she was assumed to be the family member who would experience the most stress and responsibility for the child.

Bristol, Schopler, and Gallagher (1988), conducted a study with 56 two-parent families, 31 with developmentally disabled boys and 25 with nondisabled boys. The sample included white males under the age of six. Of the 31 children identified 17 where classified as autistic, the other 14 children were not given a diagnosis yet they were identified as having a developmental disability. The researchers stated that the 14 children were not autistic. Family assessments, independent interviews and in-home assessments were conducted. They found that “mothers of developmentally disabled children carry a disproportionately heavy burden” (p. 449). In addition, parents in the study, especially fathers, “report significantly more marital difficulties than their peers with nondisabled children” (p. 449). This study documented the increase in stress and the decrease in well-being of family members when there is a child with a disability.

Emerson, Hatton, Llewellyn, Blacher, and Graham (2006), conducted a secondary analysis of a cross-sectional data base derived from Wave 4 (2002) of the Department for Work and Pensions’ Families and Children Study (FACS) (p. 863). The Department for Work and Pensions study sampled 6954 mothers with dependent children under the age of 17 years, 514 of which were supporting a child with an intellectual disability. The children were identified as having an intellectual disability if either of the following criteria were met: (a) “Maternal report that the child had a long-standing illness or disability related to learning difficulties (or mental handicap), and that this disability was reported to result in the need for extra care from their primary caregiver or affect their
regular attendance at school or college” or (b) “Maternal report that the child was identified as having SENs (Special Education Needs) due to learning difficulties/disabilities, including dyspraxia” (Emerson et al., 2006, p. 864).

The purpose of the secondary analysis conducted by Emerson and associates (2006) was to compare the levels of happiness, self-esteem and self-efficacy of mothers who did and did not have a child with intellectual disabilities. The researchers reported “that the vast majority of mothers of children with IDs are fairly unhappy or very unhappy with their lives and that any difference between their level of happiness and that of other mothers may be attributed to socio-economic disadvantage and maternal health than to caring for a child with IDs” (p. 869).

To further explore the influence of socio-economic status, Wang, Turnbull, Summers, Little, Poston, Mannan, and Turnbull (2004) conducted a study exploring the association between income level, severity of disability, and fathers’ and mothers’ satisfaction with the quality of their family life. Using the Beach Center Family Quality of Life (FQOL) instrument, a total of 130 fathers and 234 mothers participated in the study. The findings revealed that both income level and severity of disability were significant predictors of mothers’ satisfaction as measured by the FQOL (Wang et al., 2004, p. 89).

In conclusion, the researchers indicate that the severity of the disability and family income significantly affected family quality of life. This study highlights the impact of factors other than disability characteristics, that affect family satisfaction and the need for research focused on a wider range of family characteristics. Other variables that might influence stress levels include the age, gender and level of cognitive functioning
of the child and parents, as well as certain family demographic variables such as family size, income and level of social support.

Bristol, Schopler, and Gallagher (1988) explored various contributions to family stress, which included “characteristics of the disabled child, current levels of spousal instrumental and expressive support, and harmony between current support and perceived “appropriate” spousal support to self-reported and observed adaptation of both mothers and fathers,” (p. 442). They reported that “child characteristics are not sufficient in themselves, however, to explain adaptation in these families” (p. 441). They believed that the entrance of a child with a disability was a stressor yet the resources, internal and external, determine how the family adjusted to the level of stress. The extent of the stress was found to be a result of limited to nonexistent resources (internal or external) rather than solely the presence of a family member with an intellectual disability.

Hassall, Rose, and McDonald (2005) explored the association between child behavior difficulties, intellectual disability, and parenting stress in 46 mothers of children with intellectual disabilities. The mothers were interviewed using the Vineland Adaptive Behavior Scales and Maladaptive Behavior Domain. In addition, they completed four questionnaires: the Family Support Scale, the Parenting Sense of Coherence Scale, the Parental Locus of Control Scale and the Parenting Stress Index. The sample consisted of Caucasian middle class mothers’ ranging in age from 21 to 49 years and the children with the intellectual disability ranged in age from 6 to 16. The aim of the study was to test the Mash and Johnston (1990) model of parenting stress.
This model focused on understanding the contributions to parent-child stress when looking at families of hyperactive children and families of physically abused children. Mash and Johnston (1990) were interested in the direct influence of parent characteristics on child characteristics and impacts of child and environmental characteristics on parent-child stress. Hassall and associates (2005) applied the Mash and Johnston (1990) model to mothers of children with intellectual disabilities (Hassall et al., 2005).

They found “clear evidence of an association between child behavior difficulties and parenting stress, which is consistent with results of previous research” (Hassall et al., 2005, p. 413). They also reported that “parenting stress in mothers of children with ID (intellectual disability) is associated with the level of behavioral difficulties of their child, their locus of parenting control, and their sense of satisfaction with parenting” (p. 414). The researchers reported that approximately two thirds of the mothers of young children with developmental delays experienced significantly elevated stress levels. Because stress was so evident, the researchers recommended that future research “examine the potential buffering effects of positive experiences of caring for a disabled child on the parents’ emotional state” (Hassall et al., 2005, p. 415).

The research on families with a child with a disability has undergone two significant shifts to include additional factors other than maternal stress, resources and child characteristics. First, there is a growing recognition of the need for increased information and awareness surrounding children with disabilities and their families. Risdal (2004) reported that "a major thrust of these efforts has been to shift the locus of disabling conditions from individual differences residing within the individual to the
interactions of these differences with an exclusionary society” (p. 95). Second, there has been a shift to examining the benefits and positive adaptation of having a family member with a disability.

Researchers are now engaged in examining the family’s adaptation to a family member with a disability through a more positive lens, and are beginning to question the view that the impact of children with a disability on their families is exclusively negative. From this more positive perspective questions have been asked and new measures developed to test assumptions of positive adaptation, increased quality of life, and the benefit to families (Risdal, 2004). Yet these current research efforts may be difficult to implement because concepts of positive family functioning have not been clearly defined. Ylven, Bjorck, and Granlund (2006) reviewed the existing research on the positive functioning in families with children with a disability and concluded that “there is no consensus in the reviewed articles of how the concept of adaptation is defined” (p. 266).

When looking at research regarding positive aspects of caring for a child with a disability, Beresford (1996) found that this involved “the feeling of rewards and pleasures of parenthood, as well as a wider sense of moral responsibility”. Hassall, Rose, and McDonald (2005) found that reframing coping strategies and the use of resources contributed to mothers’ positive perceptions of caring for a child with a disability.

When looking at perceptions other than those of a parent or mother, siblings of children with disabilities are a recent focus in research. As an example, Giallo and Gavidia-Payne (2006) conducted a study to investigate sibling, parent and family factors
as predictors of sibling adjustment when there is a child with a disability. The study included 49 families and siblings (age 7-16) where there is a family member with an intellectual, sensory, physical, or developmental disability. In total, seven disabilities (Down syndrome, intellectual disability, autism, developmental delay, Asperger’s syndrome, angelman syndrome and multiple disabilities) varying in severity from mild, moderate, severe and unknown were included. The researchers employed a variety of self report measures for parents on demographic characteristics, sibling adjustment, parent stress, parenting and family functioning and siblings reported on their daily stress and coping.

The findings revealed that sibling adjustment was strongly associated with parent and familial factors such as socio-economic status, past attendance at a sibling support group, parent stress, family time and routines, family problem-solving and communication, and family hardiness (Giallo & Gavidia-Payne, 2006). Family hardiness is defined as the amount of control families believe they have in managing stressful situations. The researchers felt that these findings suggested that “siblings from families with fewer resources may be exposed to more stressful home environments, which may increase their risk of adjustment problems; however this risk is mediated by level of parent stress and family functioning” (Giallo & Gavidia-Payne, 2006, p.943). Although inconclusive, the researchers affirm that positive family experiences promoted positive adjustment for siblings over their own experiences of stress. Some limitations of this study dealt with under-representation of diverse socio-economic and cultural groups, mixed disability types, a wide age range of siblings and children with a disability and information primarily collected from mothers.
Some clinicians are advocating that family-based interventions consider the positive perceptions of multiple family members. When discussing sibling experiences when there is a family member with a disability, Peter Schuntermann, MD (2007) pointed out the need for clinicians to balance assessments of impairment and symptoms with “equally systematic appraisals of siblings’ positive psychosocial and relational skills,” more specifically “how do siblings successfully adapt to living with a developmentally challenged brother or sister over the course of their development” (p. 93).

Hastings, Kovshoff, Ward, Degli Espinosa, Brown, and Remington (2005) conducted a study that included parents (48 mothers and 41 fathers) of pre-school children with autism in order to determine stress and positive perceptions. The range in age for the children with autism was 28-45 months. Although the researchers noted that the parents reported stress associated with their child with autism they also “identified positive perceptions about their child, and his or her impact on themselves and other family members” (p. 641). Thus, the most unique aspect of this research was the measurement and analysis of the positive perceptions of parents of children with Autism. Moreover, the researchers stated that further research needs to be “a more dynamic and more comprehensive systemic analysis of family functioning is needed to help develop successful interventions for families of children with autism” (p. 643).

Yet there has been limited research that includes key family members other than parents. For the most part, only mothers have participated in such studies. Only one study to date included multiple family members; fathers, mothers, siblings and the child with intellectual disability, as participants in their research study. This study was
conducted by Costigan, Floyd, Harter, and McClintok (1997), who believed that
“observation of the entire family together can reveal important information about family
relationships and structure that is not apparent when only dyadic interactions are
investigated” (p. 515).

The study focus was on observing the interaction between family members in a
problem-solving situation when there is a school-aged child (6-18 years old) with mild or
moderate mental retardation. The majority of the participants were Caucasian: 84% of
mothers and 96% of fathers. The researchers found that there was an identifiable
pattern of “resilient-disruption for these families in coping with the limitations of their
children with mental retardation” (Costigan et al., 1997, p. 525). These findings indicate
the need for measuring outcomes on all individual family members as well as on the
family level when interventions are being evaluated. Most family research is based on
information gathered from individual family members who supply information about their
families, rather than on information obtained by studying families directly or by including
several family members.

Researchers are finding that not only do we need to hear the voices of multiple
family members but we also need to understand their world and bring forth their
accounts of positive adaptation. King, Zwaigenbaum, King, Baxter, Rosenbaum, and
Bates (2005) conducted a qualitative investigation focusing on family beliefs and values.
The aim was to gather information from family members caring for a member with a
disability and “obtain preliminary information about world views, values, and priorities of
families, and how their beliefs might change over time” (King et al., 2005, p. 355). The
participants comprised of 12 mothers, 3 fathers of children with autism spectrum conditions or Down syndrome and 4 individuals working in the disability field.

The participants were involved in focus groups where the goal of the groups were to gain knowledge about the belief systems of families caring for a child with disabilities, and how these beliefs may change over time. The themes that emerged from the focus groups were presented in four categories: initial reaction to parenting a child with a disability, adaptation over time, changes in world views and values, and changes in priorities (King et al., 2005). The researchers found that families caring for a child with a disability have unique sets of beliefs. These families’ beliefs and values include; seeing individual strengths, attention to the positive contributions made by their children, being sensitive to the needs of others, happiness, respect, tolerance, acceptance, achievement and cooperation.

The researchers stressed the need for additional research that focuses on understanding family perspectives and providing services in a family-centered way. With the focus on understanding each unique family, the possibility of emerging information relating to strengths and positive adaptation may be heightened. The researchers also believed that this focus would allow families to feel a sense of normality with their situation and provide a sense of meaning and control (King et al., 2005). Identifying family strengths and building on them leads itself to empowering the family. When discussing family adaptation, Trute and Hauch (1988) discuss the importance of building on the family’s own strengths.

There are few studies in which positive aspects of family functioning are the focus, which indicates that research on families caring for a member with a disability is
still strongly influenced by a deficit orientation (Ylven et al., 2006). The constructs of stress, depression or care giving burden have negative connotations. A relatively narrow and negative climate is created where observation, identification, and labeling may occur (Lamb-Parker, LeBuffe, Powell, & Halpern, 2008). Even the most severe disabilities do not automatically result in dysfunctional family patterns or symptoms. Such a negative and deficit orientation may overlook possible positive or neutral impacts of disability on the family.

Impact of Poverty on Families with an Intellectually Disabled Child

According to the 2006 ACS (American Community Survey) data, approximately 38.2 million people (13.3 percent of individuals and 9.8 percent of families) in the U.S. population had income below the poverty threshold in the last 12 months. Bradshaw (2006) defines poverty as the “lack of basic necessities” (p. 4). Bradshaw continued by stating “basic food, shelter, medical care, and safety are generally thought necessary based on shared values of human dignity” (p. 4).

Poverty is on the rise. The rate of children in poverty has increased. Emerson (2004) stated that children who grow up poor are more likely to “have impaired cognitive and linguistic development; have poorer health, be less “ready” for school; have lower self-esteem and self-efficacy; engage in anti-social behavior; experience psychological distress; have lower educational attainment; become unemployed; become disabled; and have poorer health as adults” (p.323).

Poverty not only carries adverse effects on the child but on parents as well. Park, Turnbull, and Turnbull (2002) found that “low-income adults are more likely to suffer from stress and mental health problems due to difficult life events such as not being able to pay their bills, being evicted, losing their jobs, moving frequently, and worrying about
money” (p. 157). Poverty affects all members of the family in varying degrees. Individuals living in poverty are less likely to be “insured, less likely to have access to a full range of quality services in the community, and less likely to benefit from existing services than are individuals who have better financial resources” (Robinson & Rathbone, 1999, p. 334). These are families who are struggling financially with their daily lives in addition to managing the social and cultural context in which they live.

Researchers have reported a link between poverty and the prevalence of intellectual disabilities. This link, in part, is due to poor access to prenatal care, and inadequate monetary means for sufficient nutrition and screening. Families caring for a family member with a disability living in poverty are at an even greater risk of developing negative consequences in relation to their quality of life.

Research has found that there are more children in poverty with a disability than without a disability. Emerson (2004) noted, “children with intellectual disabilities are at a greater risk of experiencing poverty than non-intellectually disabled children” (p. 324). Park, Turnbull, and Turnbull (2002) examined the impact poverty has on the quality of life in families of children with disabilities. They reported that “among children with disabilities aged 3 to 21 in the United States, 28% are living in poor families” (p. 152), while “children without disabilities in the same age range, only 16% are living in poverty” (p. 152). Moreover, research reveals that low-income families caring for a child with a disability are affected more severely than either low-income families of non-disabled children or affluent families caring for a child with a disability (Park et al., 2002). They found that there is a need to establish a systemic understanding of family support required to meet multiple areas of distress and needs.
Researchers have found a significant link between families with a child with a disability and poverty. Emerson (2006) noted “the experience of poverty is likely to have a negative impact on the health and well-being of mothers of children and upon family functioning” (p. 324). Studies have shown that having a child with a disability is a stressor and living in poverty is a stressor, the combination of the two stressors ultimately increases the amount of strain and discomfort a family endures.

The stress affecting families caring for a member with a disability could be enhanced because of the social context that is intrinsic when living in poverty. Emerson (2007) states: “The available evidence suggests that exposure to poverty may account, in part, for the health and social inequalities experienced by people with intellectual disabilities as a group and variations in health, well-being, and quality of life between people with intellectual disabilities” (p. 110). There is a lack of research studying low-income families caring for a family member with disabilities to fully appreciate these families’ experiences.

Low-income families caring for a family member with a disability are a neglected population. Researchers have found that these families are experiencing greater degrees of stress and in need of additional supports that would accompany caring for a family member with a developmental disability in poverty (Park, Turnbull, & Turnbull, 2002; Emerson, Hatton, Llewellyn, Blacher, & Graham, 2006).

In the study conducted by Emerson, Hatton, Llewellyn, Blacher and Graham (2006), results “suggest that failure to address SEP (socio-economic position) is likely to reinforce an overly ‘pathological’ orientation in which children with ID’s (intellectual disabilities) are implicitly assumed to be a ‘burden’ and a punitive cause of maternal
stress” (p. 869). The researchers emphasized up the limitations of research with individuals with disabilities in poverty by stating that there is a “systematic failure of previous research to employ representative samples of children and families or to investigate the impact of the broader social context within which families operate” (Emerson et al., 2006, p. 863).

**Research on Resilience**

As stated by Bonanno (2004), “resilience reflects the ability to maintain a stable equilibrium” (p. 20). Resilience implies more than simply coping with a situation. According to Hawley and DeHann (1996), resilience suggests an ability to overcome adversity and increase well-being. Resilience has often been misinterpreted as many theorists “have often underestimated and misunderstood resilience, viewing it either as a pathological state or as something seen only in rare and exceptionally healthy individuals” (Bonanno, 2004, p. 20). The concept of resilience appears to have been resistant to a single overarching theory, let alone a unifying definition (Grant, Ramcharan, & Flynn, 2007). Resilience has increasingly appeared in research literature yet there are still disputes relating to its components, antecedents and possible functions.

The majority society holds a pervasive deficit-based lens of individuals or families experiencing adversity. Yet some researchers have begun shifting from the deficit lens to one recognizing the potential for growth and repair in the face of adversity, namely resilience. The resiliency lens “is based on the conviction that both individual and relational strength can be forged through collaborative efforts to deal with sudden crisis or prolonged adversity” (Walsh, 2006, p. 4). Resilience is not an achieved outcome or incident-specific response, but a lifelong way of being.
Much of the interest in resilience began with the individual, with a strong focus on the child. Researchers argued against the idea that negative factors in childhood would lead to adult deficits and disorders. Rutter (1985) stated that, no combination of risk factors, regardless of severity, gave rise to significant disorder in more than half the children exposed. Werner and Smith (1977) carried out one of the most influential studies regarding resiliency. They conducted a longitudinal study focused on children growing up in poverty in Kauai. Their study progressed over 32 years; they looked at the roots of resiliency in children who effectively coped with risk factors to identify factors that assisted in the recovery of distressed children as they moved from childhood, to adolescence, and ending in adulthood.

In exploring the factors that contributed to individual resiliency, researchers began to notice the influence of family factors. Family systems theory expanded the view of individual adaptation as embedded in broader transactional processes in family and social context (Walsh, 2006, p. 12). Rutter (1987) expanded on this stating that, “we must attend to the interplay between occurrences within families and the political, economic, social, and racial climates in which individuals and their families perish or thrive.” Schuntermann (2007) added to this by stating “the capacity to respond with resilience to stressful events draws on psychological resources within the individual, the family, and surrounding social environment” (p. 102).

Family Resilience

Researchers of resilience find that untapped family resources often emerge in the face of adversity (Rolland & Walsh, 2006). Family researchers with an interest in family strengths and resources have found that many families find ways to adapt and may even be strengthened in the course of dealing with challenges. Some families are
able to rally, weather the challenges and even thrive. Studies have reported that a considerable number of families develop a positive outlook on life and good family functioning and adaptation (Li-Tsang, Yau, & Yuen, 2001; Walsh, 1998, 2003).

Froma Walsh (1998) describes family resilience as the ability to recover from adversity stronger and more resourceful. Walsh (2002) expanded this definition of family resilience as involving more than just being able to manage and survive a stressful event but instead use adversity to forge transformative personal and relational growth. Walsh recognized the potential growth that can be forged out of adversity. A family is resilient when it demonstrates strength, even if it may not demonstrate the same attribute at another point in time.

McCubbin and McCubbin (1996) describe family resilience as the family’s ability to utilize behavioral patterns and functional competence to negotiate, cope, and even thrive through hardships and crises. Hawley and DeHann (1996) describe family resilience as the path followed as families adapt and prosper in the face of stress, both in the present and over time. They believe resilient families respond optimistically to stressful conditions in unique ways, depending on factors such as developmental level, the combination of risk and protective factors, and the family’s shared outlook. Patterson (2002) described family resilience as the adaptive process families utilize to adapt and function competently following exposure to significant adversity or crises.

Although these descriptions of family resilience may resemble one another, the main constructs hold varying amounts of weight. As with individual resilience, family resilience, attention is focused on family strengths under stress rather than on pathology. Resilience also assesses family functioning in context, relative to a family’s
values, structure, resources, and life challenges (Walsh, 1998, 2002). Walsh’s theory considers resilient families to make meaning out of adversity, affirm strengths and keep positive outlooks, and have spirituality and belief systems.

Walsh (1998, 2002, 2006) has identified three domains that are paramount to family resilience: (a) the belief systems, (b) organizational patterns, and (c) communication processes. Each of these domains has sub-domains. The belief systems are comprised of sub-domains; making meaning of adversity; positive outlook; and transcendence and spirituality. Making meaning of adversity involves the viewing of resilience as relationally based, ability to normalize adversity, view of adversity as a challenge and as manageable. Positive outlook involves feelings of hope and optimism in addition to exhibiting strengths such as courage and the ability to seize opportunities and master the possible. The final sub-domain in belief systems is transcendence and spirituality. This requires the acknowledgement of a larger purpose, faith, inspiration and transformation.

The second domain, organizational patterns, is comprised of flexibility; connectedness; and social and economic resources. Flexibility is the ability to rebound and adapt to challenges, find stability and leadership though disruption. Connectedness requires members to be exposed to support, collaboration, dependability, respect and reconnection. The final sub-domain of organizational patterns is social and economic resources. Social, familial, and community connections are available as well as financial security.

The third domain, communication processes, is comprised of clarity; open emotional expression; and collaborative problem solving. The first sub-domain, clarity,
entails clear, consistent, explicit communication. Emotional expression involves the ability to share and take responsibility for a variety of emotions and empathize with other family members views. The final sub-domain in communication process is collaborative problem-solving. Shared decision making, brainstorming, goal focused and a proactive stance are characteristics of communication process sub-domain. The model of family resilience “goes beyond problem solving to problem prevention; it not only repairs families, but also prepares them to meet future challenges” (Walsh, 2006, p. 25).

Family resilience has been the focus of several research studies. Preece and Sandberg (2005) studied the relationship between family resilience and the management of fibromyalgia. The participants were recruited via Internet and comprised of 150 self-reported sufferers of fibromyalgia. Participants ranged in age from 19 to 81, with the majority (93.1%) being female. Several survey instruments were utilized; Health Care Utilization Survey, Fibromyalgia Impact Questionnaire, Chronic Pain Coping Inventory, and the Family Index of Regenerativity and Adaptation-General. The Family Index of Regenerativity and Adaptation-General comprised of seven self-report domains. These domains operationalize the Resiliency Model by McCubbin (1987). This model utilizes the stress and coping framework while emphasizing the importance of adaptation rather than adjustment. When looking at family resilience, the researchers found that “family resilience may be associated with medication use” (p.570). The researchers agreed that with future research there needs to be a focus on gathering family information relating to resilience rather than interpreting one’s member’s assessment of family resilience.
African American Families and Resilience

The protective function of African American culture has been found in current research. There are characteristics in the research literature that are associated with positive functioning in low-income African American families. These specific characteristics are a reliance on family relationships, social support, religious/spiritual beliefs, determination, and self efficacy (Todd & Worell, 2000; Jarrett, Jefferson, & Kelly, 2010).

A study conducted by Utsey, Bolden, Lanier, and Williams (2006) found that, in addition to social support and family cohesiveness, collective and spiritual coping were significant predictors of quality of life for African Americans. Johnson (1995) found that spirituality, rituals, extended family, elder advice, and family cohesion predicted positive outcomes in a sample of African American families. A number of studies have found that racial pride and racial identity function as a protective factor for African Americans (Miller & MacIntosh, 1999; Sellers & Shelton, 2003).

One significant area of support for African Americans is through kin networks. Kin networks are often a viable source of resilience (Miller-Cribbs & Farber, 2008). According to Johnson (2000), kinship networks are defined as “extended family”, including those who are connected by “blood, marriage or self-ascribed association” which goes beyond the “marital dyad, the nuclear family of parents and dependent children, or one parent households” (p. 625). For African Americans, kin and family networks can offer economic, social, and emotional resources (Miller-Cribbs & Farber, 2008).

Some qualitative researchers have focused on African American families living in impoverished neighborhoods and the impact of extended-kin networks on positive
family functioning. Qualitative researchers have found how the extended-kin network members share in childcare and other domestic tasks to encourage positive family functioning and well-being, despite individual and neighborhood impoverishment (Dominguez & Watkins, 2003; Jarrett, 1994; Newman, 1999; Roy & Burton, 2007).

Todd and Worell (2000) conducted a study looking at resilience among low-income, employed African American women. The researchers were looking to identify factors that allowed these women to lead positive and protective lives. Fifty low-income African American women participated in the study and agreed to interviews. The sample comprised of women who were employed a minimum of 20 hours a week and cared for a child under the age of 13. The women in the study identified informal social supports, family and spiritual beliefs as factors that related to resilience. The researchers concluded that “additional studies are needed to improve our understanding of the experiences and social contexts of minority groups, both African Americans and others, and to explore further the factors that lead to distress and to resilience in their lives” (p. 126).

**Family, Disability, and Resilience**

It has been extensively documented that stress accompanies a family when there is a member with a developmental disability. Because of this constant focus on the disadvantages of having a family member with a disability, the attributes, strengths and benefits of having a family member with a disability are often overlooked. Disability impacts the entire family. There needs to be an understanding of the impacts, both negative and positive, of individuals with a disability on families: “Family supports and services should be targeted on ameliorating negative and strengthening positive
impacts” (Summers, Poston, Turnbull, Marquis, Hoffman, Mannan, & Wang, 2005, p. 778).

A number of models, such as family stress theory, family resilience theory, and Rolland’s Family Systems-Illness model, have been utilized when understanding what factors contribute to family adaptation when there is major illness or disability (Patterson, 2002; Rolland, 1994; Walsh, 1998). John S. Rolland's (1999) Family Systems-Illness Model was developed as a framework for “evaluation, formulation and intervention with families dealing with chronic illness and disability” (p. 244). The strength-oriented model focuses on possibilities for resilience and growth. The model addresses three dimensions: (1) psychosocial types of illness and disability: onset, course, outcome and incapacitation; (2) time phases of illness; and (3) family system variables: family and individual life cycles, multigenerational patterns and belief systems.

More recently there has been a focus on combining Rolland’s Family Systems-Illness model and Walsh’s family resilience framework in assisting families when there is a child or adolescent illness, disability, or loss (Rolland & Walsh, 2006). Family resilience and Family Systems-Illness model may reduce strains and enhance a family’s quality of life by focusing on the psychosocial demands of illness and disability and also how they are influenced by multigenerational, life-cycle, and belief systems. By attending to family resilience and Family Systems-Illness model, positive and effective coping and adaptation may be heightened.

Certain factors that can be attributed to adaptation, negative and positive, are (a) medical factors (i.e., severity, illness-related limitations, prognosis, time phase and
psychosocial illness type), (b) quality of family processes (i.e., family cohesion, flexibility, communication, and expression of affect), (c) the life cycle phase, (d) transgenerational experiences, and (e) the balance between stressors and resources (Retzlaff, 2007). In the literature on family adaptation and resilience, family belief systems are thought to be a core aspect of a family’s overall resilience (Hawley & DeHaan, 1996; Walsh, 1998). These beliefs provide both stability and a shared sense of meaning that helps the family pull together and face the future with a sense of strength (McCubbin & McCubbin, 1986).

Family resilience theory gives families a change from what they are generally bombarded with, and that is questions regarding their difficulties with having a child with a disability. Hartshorne (2002), when discussing stress and coping models noted, “such treatments aimed at addressing primary deficits may, in fact, increase feelings of inadequacy and discouragement in families who are trying to develop the courage to raise this child” (p. 272).

In terms of assessing resilience, there has been considerable range in the measurement of the impact of risk and protective factors; however, researchers seem to concur, that the more risk factors present, the worse the developmental outcomes will likely be across the lifespan (Anctil, McCubbin, O’Brien, Pecora, & Anderson-Harumi, 2007). There is a need to identify factors which buffer the impact of risk factors. Emerson (2007) found that there clearly remains a significant task of furthering our understanding of what helps to promote resilience among individuals with intellectual disabilities (i.e., mental retardation) and their families, especially those living in poverty.
A key issue for professionals working with families caring for a member with a disability is to identify family strengths and to build on them, with the aim of empowering the family. According to Hulme (1990), “families who perceive themselves as competent and able to manage their everyday life without constant support probably will experience increased opportunities for positive family functioning” (Ylven, Bjorck-Akesson, & Granlund, 2006, p. 253).

To date only one study has utilized a family resilience theoretical framework to study families with a child with a disability. Bayat (2007) conducted a mixed methods study in searching for evidence of resilience in families of children with autism. The researcher used the theoretical framework of Froma Walsh’s resilience theory for categorization of thematic data. Participants included 175 caregivers of children with autism, 134 mothers, 30 fathers and 11 other caregivers. The researcher discusses the bias of the participants because white upper-middle class families were over-represented. In order to participate, families had a child diagnosed with autism spectrum disorder, Asperger’s syndrome or pervasive developmental disorders ranging in severity from moderate to severe. The children were between the ages of 2 and 18. This study provided evidence that a number of families show evidence of resilience. The themes of resilience identified were those depicted in Walsh’s theory of resilience.

Although Bayat reported evidence of resilience in the participating families, there were multiple limitations in this study. First the majority of the participants were white upper-middle class mothers. Second, although the family was the unit of interest, only one family member participated. Third the survey was delivered by mail rather than face-to-face interviews, which Bayat (2007) acknowledged may have accounted for the
lack of diversity with the sample size. In addition the standards for rigorous qualitative research, such as prolonged engagement and opportunities for triangulation and multiple checks, were not followed. The ability to further prompt participants was also not available because the surveys were delivered via mail rather than through face-to-face interviews. As a result, Bayat (2007) cautioned against generalizing from the findings, and recommended that future research be conducted using “qualitative methodologies with smaller sample of family members, where there is an opportunity to do face-to-face interviews and multiple data collection, and deeper analysis” (p. 712).

There is increasing evidence that families of children with disabilities demonstrate a great degree of strength, articulating the positive contributions of disability to their family’s life and well-being (Bayat, 2007; Hastings, Kovshoff, Ward, degli Espinosa, Brown, & Remington, 2005). We need to explore what resilience is, as understood and constructed by individuals with mild mental retardation and their families, even before we seek to understand those factors and processes that may promote, maintain or reduce it (Young et al., 2008). Moreover, research needs to be conducted focusing on positive functioning and resilience in families with a young adult with a disability. Such studies should include all the important family members in the social network around the individual (Ylven et al., 2006).

Conclusion

Families caring for a member with a developmental disability are likely to encounter some challenges far more frequently than parents of typically developing children (Glidden, Billings, & Jobe, 2006). Much of the research has been focused on the deficits within these families. The focus of attention is narrowed to problems, while resources, competencies, and strengths tend to be overlooked (Retzlaff, 2007):
“Typically, studies do not consider the positive contributions of a family member with a
disability, or the family’s evolving life experiences” (King et al., 2005, p. 354). A handful
of studies indicate that families of children with disabilities may see the positive
contributions of their child with a disability and thrive in the face of adversity. However,
“we know little as to how individual differences such as parental role, personality and
other family characteristics affect the choice of coping strategies and their efficacy in
ameliorating stress and producing positive affect” (Glidden et al., 2006, p. 950).

In addition to the narrow view of family and disability, additional limitations
impacting research have been identified. There is limited research relating to resilience
and disability. Grant and researchers (2007) state that “thus far there has been little
theorizing of resilience applied to families with intellectually disabled children or adults”
(p. 563). Focusing on resilience within these families will ultimately assist with service
delivery, assessment, intervention and family competence.

Another limitation of family research in the disability field has been the tendency to
use only mothers and, in far fewer cases, fathers as the unit of analysis when proposing
to measure family views and perspectives (Poston et al., 2003). Adding to this criticism
is research focused on sibling adjustment when there is a child with a disability. These
studies tend to study sibling adjustment in isolation, with little consideration of the family
or community contextual factors (Giallo & Gavidia-Payne, 2006). Utilizing the parents’ or
family members’ different attributes and contributions increases the possibilities of
success in family where there is a member with a developmental disability (Ylven, 2006,
p. 267). Since the mid-to-late 1980’s, there has been a growing awareness of the
importance of family-centered service delivery utilizing a family strengths perspective,
and the family as the unit of support (Poston, Turnbull, Park, Mannan, Marquis, & Wang, 2003). The disability research is only beginning to recognize the value of this perspective.

Additional limitations focus on the definition and representation of disability in the current literature. In a study conducted by Anctil et al. (2007), the researchers report the need for future studies to “assess the severity of the disability as well as the diagnostic label” (p. 1098). Future studies should limit inquiry to a particular disability type (Giallo & Gavidia-Payne, 2006). Current research is varied due to several studies tackling a variety of disabilities in one study. One study by Nachshen, Woodford, and Minnes (2003) studied family stress and coping with a child with a developmental disability. They included disabilities ranging from mild to moderate to severe, including Down syndrome and unknown cause, cerebral palsy, problems at birth, and fragile X syndrome. Furthermore, in a study by Emerson (2003) a child could be identified as having an intellectual disability solely from parents reporting that their child had an intellectual disability. The universal selection criterion used has not been well established and is required for a valid sample. It is not appropriate to study all disabilities as if they are interchangeable and have the same impact on a family or the individual. Each disability comes with its own set of characteristics. It is oversimplifying individuals’ uniqueness with the criteria that is currently in place.

A final limitation in disability research has been the lack of representation of diverse populations on socio-economic and ethnicity factors. Such social and demographic status variables are inextricably interconnected in the American population (Fujiura & Yamaki, 2000). Most of the participants in current research studies have been
Caucasian, middle class women or parents. This is not representative of the diverse world in which we live. Low-income minority populations caring for a young adult with a disability are severely underrepresented in the research literature. They have several social and cultural factors to contend with, yet they continue to survive. It is imperative to pull from strengths and look for resources within the individual, family and society in order to understand differing cultures to make appropriate interventions and prevention strategies and recognize resilience. What it means to be resilient in a low-income African American family with a young adult with mild mental retardation remains inadequately understood.
Table 2-1. Prevalence of mental retardation.

<table>
<thead>
<tr>
<th>Source</th>
<th># of People in the millions with MR in the United States</th>
</tr>
</thead>
<tbody>
<tr>
<td>ARC of the United States</td>
<td>2</td>
</tr>
<tr>
<td>President’s Committee for People with ID</td>
<td>4</td>
</tr>
</tbody>
</table>

Table 2-2. Gender prevalence with mental retardation.

<table>
<thead>
<tr>
<th>Gender</th>
<th>Ratio</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>1.5</td>
</tr>
<tr>
<td>Female</td>
<td>1.0</td>
</tr>
</tbody>
</table>
Chapter Overview

The purpose of this study was to describe the experiences of low-income African American families caring for a young adult with mild mental retardation and explore resilience of these families. This chapter describes the theoretical framework underlying the research method and design, the sampling procedures and description of the participants. The methods of data collection and analysis are also explained as well along with the study’s limitations.

Theoretical Framework

The design of this current study was qualitative in nature. A qualitative study is driven by theory. The theory provides the guidelines for data collection and analysis used to explore a question. A qualitative research design is typically utilized when little is known about a matter or when in depth understanding of a central phenomenon is required (Creswell, 2007; Strauss & Corbin, 1998). Hatch (2002) states, “qualitative research seeks to understand the world from the perspectives of those living in it” (p. 7). Qualitative methodology was used in this study due to the limited knowledge about the experiences of low-income African American families caring for a young adult with mild mental retardation.

Various contemporary authors stress the need for theory development related to family resilience, low-income and disability. According to Bayat (2007), operationalizing family resilience has been seen as difficult in quantitative research and it is advisable that further research employ “qualitative methodologies with smaller sample of family members, where there are opportunities for face-to-face interviews and multiple data
collection and deeper analysis” (p. 712). In this research study, a constructivist framework and a grounded theory method informed its design and guided the collection and analysis procedures used to investigate the perspectives of participants in detail and depth (Patton, 1990).

A constructivist framework follows the notion that construction of knowledge results from an individual’s interaction with the world and accumulation of experiences. Knowledge is viewed as an internal construction that is based on an individual’s experiences rather than an absolute existing outside of the individual (Miller & Dingwall, 1997). The constructivist perspective provides an appropriate framework for researchers looking to interpret and describe specific phenomena. The goals are inductive, which allows for interpretation and recognizes the roles of both the participants and the researcher (Guba & Lincoln, 1982).

The constructivist view acknowledges multiple perspectives and realities in attempting to understand a phenomenon as it exists within a specific context. This acknowledgement of multiple viewpoints and realities was paramount when attempting to understand family resilience. A constructivist view using a grounded theory method was appropriate as this framework was more interested in the views, values, beliefs, feelings, assumptions, and ideologies of participants rather than in gathering facts and describing acts.

A grounded theory method “works from the assumption that rigorous methods can be used to discover approximations of social reality that are empirically represented in carefully collected data” (Hatch, 2002, p. 26). According to Strauss and Corbin (1998), “theory derived from data is more likely to resemble the “reality” than is theory derived
by putting together a series of concepts based on experience or solely through speculation" (p. 12). Grounded theory designs create a theory that explains a process, an action, or an interaction about a viable topic (Creswell, 2007). Grounded theory “provides us with relevant predictions, explanations, interpretations and applications” (Glaser & Strauss, 1967, p. 1). It is through constant data collection and analysis that saturation of meanings, patterns, and categories occurs and grounded theory emerges (Echevarria-Doan & Tubbs, 2005). Grounded theory generates a theory concerning phenomena from which data were produced. Therefore, the theory derived was directly linked to the data. This approach was appropriate because it could explore under-theorized areas such as the resiliency of low-income African-American families with a young adult with mild mental retardation.

When engaged in grounded theory, the researcher moves systematically from data collection, through data analysis, to writing the research report and the ensuing generation of theory (Glaser, 1978). This is in contrast with quantitative research where there are prescriptive goals and the researcher is interested in providing evidence for predetermined assumptions or theories. Conversely, the inductive nature of grounded theory operates with the absence of a priori assumptions (Glaser & Strauss, 1978).

The methods used in this study were guided by the constructivist framework and grounded theory methodology which focused on the individual and family as units of analysis. The constructivist framework and grounded theory method informed its design and guided the collection and analysis procedures used to investigate the perspectives of participants in detail and depth (Patton, 1990). The use of in-depth interviews and grounded theory techniques during the analysis of interview data resulted in the
construction of a theory representing the experience of resilient low-income African American families caring for a young adult family member with mild mental retardation.

**Participants**

To do solid qualitative research, a method of appropriate sampling is imperative. This study utilized purposeful sampling. Purposeful sampling (Patton, 1990; Glense, 1999) is appropriate when the purpose of the study is not widely generalizable to a larger population (Glesne, 1999). Instead each participant was selected for a purpose specific to a better understanding of the research question. According to Patton (1990) “the logic and power of purposeful sampling lies in selecting information-rich cases for study in-depth. Information-rich cases are those from which one can learn a great deal about issues of central importance to the purpose of the research, thus the term purposeful sampling” (p. 169). Furthermore as many differences as possible in demographic information (ethnicity, low-income status, geographic location and age of the young adult) as possible were eliminated to ensure a homogeneous sample.

The study participants were members of low-income African American families receiving federal and state support through Medicaid and Medicaid-Waiver. Two families comprised the study sample. Participation from a minimum of three family members from each family was required, as it was important that “family researchers…elicit the perceptions and views all family members to get the total picture of a particular family” (Dahl & Boss, 2005, p. 66).

In addition to multiple views assisting with reaching a richer and fuller understanding of the family, previous research on families with an individual with mental retardation have typically only represented the mothers’ perspective. “We must not repeat the mistake of many researchers who interview mothers primarily to gather data
about children or families. We must attempt to hear the “family conversational voice” as a whole or to observe the “family world” as a whole” (Dahl & Boss, 2005, p. 66).

The participating families were drawn from those residing in rural north and central Florida communities. The participants were mothers, siblings, aunts and cousins, of the individual with mild mental retardation.

To participate in the study, families had to meet the following requirements: a) they had a young adult family member between the ages of 18-24 yrs who had been diagnosed with mild mental retardation, b) they received Medicaid and Medicaid Waiver services (as to determine low-income status, c) they had to self-identify as African-American d) they had at least three family members available and willing to be interviewed, e) they were fluent in English, f) they were not currently under investigation for abuse or neglect, and g) they had agreed to participate in three interviews conducted in the home. Participants received gift cards to a local grocery store chain as compensation for participating in the study. Gift cards were issued at the completion of the final interview.

**Access and Entry**

Access in qualitative research studies is a process that goes beyond initial consent, to insuring that the identified individuals are willing to participate throughout the study (Glesne, 1999). The participants must be convinced of the importance and relevance of the study (Glesne, 1999). In an effort to establish personal contact with potential participants, the researcher enlisted the support of Medicaid Waiver Support Coordinators who were previous co-workers of this researcher. The researcher was able to establish contact with the Support Coordinators who referred the researcher to
potential participants. The researcher believed that the support of that individual was critical in the level of cooperation shown.

The Support Coordinator contacted potential families to describe the goals and methods of the research study. If the family voiced an interest in participating, a meeting was scheduled with the family which the researcher and Support Coordinator attended. At this meeting the research was fully explained and consents were provided and reviewed. This initial meeting allowed the family to question the researcher and to establish rapport. After this initial contact, all of the researcher’s communications were directly to the participants.

Describing the Families

B Family

The B family was comprised of a mother, Alesha B., two sons Calvin B. and Terence B, and a daughter Danielle B. Terrence was identified as the young adult family member with mild mental retardation. Alesha, 45 years old, was a single parent to her three children. Calvin and Terence shared the same father, Frank, however Alesha reported that he was not involved in the lives of his children stating “It was his choice.” After the birth of Terence, Frank subsequently started decreasing his visits from weekly to monthly and eventually just phone calls to check in. According to Alesha she believed that the stress of having Terence was too much for Frank. His involvement now was limited to a few phone calls each year. The mother, Alesha, stated that Frank does not provide financially for his children. Danielle’s father, William, lived in the family home for approximately 4 years before moving out. Alesha and William were never married. Since then William has married and had 4 children with his current wife. He has moved
out of the area and has monthly phone contact with Danielle. Again, Alesha reported no financial assistance from Danielle’s father.

Alesha was currently unemployed and spent much of her time caring for the home and her son, Terence. Their main means of financial support was through Terence’s Social Security Disability check. The eldest son, Calvin, was 27 years old and resided in North Carolina with his wife and two children. Calvin worked as a house manager in a group home for individuals with developmental disabilities and was employed fulltime. His employer was his father-in-law who oversees multiple group homes for individuals with developmental disabilities. Terence, the individual with mild mental retardation, was Alesha’s middle male child and was 24 years old. Terence resided in the family home and attended an adult day program where he worked as a “packer” five days a week. A “packer” is an individual who fills orders for local businesses. Terence had been diagnosed with Mild Mental Retardation at the age of 2 years and received Medicaid and Medicaid Waiver funds. And lastly, Danielle was 18 years old and resided in the family home. Danielle attended a local high school. Danielle was hoping to attend a community college in the fall where she would like to study nursing. She was excited at the prospect of being the first one in her family to attend college.

The B family lived in a rural community in north central Florida. Their home was approximately 15 miles from the nearest town. According to the 2000 Census, this town had a population of 5,593. The White population comprised 67% and the Black population 29.5%. The median household income was $27,021. In this town 19.2% of the population was families living below the poverty line. Additionally, there were 23.9% individuals living below the poverty line.
The part of the town in which they resided contained many extended family members, grandparents, siblings, aunts and uncles. The immediate and extended family had lived in the community for 65 years. Alesha was one of seven children comprising a family of five daughters and two sons. Alesha was born and raised in a home less than 2 miles from her current residence, a home where Alesha’s mother continues to reside along with three of her siblings. Alesha’s sister, 50 years old, sister’s children (5) and brother, 38 years old, live in a home directly next to her own. Both of Alesha’s siblings are unmarried.

**H Family**

The H family was comprised of siblings, nieces and nephews. The family member identified with Mild Mental Retardation was Vernon H. He was 23 years old and attended an Adult Day Program 3 days a week and worked as a bagger at a small local grocery store the other 2 days a week. Vernon resided with his sister Betty H., and niece, Keisha H. On the same property was another home which housed Vernon’s 2 other sisters, Georgette H. and Latoya H., as well as their combined group of 7 children. The individuals who participated in the research study were Betty (sister to Vernon), Keisha (niece to Vernon) and Georgette (sister to Vernon).

Betty, 48 years old, was a single mother who was unemployed and received Social Security Disability funds for a back injury. She reported that her children see their fathers however the fathers do not reside in the same home. Her daughter, Keisha, was 30 years old and worked as a cashier at a small local grocery store. Keisha was 6 months pregnant and looking to “find a place” with the father of the baby. She was also planning on getting married however they had not picked a date. Georgette was 38 years old, married, and stayed at home to parent her 4 children. Georgette reported
having been married for 15 years. Her husband, George, was employed as a trucker
driver and spent most of his weeks on the road making deliveries. George was not
present during the times of the interviews due to his work schedule.

The H family lived in a rural community in north central Florida. The home was
approximately 10 miles from the nearest town. According to the 2000 Census, there
were 2,297 people who live in this town. The White population made up 73.4 % and the
Black populations comprised 22.8%. The median household income was $25, 795.
There were 22.4% families and 22.6% individuals who fall below the poverty level.

The property on which the family resided had been in the family for 80 years, as
described by Betty. She reported a small and close African American community where
“everyone knows each other.” The home where she currently lived was the home where
she was raised by her mother and father. The mother to Betty, Vernon, Georgette and
Latoya passed away 2 years ago in May, 2008. She died in her home and was survived
by her 12 children. The other 8 siblings lived in surrounding communities, with the
farthest living 30 miles away. There are 5 fathers to the 12 children in the family. All of
these fathers are reported to be deceased.

Data Collection Methods

The three members from each of the two families were interviewed three times
between March 2010 and August 2010 in their family homes. There were a total of 16
interviews. The B family completed 8 interviews, 6 individual interviews and 2 family
interviews. The H family completed 8 interviews, 6 individual interviews and 2 family
interviews. Allowing for multiple interviews over a period of time assisted with acquiring
incrementally more information and allowed for deepening the researcher’s
understanding of the participants’ experiences. Interviews allowed for a more subjective
perspective of how families themselves see the world. Telling stories about difficulties and successes and about troubles and challenges that have been mastered, helped the families to make sense of their life with the disability and to construct their own social reality (Corbin & Strauss, 1988).

The first interview occurred after initial contact was made with the family and a date was set for the interview to take place. The second interview took place 3-6 weeks after the first and the third interview was scheduled 3-6 weeks after the second, depending on the availability of the participants. Each interview lasted approximately two hours. All interviews were digitally recorded. The interviews followed a semi-structured format. The interviews focused on certain themes and included suggested questions (Kvale, 1996). A schedule of questions was prepared for each of the three interviews (Appendix A).

The purpose of the first interview was to continue rapport development with the participants. The interview was a collaborative situation, a discussion between individuals regarding a subject of shared interest. According to Kvale (1996) “the interviewer must establish an atmosphere in which the subject feels safe enough to talk freely about his or her experiences and feelings” (p. 125). In addition to establishing a relationship, participants were provided with information about the study, the informed consent procedures and asked to share any questions they had about the study. The first part of the first interview included all the participating family members. The family was asked questions relating to demographic information, family composition and disability. During the last phase of the first interview, separate interviews were conducted with each of the participants. Participants were asked to begin telling their
story of having a family member with mild mental retardation, with a strong focus on life events and experiences that brought them to the present day (Seidman, 1991).

The second interview took place 3-6 weeks after the first. This schedule allowed time to transcribe the first interview and have it available for the participants to read at the second interview for the purpose of member checking. Each participating family member engaged in an individual interview. The focus of the second interview was on examining current events in the life of the family surrounding their experiences with having a young adult with mild mental retardation (Seidman, 1991). The individual interviews served as an opportunity to address aspects of their own experiences, separate from other family members. The questions were designed to prompt participants’ description of their lives, past and present, as well as experiences with strengths and resilience. The interview questions covered topics that provided an opportunity to analyze the data collected based on several points of comparison.

The third interview took place 3-6 weeks after the second. This was conducted with the all of the members of the family as a group/family interview. A minimum of three family members was needed to participate in the family interviews. For the final interview, the focus was on family meanings and reflection on the experience of having a family member with mild mental retardation (Seidman, 1991). Additionally, families were asked to explore what they would like other families, counselors, and doctors to know about their experiences of being low-income, culturally diverse and living with a young adult family member with mild mental retardation.

**Data Analysis**

The data for this study was analyzed by means of constant comparative method of data analysis. When applying grounded theory, “data analysis begins as soon as a
researcher begins to collect data” (Echevarria-Doan & Tubbs, 2005, p. 49); as the data was collected it is coded. The grounded theory researcher was involved in a process of collecting data, arranging it into categories, gathering additional data/information, and constantly comparing the new information with emerging categories (Creswell, 2007).

Each interview produced multiple conceptual themes or categories. These themes or categories were analyzed across interviews for the purpose of generating a theory based solely on that data. According to Glaser and Strauss (1967) “in discovering theory, one generates conceptual categories on their properties from evidence; then the evidence from which the category emerged is used to illustrate the concept” (p. 23). The data analysis, constant comparison, was then used to identify variations and similarities among the participants’ themes. Constant comparison, according to Charmaz (2000), is a method of “(a) comparing different people (such as their views, situations, action, accounts, and experiences), (b) comparing data from the same individuals with themselves at different points in time, (c) comparing incident with incident, (d) comparing data with category, and (e) comparing a category with other categories” (p. 515).

The steps for data analysis with a constructivist grounded theory were: initial, focused, and selective coding which differs from Corbin and Strauss’s use of open, axial, and selective coding (Charmaz, 2006). The first step, initial coding, involved analyzing the data line-by-line, which allowed the researcher to search for categories and then define actions, or events within the data (Echevarria-Doan & Tubbs, 2005). Each line was labeled with words or phrases that interpret their meaning. Coding began the generation of theory. Line-by-line data analysis required that the researcher
remained attentive to the participants’ views and realities (Charmaz, in Denzin & Lincoln, 2000) while at the same time acknowledging the role of the researcher.

The second step, focused coding, allowed for connections to be made between categories and subcategories found in initial coding (Strauss & Corbin, 1998). According to Corbin and Strauss, a core category is selected among the major categories derived from the data to form an objective description, which will be the central phenomenon for the theory (Creswell, 2007). Once a core category and the process categories were identified, one progresses to the final step of coding which was that of selective coding (Creswell, 2007).

The process of selective coding from a constructivist framework focused on the relationship among categories. This focus on relationships resulted in a representative theory which was representative of the constructivist perspective. This final step involved integrating and redefining categories that have emerged, as well as reviewing theoretical memos (Echevarria-Doan & Tubbs, 2005). Glaser (1978) defined theoretical memos as “the theorizing write-up of ideas about codes and their relationships as they strike the analyst while coding” (p. 83). The memos were a means for analyzing data and codes throughout the research process. Furthermore, they served as a record of the decisions made upon the completion of the research process (Charmaz, 2006). It was at this stage that theoretical saturation was reached through constant comparison and the theory was redefined (Strauss & Corbin, 1998).

**Trustworthiness**

In qualitative research, reliability and validity are fulfilled through the meaningful and genuine depiction of a reality explored through inquiry. The criterion for establishing reliability and validity of a research study is based on establishing the trustworthiness of
the claims made by the researcher. Creswell (1998) described methods for creating trustworthy and transparent research. Creswell (1998) identifies the following eight methods that qualitative researchers can use: prolonged engagement, triangulation, peer review, negative case analysis, acknowledging researcher bias, member checking, thick description and external audits. However, triangulation, member checking and auditing are the three forms primarily used by qualitative researchers (Creswell, 2002). The techniques that were used to establish credibility in this study were prolonged engagement, triangulation, peer review and debriefing, acknowledging researcher bias, member checking, thick description and external audit.

The first technique used to establish credibility was prolonged engagement. The participants engaged in multiple interviews which resulted in prolonged and persistent observation. Participants were interviewed on three separate occasions in their homes, in addition to the interviews being spread apart.

The second technique used to establish credibility was triangulation. Triangulation is achieved when various sources are used to confirm data interpretation; theories, methods, data sources, or other researchers (Denzin, 1978). Triangulation was implemented in this study through the use of multiple interviews with each participant and through multiple perspectives. Multiple ideas and possible interpretations of data were considered as well as memos, field notes and interviews. The researcher kept an audit trail and documented her reflections and process of interpreting data through the use of theoretical memos.

The third technique used to establish credibility was peer review and debriefing. This was attained through meetings with committee members. The researcher worked
closely with her committee chair and her external committee member to explore and refine interpretations of the data and check for researcher biases. This entailed a review of methods, procedures, and findings throughout the study.

The fourth technique used to establish credibility was acknowledging researcher bias. Acknowledging researcher bias can be accomplished through a subjectivity statement that provides a clear statement regarding the researcher’s biases. Identifying any existing perceptions and biases allows the researcher to put them aside in order to understand the experience under study without imposing prior biases (Creswell, 1998). The subjectivity statement was presented in this chapter.

The fifth technique, member checking, was used for participants to confirm or disconfirm the researchers’ transcription of the interview and/or outcomes of the analysis. Participants were given the opportunity to check interview data for accuracy and to comment on emerging themes that were identified from the interviews. The member checks were conducted during the beginning of the interviews by exploring interpretations made from the transcripts.

The sixth technique, thick descriptions, was provided. This entailed developing detailed descriptions of interviews and interpretations from the transcripts. The researcher attempted to provide rich and thick description to provide the reader context. This will be found in Chapter Four.

The final technique employed was external audit. This consisted of the dissertation committee examining all the material.

**Subjectivity Statement**

I attended school from first through eighth grade with children who were diagnosed with a developmental disability. These children were often placed in foster homes due to
abusive conditions at home, and many of them experienced difficulties at school. This made me interested in working with this population and understanding their life circumstances. Through working as a volunteer in my school and in outside community agencies, I learned from them about their experiences, and I believe that learning about the harshness of some of my classmates’ lives so early in my own life helped me to determine what I would focus my studies on when attending college.

Because of my early experiences, my studies have focused on understanding interpersonal relationships and experiences of individuals, especially those in minority populations. Through my graduate program I was able to gain the skills necessary to effectively and successfully work in diverse settings. I was able to refine my interviewing and interpersonal skills. These skills assisted me in my work as a case manager and as a therapist working with families’ caring for a family member with a developmental disability. From these work experiences I gained a wealth of knowledge regarding disabilities and observed a variety of strengths and family resources that families in these situations demonstrate. Although I was seeing tremendous strengths in these families, I noticed that helping professionals focused on the deficits these families’ possessed. This discrepancy between what I observed in this population and how they were depicted in the professional literature stimulated my interest in learning more about the strengths these families bring to their lives so as to expand the information base of research on families dealing with disability.

In addition to these personal experiences, I have gained skills conducting qualitative research through my graduate coursework studies. In qualitative research, the researcher is both the tool for data collection and the interpreter of data. As such,
the biases the researcher has must always be considered, and the role prior knowledge and experience might play in the interpretation of data must also be taken into account. Therefore, as the sole researcher responsible for collecting and interpreting the data, I gave careful thought to past experiences that could potentially bias this role. In this work, I acknowledge my status as an outsider. I am not the child of a poor family, nor did I have a member with mild mental retardation in my family. My family is White and middle class. I grew up in a small Northern town in the United States.

**Conclusion**

A constructivist grounded theory approach provided a means for establishing a base of knowledge regarding the lived experiences and forms of resilience of low-income African American families' with a young adult with mild mental retardation. This chapter outlined the procedures used to achieve this goal and included a description of the study and participants; sampling criteria, methods of data collection and analysis and procedures for ensuring trustworthiness.
CHAPTER 4
FINDINGS

The purpose of this study was to form an understanding of the lived experience of low-income African American families caring for a young adult with mild mental retardation. This understanding was developed through intensive interviewing of two families caring for a young adult with mild mental retardation. Members of these two families were interviewed on both an individual basis and as a family to gain an understanding of their perspectives about how they functioned as a family.

Four separate research questions guided the interview process in this study. The first question concerned what family factors promoted family resilience in the face of adversity. (e.g. What factors promote resilience among low-income African American families with a young adult with mild mental retardation?) The second question explored what family characteristics influenced positive adaptation in low-income African American families. (e.g. What influences positive adaptation in low-income African American families?) The third question sought to identify what experiences typify low-income African American families who are caring for a young adult member with mild mental retardation. (e.g. What experiences typify low-income African American families who are caring for a young adult with mild mental retardation?) Lastly, the fourth question sought to learn what qualities helped such families achieve positive adaptation over long periods of time. (e.g. What helps such families achieve positive adaptation over long periods of time?)

Interviews were the exclusive source of data collection. In each family there were three family members who agreed to participate. Each family member participated in two individual interviews and two family group interviews. The participating family
members were immediate family members of the young adult with mild mental retardation who were living (or had lived) in the same household as the young adult for extended periods of time. The individual with mild mental retardation was not included in the interviews. Additionally, extended family members who did not live in the same household did not participate in the interview process.

The interviews were conducted in the home of each family on three different interview days. Both individual and family group interviews were completed with both families. The individual interviews with family members were conducted in a location in the family home that was private and away from other family members and was chosen by the members being interviewed. Typically the locations chosen for the individual interviews were a bedroom or outside while the location for the family group interviews was conducted in the main living area. All participating family members were engaged in two individual interviews and two family interviews with the exception of one individual in the B family, Calvin, who did not participate in his family’s second family group interview.

Participants and Context

Prior to describing the families’ understandings with excerpts from interviews, a brief description of the differences between the families is provided in the following section. Family members have been given pseudonyms to protect their identity (Table 4-1).

The B family was comprised of a mother, Alesha B., two sons Calvin B. and Terence B, and a daughter Danielle B. Terrence was the adult family member with mild mental retardation. The B family lived in a rural community in north central Florida. Their home was approximately 15 miles from the nearest town. The H family was
comprised of Betty H. and Georgette H., sister to Vernon H. and Keisha, niece to Vernon. Vernon was the adult member with mild mental retardation. The H family lived in a rural community in north central Florida. The home was approximately 10 miles from the nearest town.

The families reported multiple generations residing in their current homes and communities for many decades, for the B family 65 years and the H family 80 years. The participating families described their homes as the homes they grew up in, the homes that their children grew up in and the homes that their grandchildren will grow up in.

The homes were located miles outside of rural towns. To get to both of the homes required driving on several dirt roads. When arriving at the B family homes, there were three homes connected by a single dirt road. Alesha stated that extended family members resided in the two other homes. Each home was a single wide mobile home. It was apparent that the B family home had some structural damage, due to some boarded up windows and holes in the porch. The interior of the home was sparse of furniture. The main living area had 3 couches and a coffee table. There were family photos on the wall and religious pictures of Jesus and the Virgin Mary.

Similar to the B family, the H family lived off a dirt road. To arrive at the H family home one had to drive down a mile dirt road for ½ mile. At the end of the road there were two single wide mobile homes. Vernon and his sister resided in one and additional family members lived in the other. When approaching the home there were multiple cats to greet visitors. The home for the H family was extremely run down. Each window was covered by plastic. The front door was a screen door that had half of the screen. When
entering the home, even though it was close to 90 degrees outside, there was no air conditioning. This did not appear to bother the family, as they were not fanning themselves or sweating. There were holes in the walls and the majority of furniture was worn and dusty. The family appeared comfortable in their surroundings and welcoming of this researcher.

Stylistic Differences Between Two Families

Although the two families represented in this study had similar demographic characteristics in that both were African American families and both were low-income, there were some interesting stylistic differences between the B family and H family. The families differed in regards to their emotional expressiveness and styles of interacting. However there were strong similarities between the two families in terms of their overarching beliefs, level of emotional support, and proactive stance.

Members of the B family exuded warmth, affection and nurturing in their interactions with each other. There was a lot of smiling, laughter and physical contact demonstrated between family members. An example of this was demonstrated during the first family interview when the family was asked to describe who was in their family and what they meant by family. The mother, Alesha was the first to respond stating that the kids make up her family. When I asked her children if they would have a different understanding of family, the son Calvin joked and said the woman down the street was like family because she “wants to be my momma”. In response Alesha stated “she is not your momma”. All three members laughed and joked with one another, giving light physical pushes. It was apparent that they had a running family joke regarding the neighbor and her intended role in their family. They were smiling and gave the
appearance of enjoying their interactions with each other. Even though they were being interviewed they demonstrated a playful attitude with one another.

In contrast, members of the H family were more business-like and serious. During their initial family session, Betty, the oldest member of the group, was the main responder to the question of who they considered to be in their family and how it was determined. She explained that “family is blood” and there is no other family aside from blood. She was very matter of fact, not smiling or encouraging family discussion regarding the question asked and other members did not voice their views. When the other family members were asked if they agreed or wanted to add something they said no with a shake of their heads. At this response Betty spoke up and said “no, what?” which elicited a “no, ma’ma” from the other family members. The family members did not interact playfully with another and appeared to take the interview with a great deal of seriousness. Moreover, throughout the series of interviews, the H family interacted with more structure, silence and task focus than the B family.

Family Defined: “This is My Family”

For both the B Family and the H Family, family was defined by those whom you are living with and who are blood related. In the B family Alesha, the mother, explained that there were two different kinds of family, the family that is in the home (immediate) and the family that resided outside of her home (extended). They are all considered family yet when she is asked who makes up her family she first responded by saying “My kids and me”. For Alesha she had an understanding of a larger family network yet when she is focused on the day to day aspect of her life she immediately thinks of her children when defining family. Both Calvin and Danielle verbalized their agreement with their mother’s description although Calvin added that membership for immediate family
shifts depending on where he is. When he is in the home that he grew up in and for the context of this interview Calvin stated family as “mom, brother, and sister”. However, when Calvin returns to his current home state of North Carolina family is stated to be “wife and kids”.

In the H family, when Betty was asked who makes up her family and how this is determined she responded “Um, we do. We family”. It appeared that this was not something that Betty had given much thought to in the past. Family is family without the need for a definition. When Betty was asked additional clarifying questions she went on to explain that family are the people who are blood related “neighbors are neighbors and family is family”. When prompted Georgette and Keisha nodded their agreement. In contrast to the B family the H family thought of immediate and extended family when defining and describing family.

**Major Themes**

Examination of the family members’ responses to the four research questions revealed that the family strengths were so intertwined, that these four questions were most effectively answered as one question rather than four. Thus, in this chapter a theoretical schema was presented depicting three major dimensions of family functioning. These dimensions were (Table 4-2): Overarching beliefs, collaborative communication, and positive meaning making. The major theme of overarching beliefs was defined as a strong sense of group identity, an ethic of shared responsibility, mutual support and relying on faith. The major theme of collaborative communication was defined as fostering communication as well as shared decision making. The major theme of positive meaning making was defined as normalizing disability, the impact of disability, taking a proactive stance and learning to from professionals.
Overarching Beliefs

Throughout the interviews there were consistent themes that emerged related to specific relational and emotional connections as well as overriding strengths. Much of this can be characterized as the beliefs held by the families. These beliefs (Table 4-3) focused on identity, responsibility, support and spirituality. Identity was defined as identifying oneself in relation to the family and not the individual. Organization was how the family viewed their structure. Responsibility was how the families set up roles and expectations of one another. Support was defined as the belief, dependence and expectation of emotional and functional support. Lastly, spirituality was a reliance of each participating member on faith and religion.

**Strong Sense of Group Identity: “There’s No Me if I Ain’t Got My Family”**

Belonging to their “family” appeared to be of enormous value and power for the members of each of these families. When the families were asked to discuss “family” they would relay the importance of being in a family. For example Calvin stated “If you have family you can get through anything” yet when asked how this belief in family came members hesitated and had trouble responding. This commitment to the family was not something that was discussed nor needed to be defined. When asking Alesha about family and how her family talked about family or defined family she responded by saying “Well what do you mean, it’s not something we talk about. It just is what it is. I guess it is more what we do”. There was the expectation that “we are family” and “we are going to do this together”.

Family was understood by the interactions, verbal and nonverbal, between each member and the expectations that were established. Danielle described growing up in her family with her mother teaching her about the importance of family. Danielle stated
“always knowing that what I want has to be what the family want”. When asked to expand on this more, Danielle described growing up with her brother Terence who had mild mental retardation and the challenges she faced in school. Danielle stated being repeatedly told by her mother that “what is important is family” and that “she is who she is because of family”. When Alesha was questioned about statements made by her daughter Danielle she described raising her children and showing them that they “always have to put family first”. She reported doing this by modeling, “I think by me doing’ it with my own family. I show my kids what we do”. The idea of family as the primary value impacted every area of their lives. It was how the members defined themselves.

The H family shared similar beliefs regarding individual versus family. Generally the family was thought of as the primary focus rather than individual members. When questioning Georgette regarding difficult times faced in the family she continually referred to “tough time for the family” and how “the family worked it out”. When pressed about the impact to her personally, Georgette again went to family “Well you see we figure it out together so I ain’t got to do it alone”. Even when pressed to separate self from family, the lure was to go back to family. Although individual family members had their own interests and abilities, their focus was always on the family and not the individual parts.

This commitment to the family over the individual was evident throughout the family interviews as well as the individual interviews. The researcher had the opportunity to interview each member alone and within the family context. This allowed for questions to be asked in both the family setting as well as an individual setting. This
provided a forum for individuals to voice possible alternative stories during the individual interviews. However regardless of the interview setup; individual vs. family, the responses were consistent. For example, Keisha, niece to Vernon was asked to describe challenging and difficult times that she has had to face. This was asked in the individual and family group interviews. Her response was consistent regardless of the interview setup. There were no additional concerns mentioned when she was alone with this researcher or when she was with her family. This went beyond the verbal discussions families had to encompass a family narrative. It appeared that there was a certain level of disclosure and consistency among the family members.

It was as though the family members had shared perspectives rather than independent perspectives. The stories that the families told were one story with minimal variation whether in the context of a family interview or an individual interview. While interviewing the B and H families it was noted individual family members shared a similar perspective regarding events, experiences and responses. When discussing hardships for the B family, more specifically disability discrimination felt by the family, Alesha explained during an individual interview “Things were tough. There are times when I just stay at home ‘cause you don’t want to deal with what might happen. And I know this is how it is for my kids too. But we got to look at it because we is strong and we can face anything. I don’t stay at home as much because that’s not who we is. We face it now.” When speaking to Calvin during an individual interview regarding discrimination Calvin stated “Oh man, you know it happen a lot. You know…people they look and stare and…I don’t know…I guess it was easier to not go and not do. But that’s not how it is now. Now we go (laughter) and we do (laughter). You gotta stand up for
yourself man…you know.” This perspective was shared by all family members, even separately during individual interviews. And again while engaged in the family interview all participating members demonstrated agreement. The B family had a shared experience which also ended in a shared meaning of the experience. They are stronger now because of the discrimination.

For the H family they also displayed similar shared meaning when discussing future planning for Vernon. When asked how this would be determined Betty explained during an individual interview “family will take care of it. If one not here another will be.” During Georgette’s individual interview discussing the same topic she stated “I guess it just going to be what it be. We know we be takin’ care of Vernon. We ain’t got to talk about that ‘cause it already what it is. Betty not here, I be here…I not here my daughter be here…you see we got it.” Keisha during her individual interview remained on the same line as her mother and aunt stating “Well I don’t have to do much now but I know if I need to I will do it”. When asked how she would know if she needed to step in and care for Vernon she replied “I don’t know. I guess I will know if it happens.”

There was such a shared meaning and perspective that it did not matter if the individual was asked with the family present or without the family present. It was understood by all members that this is the way that they are going to function. Their experiences and their understanding were shared.

**Clear Organizational Hierarchy**

In each family there were three members who participated in the research interviews. The identified “head” of each of the households was a female. This was the woman whom the researcher had made primary contact with to ask for and arrange the interview with her family. She was responsible for getting agreement to participate from
the other family members, to scheduling the interviews, and to informing others of meeting times. For the B Family the head of the household was the mother, Alesha. Her children appeared to have been raised to listen and respect their mother and the role she embraced as managing and running the home. When asking her children Danielle and Calvin about rules in the home and how they were established, they each referenced their mother’s role as “setting the rules” while they “follow the rules”. As Calvin stated “My mama know what she be doin’ and I know I got to be doin’ what she be wantin”. Both voiced the ability to “talk about rules that don’t work” however the understanding was that their mother, Alesha knew what was best and would guide the family appropriately.

Although the H family was no longer headed by a mother or father as they were deceased; Betty, the eldest sister in the household, was identified as the head of the household. She was generally responsible for overseeing the day to day activities of the home. Members of the H family acknowledged Betty’s role and appropriately adjusted and accommodated to her leadership. When conversations would begin during the family interviews, Betty would lead the family. Betty would set the tone for the others by speaking first and providing full descriptions related to the question asked. It appeared that Betty held the power in the family and did not require affirmation or input from others when responding. The conversations were primarily moderated by Betty. Betty would not engage others in completing a response; this did not appear to be seen as ignoring other family members. Other family members listened intently and offered insight when prompted by Betty or the researcher. The other members did not appear
agitated or silenced by this interactional pattern. It seemed that this family worked with all members involved with the understanding that Betty oversaw it all.

An Ethic of Sharing Responsibilities: “We Do it Together, That’s How We Work it Out”

The mother of the B family, Alesha often received enormous amounts of assistance from her children. This assistance would mainly come in the form of completion of household duties and the day to day running of the home. Alesha also reported a level of emotional assistance as she was “a single parent” and at times “talked to” and “needed” her children more than she would have if another adult were present in the home.

In the B family, the oldest male in the home, Calvin, 27, often took on adult responsibilities of caring for his brother Terence. Both Calvin and Alesha the mother recalled times when because there was no other male presence in the home, increased responsibilities would often fall on Calvin. Alesha and Calvin reported that there was never a conversation between them about the role Calvin would play, it was more something that he grew into “I guess he (Calvin) just saw what was happening, he just did it, we did what we needed to have done” explained Alesha. Calvin took on feeding, clothing and bathing his brother. Often Calvin would have to “come right home after school” because his mother required assistance with Terence.

Alesha, the mother recalled “This was before his sister come along so it was just the three of us. Their father was, we were never married, but he was like in and out of the picture. I didn’t have his father help with things that I had to do with Terence, you know, so it put a lot on his brother, you know, to help”. As Alesha was speaking her eyes began to water. It was apparent that she struggled with some amount of guilt
related to the role that her son had to take on. Alesha was able to recognize that additional pressures were placed on Calvin given the absence of his father. One might assume that if the father was around Calvin may not have had to take on certain responsibilities for Terence.

Unlike Calvin, Danielle, the 18 year old daughter in this family had a more typical child’s role in the family. She did not have the same type of responsibilities placed on her as were expected of her brother, Calvin. Alesha, the mother, talked about trying to make sure Danielle was not being “limited” by Terence, her brother with mental retardation: “You see I do things different with Danielle, you know, when she asks to do something I make it happen whether it is something I can do or if it’s something I need my family to help her do. I didn’t…I don’t want her to be limited because of Terence. Calvin…I know he wishes I did things different. So I make sure Danielle have what others do and not the responsibility of it all”.

Even with these apparent safeguards in place, Danielle would often seek out ways to assist her brother Terence. It appeared that through the modeling by her mother and her brother, Danielle felt a pull to contribute and take on some level of responsibility. She saw this as what family members do for one another and wanted contribute. Danielle appeared to be drawn to her brother and to feel responsible to offer care whenever it was needed. This was not something that was being asked of her but it was something that she saw among other family members and was looking to do the same. Alesha did not try and keep Danielle away from gaining additional responsibilities yet it was not something that was expected like it was with Calvin. Danielle did not see it as additional responsibility; to the contrary she frequently found enjoyment and fulfillment
interacting with Terence. As Danielle explained, “The responsibility thing can be hard sometime but I am happy doin’ it. I know I got to help him with stuff but he helps me too. And I don’t think people get that…that part of Terence, the…I don’t know. I feel lucky that he is my brother”.

In the H family, Betty, who was not the oldest sibling but was the oldest female among her siblings, reported taking on responsibility at a very young age due to her mother’s poor health. She explained “When I was young, I had an older brother but he come and go. So it came to me. So I just thought about it and took it as a responsibility. Well it’s like this, I either accept it because if I don’t then I won’t be around them. I’m going to miss them and then I won’t get a chance to know how their life is going, how they’re living their life. And I won’t know about their life. So I just stuck to the responsibility and went along with it.” It appeared that Betty took on the leadership of the family with open eyes. It was not something that gradually happened. Instead she made a conscious choice to stay with family and took on an enormous amount of responsibility. It happened by necessity due to her mother’s failing health and the need for someone in the family to step up. It appeared that Betty learned her role from her mother who had previously been the matriarch of the family. Betty, the oldest female child, felt it was her duty to care for the family. This happened at a very young age for Betty and it continues to this day.

If Betty were to fall ill, the second oldest female, Georgette, who resided on the same property, acknowledged that she would take the family leadership responsibility. During an individual interview Georgette described her responsibilities as the second oldest female sibling, “I mean we all help. If Betty ain’t there I be there. That’s just how
we do...when Betty not around I know I be taking care of Vernon”. With the H family the main responsibility for managing and maintaining the family and the care of their brother with mental retardation resided heavily with the females.

It appeared that the role of each family member evolved over time without a great deal of explicit negotiation, it was determined day by day. Because there was an aspect of the unknown regarding the needs of the disabled member each member had to redefine their original role in order to fit what was needed for the family at different stages.

**Sense of Mutual Support: “We Are There For Each Other”**

Support was a major component for the families. There was a steady belief of “we are there for each other” in both families. There were many times during the interviews when both families would respond to questions with “We’re family”. This saying says it all: “We survive because we are family”, “we get through tough times because we are family”, “we know we can move forward because we are family”. There appeared to be an unbreakable bond with immediate family and extended family. The support that each member felt spoke volumes. Georgette stated it best “The love and support of the family, that’s what kind of keeps you going”. There were three identified levels of support. There was support at the functional level, at an emotional level and on a community level.

**Believing in functional support: “We just do what we do”**

Functional support was seen as family providing assistance with activities of daily living. Many times during the interviews, the explanation for how or why things work was answered by describing functional support. Calvin stated, “It’s like, man…we help each
other and you ain’t alone”. Danielle stated it best when she said “they are always there” in reference to her family.

Both families described having family member available whenever it was necessary whether it was to babysit or to mow the lawn. They may not see family members’ everyday but they know that they are there if needed. Even some members they only see when there is a need as Betty stated, “they come when I need them. We’re not around each other too much until we need something, then we’re there”.

Georgette provided an example of functional support when describing an incident where she was unexpectedly rushed to the hospital. When arriving to the hospital, she was told that she would have to stay there overnight for observation. It happened to be the same night that she was the main caregiver for her brother Vernon. Georgette was in charge of making his dinner, giving him his medications and making sure he got up in the morning, ate his breakfast and got to work on time. Georgette was asked to describe how she managed her responsibilities to her brother as well as to her health. Georgette replied with a smile “because of family”. Although she may have felt stress due to her obligations to her brother she knew that her “family would take care of it.”

Another family member, a sister, knew that Georgette went to the hospital and that she needed to step in to the role of caring for Vernon that evening. Georgette stated that there was never a time when she felt she would need to call anyone to check up to make sure Vernon was being cared for because she knew her family was there to help out.

The role of functional support goes beyond the day to day. It also encompassed the past and future. Alesha talked about the role her family has had in her decision to
have Terence stay in the family home rather than be moved to a group home. She was aware that without the day to day support from her family she may have needed to make alternative decisions, and it would have altered Terence’s future: “Yeah because if I did not have family and stuff, it might have led me to want to put him (Terence) somewhere, you know? But with my family, it made it that much easier”. Alesha did not take the support of her family lightly and realized what her life may have been like without their support. She was thankful and grateful for what she had been given.

This expectation of family support was also demonstrated in the families’ conversations regarding the future. These families believed that their families would be there to provide for the family member with a disability. It appeared that this was not something that had been discussed in a formal family meeting however it was something that was known and readily agreed to and accepted by all members. As Alesha talked about future planning for her son Terence and explored what would happen if she was not around, she demonstrated a sense of conviction in knowing what would happen. Alesha appeared to be sitting up a little straighter and her voice became more firm. Alesha explained that professionals often want her to write a will placing Terence in a group home when she passes but this was not something that she or her family would consider “Even if I leave here, my family’s not gonna let him, even his brother and sister, they will fight to keep him home. A lot of the programs and things that they have I don’t really get into them like that because I know I have family, you know. Even far family, cousins, they still be there to help”.

This belief regarding the role family functional support was felt by members of the H family as well. Betty stated very clearly when asked to explore future planning for
Vernon “We’ll take care of him. We got a lot of support here. We look out for Vernon, we know how he is and we help look out for him”.

This shared belief among all members that when necessary family would be there to provide whatever support was necessary was quite clear. This support was something that did not need to be checked to make sure it was still present because it would always be there without a need to question its reliability. Alesha described this by saying, “Yeah, I’m glad we have as many people in our family as we do. Because if one is not there, we have someone else….” Not only was there the understanding that if one family member was not able another family member would step in but this was believed to the point where they had blind faith to the fact. Family helped family and this does not need to be questioned.

**Dependence on emotional support: “When you got family who love you it’s easier”**

Emotional Support was providing assistance to other family members at an emotional level. It was the interactions between family members that fostered emotional bonding and connection. This was evidenced by engaged listening, empathizing, encouragement, humor, belief in each others’ abilities and strengths. A strong emotional connection was evident among the families. This was a connection that went beyond providing basic sympathy and support: it was a connection that allowed each family member to know that their relationships made events manageable and life worth living “when you got family who love you, it’s easier”. This connection was seen as something that helped them survive and endure difficult times.

During the initial family interview with the B family there was a clear understanding of the bond that the family members shared. While the mother, Alesha, was describing
family support and retelling a story of how she has had individuals come up to her and say how they envy her family and she stated how she “believes (her own children) realize what they have”. Alesha explained how her son Calvin had moved out of Florida to start his own life. Yet even though he was away he was in constant contact with his family and makes frequent visits. While Alesha was sharing her views of her son’s actions she was holding Calvin’s hand. Calvin was smiling and looking down at the table.

Alesha went on to report that “just last week you know I was with my son, he called, he would call me to you know touch base to see how we all is, but I think he gets homesick too being so far”. Alesha looked at her son as she was saying this and leaned over to kiss his cheek. Calvin responded by saying that he called because “she likes it.” Calvin was laughing and clearly joking with his mother. They were making eye contact, holding hands or nudging shoulders. The daughter, Danielle chimed in saying “sometimes when Calvin be calling I ask him why are you calling so much?” At this point all three family members were laughing. They were teasing Calvin yet he did not get upset but instead continued the use of humor stating “You be cryin’ if I don’t (call).” There was an ease with which these family members shared their views. Whether they used humor, physical contact or verbal encouragement it was clear that there was safety with sharing and a belief that one will be supported.

During an individual interview, Alesha was asked how her family has managed struggles and difficult times. Alesha took a moment to respond, looked away from the researcher and when she looked back to respond there were tears in her eyes. She said, “The love that we have for each other, that you…it makes it go well. Because we
have this love for each other and it takes things a long way”. It was not only in her words but in her actions and appearance that relayed the deep emotional bond she shared with her children. Alesha put thought into answering the question and almost appeared to come to the realization in the moment how incredibly dear her family was to her and how they had given her the strength to move forward when things were hard. Although she was crying when she responded it did not appear that this reaction was coming from a place of sadness, more like a place of gratitude.

When Alesha the mother was asked what was the best part of being in her family, she stated: “Well, the best part about being in it is having my kids”. Alesha’s daughter, Danielle, when asked the same question individually stated “That they take care of me.” When Calvin, Alesha’s son was asked he responded “We have fun together…ya know…ya know it’s just, man, we laugh…a lot. So ya know the best part is all the laughing”. Even as Calvin was responding to the question he was laughing and smiling. It was as though he was remembering enjoyable times which bring him fond memories. Each member immediately goes to the relationships they had with other family members when describing the best part of being in their families. They had a genuine appreciation and admiration for one another that went beyond basic responsibility for family.

Although the H family was not as overtly emotional as the B family, they shared common themes related to the relational bond that was among family members. When Betty was asked how she managed difficult times she described her mother passing away two years ago and how she was able to heal through the support of her family. Betty explained “You see, when my mama passed…it was hard…real hard. I been
carin’ for her for so long that…you see it’s just what I did. I didn’t know what to do but I…I got my sisters and they know and they be there. They be knowin what I need and…it made it better…just havin’ ‘em there…close by”. During struggles Betty found comfort in knowing that her family was near. Just their presence made it possible for Betty to manage her grief.

This connection was seen in both families at varying levels. It was seen in the relationships that they had developed and the ongoing style of interacting with each other that continued to build this connection. These relationships can best be thought of as positive interactions among family members. These positive interactions were seen through the way members attended to one another by listening intently and empathizing, by believing in one another, and by engaging each member and focusing on successful outcomes. Family members acknowledged and attended to each other’s thoughts, feelings and needs of other family members through their words and actions. This also involved a level of engagement by each family member. Individuals were brought into the conversation if there was a sense that they were not contributing. This was often attained by making eye contact, positioning oneself in a way that encouraged participation by all.

Much was conveyed by the nonverbal interactions among family members during the family group interviews. For the B family, when Alesha would become emotional, crying while sharing memories, her children would often move in closer to her on the couch. They did not make an enormous amount of eye contact but would hold hands or pat another’s hand. For the H family these nonverbal interactions were seen throughout the interviews as well. Although they did not offer the clear explicit displays of affection,
they were actively engaged when another was speaking. Members would increase eye contact, use heads nods in response to what others would share when more intense feelings or situations were being shared. Often facial expressions would change depending on the conversation, if the speaker appeared happy or upset, the other members would appear to be feeling the same emotions. For example, when Georgette was describing her husband being on the road fairly often due to his job, it was evident that this was difficult for her. Her voice lowered, speech slowed and she limited her eye contact. Because of the difficulty Georgette was having, her sister and niece increased their eye contact and appeared to be feeling the emotions Georgette was having. They looked concerned when Georgette was describing struggles she faced when her husband was not home. They used head nods and verbal acknowledgments as a way to affirm Georgette’s feelings and descriptions. They were fully feeling and responding to what another was feeling and offering support.

Another way emotional support was shared in the family was seen through empathizing. In both families the family member made an effort to understand and share understandings regarding what they believed to be true. Alesha would often ask her children “Was that how is was for you? Did you feel left out and like you wasn’t getting enough?” This mother would not make the assumptions that she knew how her children were feeling. Instead she attempted to understand their thoughts and feelings through her own interpretations. Asking each family member for clarification until a full understanding was attained was an important factor for the families.

The following is an example of how this emotional support was displayed by the B family during a family interview. The family was being questioned about how difficult
times are managed. Alesha, mother to Terence responded, “It was family and support and my faith. I don’t know how I would have done it without those things... Cuz my family know we need to be together and help out when we can”. This was said during the family interview with Alesha, Calvin and Danielle. As the mother was speaking she was crying and appeared to be overcome by the emotion of it all. Her children were actively engaged in the conversation, Danielle holding her mother’s hand and Calvin nodding agreement to Alesha’s statement. At times the children would respond with supportive “yup” “um hum”. These gestures provided by Calvin and Danielle appeared to offer Alesha encouragement and calm. She would look at her children and smile, squeezing one of their hands. Even when Alesha was doing the majority of communicating during the family interviews, she would often glance at her children for affirmation, squeeze a hand or a leg and ask them for their reactions. The support went beyond a verbal confirmation by each member but was evident in the physical contact, respect shown and display of genuine emotion.

The H family frequently spoke of the relationships among family members and how they supported one another through “listening” and “making things better.” These were things that were highlighted when discussing the best part of being in their family. Georgette stated, “They be there and they know what I be needin. It’s not like we got to try to hard.” Georgette found the emotional support she received from the family as effortless. Family members provided this level of support without pressure or second thought. For the H family it was realizing that there was a connection among members and using that connection to sooth and comfort.
This support was mutually reciprocal and included the family member with mild mental retardation. It appeared that these family members did not perceive the person with the disability as helpless and requiring family members to provide only one-way support to the family member with a disability. Instead this individual was viewed as much a contributor to emotional support as any other family member. For example, during a visit to the doctor, Alesha explained how Terence treated her when they were there “you see Terence, we be sitting up in the waiting area and Terence he’s gonna sit there and he’s gonna hug on me and kiss on me, he’s gonna hug his sister, and his brother and you get some people there and they be looking at you and some of them look at you like why would they do that but then you remember that’s what makes us us and this is loving and sweet.” Alesha struggled in the beginning with worrying about what people thought of her and her son. She would wonder if they were talking about her or making rude comments about her son. It was a time when she was not able to see what support Terence offered, which was often on a physical and emotional level. However, she now accepted what Terence’s ways of expressing his love. She had taken this unconditional love that he provided and found strength and support.

The H family shared the same belief regarding Vernon and the level of emotional support he provided the family. Betty consistently stated that, “Vernon like the rest of us...he do what we do and he just as important as the rest”. When speaking with Keisha about family relationship she discussed her relationship with Vernon. She described not always spending time with Vernon but knowing that when she needed a family member to listen to her she always knew she could go to Vernon: “See he’s the best to talk to.
My mama might get upset when I be talkin’ to her but Vernon he just listen. He ain’t gonna yell or nothin’. He listen to me…he just listens”.

**Expecting community support: “We been here all our lives, everybody know everybody and they be helpin’ out”**

Family members also perceived themselves to be provided with support beyond what was offered through immediate and extended family members. What was unique to both of these families was the communities in which they resided. They both lived in small rural communities which were predominately African American. Additionally, each of the families had spent many years in these communities and established themselves in their communities. Both families stated that most of their neighbors had been there for similar lengths of time. They were communities comprised of similar if not identical demographic makeup. Both families described their community as a place where “everybody knows everybody”.

This had been a major source of support for the family. Both families described a sense of comfort and safety in interacting with members of their communities. They believed that people looked out for one another, even if you did not know each other by name. Calvin explained, “Everybody here, man…they be lovin’ Terence. He go outside and everybody be talkin’ to him. We know he safe out there cause they be knowin’ him and they care…man he is known”.

Georgette explained how the community had supported their family even if they are not close. “Well, we have…we get a lot of support because everybody here knows Vernon and they look out for Vernon. We don’t have to talk to them, we don’t have to know them, you know, and we don’t have to be friend to them. They know, Vernon, they know how Vernon is, and they help look out for him”. For the H family they found
support in community members that they did not have a relationship with. There was such a sense of ease as Georgette was describing the support offered by the community. It was the idea that people look out for one another, and this is assumed rather than questioned.

Betty relayed a similar confidence in the neighborhood community “And see I knew, I won’t move Vernon because, see that’ll become a problem, because he knows this place, he knows the people here and they help him. If there’s anything he wants, you know, they try to make sure he gets it, or they will see can they get it for him. And if he needs a ride home, they’ll give him a ride. So you know, he’s just right at home here.” The palpable sense of support provided by the neighborhood community had assisted this family in making decisions about possible future placement of their adult child with mental retardation. Because of the neighborhood community support, as well as other family factors, this family was able to care for Vernon and continued having him reside in the family home rather than seek out alternative placement options.

The neighborhood community was viewed as an extension of the family. They had a certain level of trust in the neighborhood and community knowing that Vernon would be cared for and provided transportation or oversight if a family member was not available. This had allowed the family to experience additional support. When Vernon was out of the home, he was able to go on his own because of the high level of trust in the neighborhood community. Vernon was able to have a life outside of his family without constant monitoring by his family due to the community monitoring provided for Vernon.
There was not only the support felt from persons in the immediate neighborhood but support that included the community as a whole. When speaking with the mother Alesha about supports outside of her family she recalled a high school coach that had a long-lasting impact: “So I really thank the ones that took the time. Because Terence, I guess with his brother being in sports and stuff, the coaches and stuff, I guess they got attached to Terence. They even had all the players, they signed the basketball for Terence. The coach took pictures and everything with Terence and this is good because they kind of relate and everything and they knew Terence, so it’s a good thing...” This was a fond memory for Alesha. As she recalled the memory she is laughing, explaining that this gesture might have meant more to her than it did to Terence. Even now she was touched by the actions of this one coach. It made her believe that she was not alone and others were there to offer support: “That’s the thing. That’s why I’m saying about the coach. He’d get Terence, take him just like Terence is theirs, you know”.

The H and B families were not remembering or stating huge monumental expressions of support from the community. They were stating small acts of support that had made an enormous impact on their lives. It was the day to day acts that spoke volumes for these families. Alesha provided a great example of this when she was retelling the story of Terence’s graduation. Because of his disability Terence stayed in high school and graduated when he was 22 years old. Although Alesha reported some struggles with the school, the memory that she holds dear was one of support: “When Terence graduated, his teacher was there. She was at the graduation to help out, not
just sit there and…she was hands on, right there, in that situation, making sure that Terence was included just like normal, you know? So that’s really something”.

It was those small acts of kindness which appeared to be valued the most by these families. They believed that they were not alone and that there were others outside of the family who were open to assisting, without being asked.

**Relying On One’s Faith: “The Lord is Going to See Us through”**

Faith and spirituality were important coping resources in the lives of both families. The members of each family as a group and also in individual interviews identified themselves as Christians, more specifically Baptists. This faith was not something that they took in passing; great weight was placed on how it impacted their lives. The families explained their faith as guiding their deepest values and meanings by which they live: “Jesus shows us how to live our lives” as stated by Betty. Both families reported attending church related services 2 to 3 times a week. It was a major presence in the lives of these family members.

Not only had this faith assisted with shaping their beliefs and values but it also served as guidance for handling day to day life circumstances, and prayer was something that all family members engaged in. They place full responsibility and guidance with God. While talking about faith and how it impacted his life, Calvin said: “It’s what helps our family and provides us with direction”. When describing the role faith played in her life Alesha stated, “Because when we go through things, I have to pray and you know? And I tell my son too, you know you can talk to me but you need to have faith and talk to the Lord, and He’s going to pull us through, you know? He’s going to make a way for us too, you know? It’s not always going to be like this because the Lord is going to see us through”. Faith was seen as being bigger than oneself. There were
things that you can do but in the end God had the final say and He would do what He thought was best.

It was evident for these families that especially during difficult times their spiritual faith and religion assisted with managing these struggles. Faith was something that provided immense support and allowed individuals to find the strength to endure. Betty expressed her complete reliance in faith: “As long as I keep praying and asking the Lord to watch after me and give me strength to deal with this and that, things turn out ok”. There was a notion of giving oneself over and placing your life in the hands of God. Knowing that in the end He would make the right decisions for you and would provide you with what you needed when necessary. “If you have faith, and you talk to the Lord and take each day as it comes you don’t have to worry about the future, you just go along with each day as it come” as stated by Georgette.

The families admitted to times when their faith was put to the test, yet they always remained faithful and knew that faith was the right path for them. Georgette described times in her families past when they struggled through deaths and unexplained difficulties. Georgette explained: “Oh things are not always how they should be. Some family be thinkin’ that turning away from the Lord is the answer…oh Lord…the devil be tempting but that’s not the answer”.

Alesha described an incident where her faith was tested during a visit to a new church. Alesha was accompanied by her son, Terence and daughter, Danielle. Her son, Terence, although he was able to communicate tended to make indiscriminate noises when he got excited. She described an experience of discrimination and insensitivity that shook her belief. Alesha described the experience “We went to this church, we visit,
everybody’s looking when we passed, the pastor kept on stopping service and saying what is that noise, they really made us feel uncomfortable I never went back to that church again. Even though my son didn’t realize what was going on he was happy, he was praising, you know clapping with the music, everything, that’s how he acts but they don’t understand…it was hard because you wouldn’t think you would never that a pastor would be…not a pastor. We just left it, God has to deal with this because something’s not right, yeah something’s not right”. In the end Alesha used prayer, belief and her strong faith to make sense of the experience believing the incident was something God would take care of. She had complete faith that God would do what was necessary.

Danielle explained that even when she was going through difficult times she knew that she could turn to the Lord to help her through. She used the Lord to help her through the incident at church. Danielle believed that if you have faith in your heart things will turn out for the best; “You have to talk to the Lord, you need to have that faith, and stuff you take each day as it come I don’t worry about that future thing I just go along with each day as it come”. There was a sense of peace that comes with this level of faith. The belief that God would not give them more than they can handle and when things were hard they relied on their faith to see them through.

**Collaborative Communication: “We Got to Talk, We Have to Talk”**

Communication was seen as paramount for both families (Table 4-4). Collaborative communication was a necessity for the families when managing day to day life circumstances. What was unique to their style of communication was the common narratives described. When sharing responses, whether it was during the individual interviews or the family interviews, all members had the same response. There appeared to be a certain level of agreement and certainty among the members.
There was one story to share regarding their family rather than multiple different stories from each member’s perspective. There was a focus on the “family” story rather than the “individual” story.

**Fostering Open Communication: “Well…it is How We Get Through Things by Communicating”**

The communication used among both families was clear and genuine. It was something that was expected of each member. Communication was something that the families established in the beginning, it was expected but taught at an early age. Alesha explained that she “teaches her kids how to communicate” from the beginning. She felt that communication was a core part of building a strong family and needed to be taught early on. Alesha would allow her children to share their thoughts and encouraged open dialogue.

When open communication was maintained, the belief was that the family could manage anything that was sent its way. When acknowledging struggles in the family Alesha felt that communication was what could help them through. At times when Alesha felt she was not involved enough with her daughter or her daughter was upset, she relied on open communication: “some things might be going through her mind, but I try to keep that open relationship so that she can feel like I love her and I will listen to whatever she has to say. We have to do this together and support one another…”

Communication was something that keeps this family together, strengthens their relationships and builds family bonds.

Communication was a way for these families to show their love and respect for one another. Speaking to Betty about communication and its importance with her family she stated that it was “very important”, it allowed for members to be heard and feel a
part of the family “as long as we can get to that open...have that conversation about what’s really happening, everything works out”. What this family was able to control was how they understand one another. This understanding was met by fostering and modeling open communication.

Within each family, members appeared comfortable with the interview process and open to genuine discussion. Although there were similarities related to themes in their communication styles the families differed in their approach to communication. The B family approached the interviews in a collaborative manner. During the family interviews each member would openly participate. There was not one designated main speaker; each would feed off of information provided by another. While Alesha was speaking she would often look at her children and encourage their participation by asking them what they thought. Alesha positioned herself in the middle of her son, Calvin and her daughter, Danielle during the family interviews. Even when Alesha was speaking she would often smile at her children, touch them, pat their arms and gently push them when she would make a joke. In response Calvin and Danielle actively listened to their mother as displayed by their use of eye contact and head nods. Additionally they responded to questions and prompts by the mother when she was speaking, appearing relaxed and calm which the engagement.

Each member was clearly connected to one another. This was evidenced by how members would respond to one another when emotions were intensified. Calvin and Danielle would often comfort their mother when she would begin to cry, holding her hand or giving her a smile. In return Alesha would offer the same when her children were speaking.
The way of communicating in this family was open and flexible. Each member was able to voice their own reactions and thoughts, generally encouraged by other family members to do so. As this family discussed past experiences they each shared a part of their own memories making up the entire story. The B family took a collaborative approach, working as a team to recreate the past and explore alternative meanings to their understanding.

Alternatively, the H family displayed a more traditional sense of family. Although the family was not traditional in its makeup (i.e. mother, father, son and daughter) the way of interacting would be described as more traditional. Betty was the clear matriarch of the family. This appeared to be a position that the other family members accepted and respected. During the family interviews, Betty was the main responder/the spokesperson. She positioned herself in a lounge chair, while Keisha, her daughter, sat on the floor and Georgette, her sister, on the couch. Physically they were separated by a couple feet as opposed to the B family who chose to all sit on a couch, touching knees.

Betty appeared confident in her responses and did not look at other family members for approval of shared information, which was in direct opposition to the way of interacting with the B family. In the H family each individual would respond separately without collaboration from others. When Georgette and Keisha contributed they would look at Betty when they spoke and after they spoke. It appeared that they were attempting to take her lead and were looking for signs (verbal or nonverbal) of approval. They did not appear intimidated and threatened by this way of interacting, it just appeared to be how their family was structured. The researcher often had to solicit
responses from the other participating members as their responses were not free flowing, yet when each provided a response there was a clear shared story being told. Although, the collaboration may not have taken place during the interviews it was apparent that the stories had been fully explored. Often they would laugh and joke when describing past experiences, although generally their tone was more serious throughout all of their interviews.

The H family communicated openly however it was in a more rigid and structured way. There was little sharing of emotions, instead events were facts with outcomes rather than an emotional response. For an example, during an individual interview with Betty when asked about tough times in her family her response was “Nothing’s hard too much. Just sometimes you get a little aggravated with things that you have to do but then it doesn’t stay, because you know that you have to do this or do that. So you just go on and do it, and do what needs be done”. There was still a depiction of emotion but it was not dwelled upon or encouraged as it was with the B family.

**Shared Decision Making: “We Work it Out”**

Each family functioned as a unit. They took on a view of being members of a group or a team, looking out for one another rather than looking out for individual needs. This was evident when discussing decision making processes the families possessed. When asking Betty, brother to Vernon, how she made decisions she responded, “Um, we do. We family, we make it out. We sit down, we talk about it and then we come out on an agreement with it”. Each situation and decision was taken by the family as a whole rather than by its individual parts. It was not a question of making individual decisions as this was not something that fits for this family. The question was more how do “we” address this issue, not how do “I”.
Georgette, Vernon’s sister, stated, “Well, we try to pretty much stay at the same level, you know, look after one another. If there’s a problem we sit down and talk about it, we discuss it, we come on agreements and that’s it. And whatever we think is best, that’s what we go along with. And so far, we’ve been doing pretty good with it.” For this family, decision making was best met through communicating and being there for one another, support. Alesha expressed that same desire for shared decision making when she discussed how schedule conflicts were managed: “There are times when my kids want to do something and it’s not always going to happen. I don’t just tell them no, you can’t do that…I mean I try and talk it out. We talk, we talk about what we need and how we can make it happen…but if it can’t happen we talk about that to. You know I think it helps…that way the can say what they need to say and we come to a decision”.

Their communication style was one of shared decision making and brainstorming. All members were heard and no one was silenced. Betty explained that when there were areas that were up for discussion and people had differing views they “come to an agreement” and never cut another down by saying “No, I don’t want this”, “I don’t want to go along with this” or “You’re wrong”. These are statements that are not made instead they look for ways that they are in agreement and where they can find a solution. Each member was included and communication continued until an agreed upon decision was met. Even if there was one family member that was considered the head of the family, as were Alesha and Betty, there was a collaboration regarding decisions made for the family. One individual did not make choices for the entire family although there may be one speaker for the entire family. Calvin described, “My momma always want to know what we think. We figure it out as family”.
Positive Meaning Making: “Look at What We Got, Not What We Didn’t Get”

Throughout the interviews the researcher noticed that when family members were speaking together or individually they were all exploring past experiences. As they explored past experiences they were defining and redefining those experiences. Generally speaking a difficult or stressful time in the past was often explained as contributing to their current positive views (Table 4-5).

Danielle depicted this by stating, “I mean I used to be jealous of my friends, thinkin’ that they had it easier and they didn’t have to worry about a brother. But I mean they also don’t know what it’s like to have a brother like Terence… I mean I love Terence and I don’t mind helpin’ and takin’ care of him. You know when you meet Terence he is just so happy and it makes you feel good. Terence’s always got nice things to say…I mean…he just…I feel blessed and I thank Jesus for Terence and my family. And I mean I be seein’ other families and they fightin’ and it don’t never end…my family is not like that”. Danielle was recognizing difficulty but choosing to focus on what she had gained from the experiences she has had. Instead of becoming consumed by jealousy and looking for ways that her life was negatively impacted by having a brother with a disability, she turned this into a story of what others were missing out on by not having a brother with a disability. While her friends may not have had the same level of responsibility, they missed out on the experience of having a brother with a disability.

Danielle was genuine in stating that things are not always easy. She stated that it can be really tough and she can become extremely upset because her brother needs more assistance than she does. Terence needed someone to watch over him to make sure he was safe and at times this hindered what Danielle and her family was able to do. This had often interfered with activities in which Danielle would like her mother to
have participated. Alesha was not always able to physically support her daughter by attending school or extracurricular events. This was in part was due to community restraints with wheelchair accessibility but also Terence’s behavior of making loud noises when he gets excited. It may have bothered her but she understood and was not willing to let it consume her, “So even when I be upset I mean I know she loves me and is tryin’… an I know that Terence needs it more than me”. Yet even with the genuine emotions of frustration she brought it back around to knowing she was loved and that her family tried and that she realized that her brother may need more at times.

**Normalizing Disability: “He’s Just Like the Rest of Us”**

During the interviews the families were asked to describe how their family talked about disability and how this was relayed to others. When the disability had to be explained Alesha, Terence’s mother would say “he’s slow, he has some disabilities with him, but he’s a loving uncle. Being around us and seeing what we do day to day, you just catch on, you know accept it and go on like it is nothing, just like Terence is a normal child”. For the H family Betty explained, “Vernon not on the same level as us but that’s about it. He’s got a disability and we do what we need for him but it’s not much. He can’t see after himself like a normal person does. But other than that, it doesn’t change, he just like us”.

When Alesha was asked how her family talked about disability she hesitated. She paused for long periods of time attempting to find the right words. It appeared that normalizing the disability had become the way of life for this family that it was hard for Alesha to remember how they went about understanding disability. After several minutes of thinking Alesha responded “They know he’s handicapped, its not like, how would you put it? To me, really, my family, its hard to describe because my family don’t
see disability with him, you know what I’m saying, that’s why I’m saying its hard to put in words I guess because they’ve been with him”. Alesha and her family viewed Terence as Terence and not as the adult with mild mental retardation.

Danielle recalled growing up and learning about Terence’s disability: “Well ya see I just kind of grew up like that. When I was real little I just thought Terence was normal, I didn’t know nothing was wrong. He was just my brother. It wasn’t like one day my momma sat down and said Terence is handicapped. It wasn’t nothin’ like that.”

Vernon’s niece Keisha had a similar experience to Danielle. When Keisha was asked how she learned about Vernon’s disability, “Well…um…I don’t know. I don’t even know. I don’t think my momma ever said nothin’. It just be Uncle Vernon.” After probing Keisha expanded, “He just have a disability but it ain’t nothin’”. They saw beyond the disability and encouraged interactions with Terence and Vernon that they would have with any other family member. This belief of “not seeing the disability” was felt by all family members.

When asking Calvin, brother to Terence, how disability was understood in the family he recalled growing up and how his relationship with his brother was shaped. He also talked about Terence’s view on his disability. Even Terence was raised in the environment where he does not see the disability. Calvin stated “It’s like he don’t know he handicapped and stuff ya know. He go about actin’ like he can do it all and he ain’t know that he can’t do it all. Man it’s because we always treated him like everyone else. Kind of like nothin’ was wrong with him ya know. My momma always had me act with Terence like I be actin’ with any of my friends ya know.” It was understood that Terence would not be treated differently.
The H family carried the same beliefs. Betty described Vernon, “He cooks and cleans, just the other day he be washing his dishes…I didn’t know he could do it so good but he did. I guess if we got to do it he got to do it too.” This was followed by laughter among the family members and nods of agreement. Terence and Vernon needed additional assistance at times but the family chose to focus on how they are like everyone else in the family without shining a spotlight on the disability.

The families took it to a level of Terence and Vernon defining the disability not the disability defining them. They refused to have their family member seen as the individual with mild mental retardation and assumed to have limitations. Alternatively they looked to have Terence and Vernon seen for them. There may be limitations but they do not define who they were, they only added to their personalities. Terence’s mother explained, “because we’re so used to it we don’t see these disabilities, you know because he’s family. He’s just like the rest of us”. Similarly Georgette explained, “He (Vernon) is no different from us”.

Throughout both families there was a sense of decreasing the focus on the disability, while increasing the focus on the individual. The family member with mild mental retardation was not defined by their disability instead they were defined as a unique individual with a distinctive personality. For the families the disability was not seen, it was everyday life.

The Impact of Disability: “More Advantages Than Disadvantages”

The support that the families relayed surpassed what may be expected. The motto “you get more than you give” was evident among the interactions within these two families. When asked to focus on relationships and what they have meant generally the members shifted to what had been gained rather than what had been lost. Having a
young adult family member with mental retardation was viewed as increasing value to ones life. The disability was seen as positively adding to the makeup of the family and individual members.

When Alesha was asked what mental retardation has meant to her family she explored how her life and the lives of other family members had been enriched by this experience, “Patience (Laughter) yeah, patience and showing me, you know, to be more loving and understanding, you know because, probably if I didn’t have Terence and the love and affection that we have, I probably wouldn’t have had that, you know, and I have people tell me right now today you know. I have kids, kids are always over here, my nephews and stuff, they wanna be here than somewhere else you know with their own, so I think it showed me and my family, gave me a lot of love you know”. Although this mother shared how difficult the beginning years had been for her while caring for a child with a disability, what limitations had been placed on her life because of mental retardation she instead placed the focus on what she and her family had gained from Terence. Alesha believed that she had been given much more than she had to give or give up.

It was a humbling stance that each member took. It was realizing what was gained from relationships and viewing them as supportive rather than viewing them as draining and selfish. The following was from Georgette, sister to Vernon, when asked how she was able to manage day to day caring for her brother, “It was family and support and my faith. I don’t know how I would have done it without those things….cuz if I keep it to me you know and they would tell me you gotta let someone else you gotta. Cuz my family know we need to be together and help out when we can”. Georgette did not focus on
what else she might have needed during those times instead realized the importance of
her family. She believed that she would not have been able to successfully manage
without the support of her family. Although there were undoubtedly difficult times, the
support and caring of family was what was remembered the most, what was offered
was the focus over what was not available.

When Danielle was speaking of the assistance her brother Terence required she
stated, “I know I got to help him with stuff but he helps me too. And I don’t think people
get that…that part of Terence, the…I don’t know. I feel lucky that he is my brother”.
Even though she felt a certain level of restriction for the care of her brother she saw the
relationship as reciprocal. She even went so far as to say that she felt lucky that she
had the brother that she did. There was a great deal of research focused on the sibling
strain when there was a disability however when given the chance it appeared that
there maybe strain yet it was overcome.

The following was from Alesha. She was describing what disability has meant for
her family, “And its like I say, What’s going on how my daughter came up, how my son
came up, its really showing us how to love and be patient with him, there’s a lot of
advantages to me that come with this even though you have those disadvantages you
know, but its just been a blessing to me, I say this sometimes I thank the Lord I say Lord
I wish I had another child that’s handicapped because my child is just loving, sometimes
you think about some of your kids the parents that have normal kids think of doing
horrible lot of stuff worse than what I go through with mine, and I be thinking…and they
think its normal, a normal family don’t have that love that’s why I think having a
handicapped child it puts that love more and understanding but you would have to go through it you know…”

This focus was on recognizing what was being offered and supplied by other family members. Each member felt they were receiving more than they were giving, which means that all members were giving. They did not realize their personal contribution but highlight the contributions of others. While Betty was describing growing up with her brother Vernon and struggling because of the added responsibility she also highlighted what she received from her family and Vernon during those times. Betty explained, “It was hard, real hard. Times I felt is was unfair. But I did it and so did my family, couldn’t of done it without my family…We stronger because of it (1 minute silence). Now if there were no Vernon, I’m not sure I would be the same. He makes me real good at patience. My family we understand and we cooperate because of Vernon…and we talk (laughter)...we sure talk...when it come down to it ain’t nothin’ the tough times cuz we still here and better for it.” Betty did not stress the difficulties she endured, even though she made it clear that things were hard, rather she shifted to the growth and strength gained to her and her family through the difficult times.

While interviewing Danielle and when asked about her brother Terence and the impact mental retardation has played on her personal life, she stated “Terence is really funny. He makes me laugh so that’s good right? A lot of my friend’s brothers are not funny like Terence and they are not nice to their sister, Terence is always nice and good to me. Like when I am upset he just knows it and he be holdin’ my hand…this one time I was cryin’ and he cried too”. The relationship this sister was describing was mutually beneficial. Danielle may have needed to be there for her brother but her brother was
often there for her. Terence did not always know what to say but the act of sitting with his sister and holding her hand when she was upset showed the depth of the emotional connection among the siblings. A little later during the same interview Danielle stated “I feel lucky that he is my brother.” This was a statement that Danielle first stated during an individual interview and again during the family interview. Even as this sister was talking about her brother she was smiling. She was relaying a strong bond between the siblings. This bond had grown through past experiences.

The following was an example from Calvin whose brother had a disability “Yeah, yeah but it's family ya know. I guess…I don't know I guess it was hard and…I don't know (2 minute silence). Well it's like growin' up I had to do things different. My momma, we talk about it now and ya know how it was and what was goin' on. My momma missed things for me because of Terence ya know and all the doctors he had and him not being able to be alone and stuff. It's like bein' left out but not 'cause you have a lot you have to do for Terence, I don't know man. Does that make sense…I mean we had Terence and that was that ya know and things were different. Well ya know he needed more than me and got more of my momma's time and all that. (laughter) We be talkin' now about Terence be my momma's husband man (laughter). Yeah but man ya know we did it and it be hard at time but it's family and I got a good family." When prompted further about past struggles and the impact they had on the family, Calvin stated, "ya know it's like I be tellin' her (his mother, Alesha) we did what we did and we a strong family now". He was exploring past experiences yet used them to discuss the strength that was now in his family. It was a way of redefining situations and shifting from overwhelming
Struggles which may lead to hardship to positive growth that was attained through hardship.

There was not an avoidance or minimization of the past however there was a shift in thinking. The emphasis was placed on what was gained and learned. It was almost as if this family felt it was something that happened that was not just going to be a negative influence on the family but rather it defined who the family was. Family members seemed to talk about their experience and view them as positively shaping their current beliefs as well as their lives. Calvin explored this, “well my momma might have said I don't know but I work with people like Terence…Yeah I do that now. (laughter) I wouldn't think I be doin' this before ya know. Crazy man…It's like I just know it's what I should do. My momma, we talk about how it is like me givin' back. Terence taught me…well still does (laughter) ya know.” The experiences this brother had, no matter how trying, assisted him with a future career path. He was grateful for what his brother gave him rather than feeling robbed of what he missed.

Taking a Proactive Stance: “We Don’t Always Win but We Keep Tryin’ and Tryin’”

The theme of taking a proactive stance was most readily seen in regards to problem solving. The families were taking a proactive rather than passive stance to problem solving. Rather than a problem continuing without discussion, which could potentially lead to negative outcomes and dysfunctional relating, that problem was tackled head on. When asking about tough times and how they are managed: Danielle said “Well I guess, I just…I mean…I just want to help my momma and cryin’ and fusin’ won’t help. So it’s like a team…we don’t always win but we keep tryin’ and tryin’.” This was an attitude of never giving up and viewing a problem or tough time as something that can be handled. They encountered a difficult time with a positive view knowing that
they would overcome because they were going to continue putting forth the effort. For these families the notion of not finding a solution or maintaining disagreements was not an option. When incidents arose it was assumed that it was something that they can do, becoming stuck was not an option. Betty stated, “We know we are going to do it, it might take long sometimes but we know we goin’ to find what works and we keep goin’ til we find it”.

When speaking with Alesha about the struggles she has had to endure mainly, learning her child had a disability and rearranging her life to accommodate this surprise. Alesha was open when discussing how “trying” the beginning was and feeling “overwhelmed” and “stressed everyday.” Alesha reported making multiple mistakes and having a significant amount of guilt related to her coping abilities at the time yet she was able to see what was gained. By taking a proactive stance to remembering difficult times she was able to talk about the strength she has gained from those experiences and how she now takes each situation and realized “you can bounce back from everything”. Alesha did not ignore difficulty or struggles but choose to see each situation as a chance to grow and become stronger and more capable the next time around.

Learning From the Professionals: “You Have to Speak Up”

A unique aspect to interviewing these families was the history and perspective they could offer. Given the age of the family member with mild mental retardation there was a wealth of knowledge that the families could pull from. They had gone through finding out about the disability to various developmental life transitions. At this point, they had reached and overcome multiple milestones as the family member with mild mental retardation entered adulthood. Because the family member with mental
retardation was a young adult many of the struggles relayed in early childhood had
been successfully worked through.

Both families reported already living through and managing the toughest times and
now being able to share how their views had changed and what they wish they had
known. Much of what they would like to have changed focused on interactions with
professionals and services providers. The families were now able to look back on their
experiences and reflect rather than being caught in the midst of those experiences. The
researcher believed this allowed the families to relay rich and clear perspectives from
their experiences. This section focused on those experiences with professionals in their
community: doctors, therapist, case managers, etc.

The main overarching theme was what they, as a family, gained from those
experiences with professionals. Through the professionals Alesha stated “I learn things
and see things, because you do learn a lot, that’s the thing too, you learn a lot going to
these doctors and everything.” Alesha learned about disability, treatment and placement
options, as well as home care, “They helped me understand a lot, what was going on
with my son and different things they could do to help with him”. That was information
Alesha previously did not know. She needed the guidance from the professionals which
she stated she received. However generally speaking, although professionals offered
helpful insight and guidance, the experiences were explained more as a divide between
the family and the professionals. There were many times when the experiences were
seen as what they want versus what we want.

While Terence was a child it was necessary for him to go to multiple doctors to
assist with increasing his abilities. In addition to being diagnosed with mild mental
retardation, Terence struggled with significant seizures and ambulatory limitations. The experience of having a child with special needs was new and frightening for Alesha. In the beginning Alesha reported “going along” with the doctors because she believed they knew what was best. Even when she was listening to the doctors and taking their advice she often felt unsure and the path she should take with her son was not clear. She knew what the doctors were saying regarding treatment needs for her son were accurate yet she always felt the doctors were missing a key piece to understanding Terence’s needs; “See I went through experiences with the therapist, trying to tell me that this is what my son needed but I’m seeing it different, you know? You don’t see what I see because this is your job, this is what you’re trying to do, and that’s that next step that you’re supposed to take, but I’m not seeing it”.

While Alesha was working with doctors and therapist to find what was the best course of action to take for her son, she was feeling a divide. She did not comprehend what the doctors saw as necessary. She was struggling with what the doctors/therapists are telling as true and what she was feeling in her heart as true. There was a clear separation for Alesha between what she viewed as her son’s needs and what the doctors viewed as his needs. She often felt that doctors only followed a prescribed course of treatment rather than paid attention to the unique client needs. Hence, she felt that her son was treated by the doctor as just another patient with a disability and with that disability certain actions were taken.

However, Alesha admitted that she usually went along with professional advice. This was something that to this day she still regretted. Alesha believed that there were times when the professionals involved were amazing and extremely helpful but she also
wished that she had listened to herself more frequently. In the beginning Alesha stated “not having a voice” and needing to find this voice along her journey in caring for Terence. Alesha started off angry at professionals, “Yeah and because you got this education and everything, well I don’t know nothing, you know, this is not right, so you’re going to fight me, you know and make it hard for me because I’m trying to tell you, no, my son doesn’t need this. See that’s the thing, they went to school but they don’t have the hand on”.

As Alesha was able to work through her guilt of not advocating for her son and not asking questions she began to see that she could work with the professionals and not feel her only alternatives were either to fight them or to comply with their directives. Alesha, “You gotta speak up, cuz if they see your not worried about it you’re not saying nothing you’re just going along that’s how they’re gonna go with you they’re just gonna go along that this is what we gotta do and stuff this is how we’re gonna do this here and that’s it. Don’t sit back and let it all happen, cuz they will listen if you speak up”.

Because of those experiences when Alesha felt “they did not explain things to me” and she was “in the dark” she learned to advocate for herself and for her child. Alesha chose to have a voice and gain the confidence to advocate of behalf of her son: “And I tell them, you know, don’t think that because your child is handicapped, and he has these disadvantages, that you have to put them somewhere, you know. You don’t have to accept everything that the doctors and therapists give to you, tell you, you don’t have to do that because I learned that a lot of things they give you and tell you to do, it’s not what your family wants”. There was a sense of trying to balance what professional are telling you with what works for your family. The options that professionals give were
choices and not directives; they may work for some families and not for other families. The families had a responsibility to “speak up” and voice what will fit for them and what will not fit.

In the H family, they reported initially pulling away from professionals but finding that some of the support and guidance provided was necessary and needed. They gave examples of not feeling they were being heard or understood but finding the need to voice their concerns and obtain what they need. Georgette stated “We pull away some because they got different ideas. But that don’t make a difference because what I learned was to speak up, and I didn’t used to speak up with the therapists. We just went along but it showed me to speak up rather than go away, cuz we be needin’ some of the help”. The H family was trying to find a balance between following everything they were being told with pulling away completely. Betty stated the need to get along with professionals “You have to cooperate with them. So, mostly that’s what you have to do, because if you don’t, it gets hard to get along with and you can’t get anything done.”

Although there are difficulties that the H family reported while working with professionals, the family acknowledged that they needed the professionals and they needed the support that only the professionals could offer.

Clearly there was conflict and misunderstanding between professional and these families. It was evident that they both can learn from one another yet communication and the ability to be open to input and feedback needs to be present. While both had the goal of appropriately managing the life of a family member with mild mental retardation the road that they take was quite different. That was not to say that one path was better than another, they are just different. It would appear that a shift in thinking
and responding was necessary to appropriately care for a young adult with mild mental retardation.

**Conclusion: “It’s My Life, This is Our Life, This is Everyday”**

These overarching beliefs and how the families made meaning of their experiences enabled these families to present as resilient and strength driven. What appeared to strongly contribute to this resilience was their reliance on communication and support. There were many examples provided by the families that would support these families being characterized as resilient. For these families resilience was not something that was maintained by each family member but by entire family.

A major component to defining family strength for these families was the display of unwavering love and respect. This came through during individual and family interviews. They may not always agree yet they would respect and honor one another. As Danielle stated, “Well I guess that I am happy and I love my family. I mean we all want to change stuff but I don’t want to change my family for another one”. Regardless of the position in the family, mother, brother, etc., each member was aware of the bond that the family members shared and viewed the bond of something that was unbreakable. “I think any person… if they have love and know that they have family and someone that is loving and caring, it would take them a long way” as stated by Alesha when describing individual strength.

When the focus was on the family and the way individuals interact in support of one another people can overcome anything; “We made it cause we family” stated Betty. This was something that was necessary for outsiders to see, the strong bond of the family and what was gained through members in your own home. Having a child with a disability, for these families, was not a mark of defeat or anguish. The opposite was true
because of what the family member with mild mental retardation brought to the family. Whether it was their unique personalities or the way the family bonded together to care for and make sense of disability. Alesha stated it well, "In my family, the best thing I can tell you, you have to experience this and with that child, you're gonna get that love you know? You're gonna see that things are not so bad trying to raise your child that has disabilities, it's not so bad cuz a lot of love is gonna come out of it and you're gonna feel better about it". The focus continued to be on what was gained rather than what was lost. Disability for these families was seen as a blessing not a curse.
Table 4-1. Family composition of study participants.

<table>
<thead>
<tr>
<th>B FAMILY</th>
<th></th>
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<th>H FAMILY</th>
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<tbody>
<tr>
<td>Name</td>
<td>Age</td>
<td>Role</td>
<td>Name</td>
<td>Age</td>
<td>Role</td>
</tr>
<tr>
<td>Alesha</td>
<td>45</td>
<td>Mother</td>
<td>Betty</td>
<td>48</td>
<td>Sister</td>
</tr>
<tr>
<td>Calvin</td>
<td>27</td>
<td>Brother</td>
<td>Georgette</td>
<td>38</td>
<td>Sister</td>
</tr>
<tr>
<td>Danielle</td>
<td>18</td>
<td>Sister</td>
<td>Kisha</td>
<td>30</td>
<td>Niece</td>
</tr>
<tr>
<td>Terence</td>
<td>24</td>
<td>Adult with MMR</td>
<td>Vernon</td>
<td>23</td>
<td>Adult with MMR</td>
</tr>
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Table 4-2. Major themes.

<table>
<thead>
<tr>
<th>Overarching Beliefs</th>
<th>Collaborative Communication</th>
<th>Positive Meaning Making</th>
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<tbody>
<tr>
<td>-Strong sense of group identity</td>
<td>-Fostering open communication</td>
<td>-Normalizing disability</td>
</tr>
<tr>
<td>-Clear organizational hierarchy</td>
<td>-Shared decision making</td>
<td>-Impact of disability</td>
</tr>
<tr>
<td>-An ethic of sharing responsibility</td>
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<td>-Taking a proactive stance</td>
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<tr>
<td>-Sense of mutual support</td>
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<td>-Learning from the professionals.</td>
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<td>-Believing in functional support</td>
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<td>-Dependence on emotional support</td>
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<tr>
<td>-Expecting community support</td>
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<tr>
<td>-Relying on ones faith</td>
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Table 4-3. Major dimensions of overarching beliefs.

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<th>Overarching Beliefs</th>
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<td>Strong sense of group identity</td>
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<td>Dependence on emotional support</td>
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<tr>
<td>Expecting community support</td>
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<tr>
<td>Relying on one’s faith</td>
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Table 4-4. Major dimensions of collaborative communication.

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<th>Collaborative Communication</th>
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<tbody>
<tr>
<td>Fostering open communication</td>
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<td>Shared decision making</td>
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Table 4-5. Major dimensions of positive meaning making.

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<th>Making Positive Meaning from Adversity</th>
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<tr>
<td>Normalizing disability</td>
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<td>Impact of disability</td>
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<td>Taking a proactive stance</td>
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<td>Learning from the professionals</td>
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Existing research highlights the negative impact of having an individual family member with a developmental disability on family life, the marital dyad and sibling relationships (Eisenhower, Blacher, & Baker, 2005; Whitman, 2008; Risdal & Singer, 2004). For example, several studies have revealed a disproportionately heavy amount of stress and burden placed on family members with the presence of child with a developmental disability (Blacher & Baker, 2002; Hassall, Rose, & McDonald, 2005). Typically these studies have examined the perspectives of middle class White women who are mothers and have focused on the struggles and strain of having such a child. More often than not, researchers have viewed these families through a deficit based lens in which they have looked only at family problems and family dysfunction. For example, in a study conducted by Bristol, Schopler, and Gallagher (1998), the researchers found that mothers caring for their developmentally disabled children are more likely to report higher levels of marital dissatisfaction and overall increased life stress than mothers with nondisabled children. Similarly, in a study conducted by Timmons, Whitney-Thomas, McIntyre, Butterworth, and Allen (2004) investigating transition experiences of parents of young adults with disabilities, the researchers found that these parents reported significant and at times overwhelming stresses and challenges.

This deficit-based lens has also been used to examine the experiences of low-income African American families presuming that all such families are at “high risk” for developing psychological problems. Turner, Wheaton, and Lloyd (1995) reported
greater adverse psychological effects among low-income African American individuals than other higher status groups. Additionally, when researching high risk populations and the lack of mental health service follow through, de Figueriredo, Boerstler, and Doros (2009) stated that: "Individuals in need of services come from groups that maybe underserved or more vulnerable to demoralization and mental health disorders, such as the poor, the homeless, the elderly, immigrants, residents of rural areas, and racial or ethnic minorities" (pg. 92). Thus it appears that the majority of psychological research on African American families has focused on family deficits, rather than on the strengths that African Americans possess and routinely use (Lynch & Hanson, 1998).

Although most of the existing research literature examining the impact of disability on families has been dominated by this deficit based lens, researchers have recently begun to examine the positive adaptation of families caring for a child with a developmental disability (Risdal, 2004; Ylven, Bjorck, & Granlund, 2006; Beresford, 1996). In a study conducted by Hastings, Kovshoff, Ward, degli Espinosa, Brown, and Remington (2005), the researchers found that parents of children with autism “identified positive perceptions about their child, and his or her impact on themselves and other family members” (p. 641). Moreover, several recent studies have sought to identify resilience factors among low-income African American people (Todd & Worell, 2000; West-Olatunji, Shure, Garrett, Conwill, & Torres Rivera, 2008; Jarrett, Jefferson & Kelly, 2010). However, there is limited research using a strength-based lens to describe the lived experience of low-income African American families caring for a young adult with mild mental retardation.
This study utilized a strength-based perspective to examine the lives of families with an adult with mental retardation. The theory that emerged from the findings of this study revealed an intricate process by which the participating families created shared beliefs, communication styles and constructed meanings about the adversities they experienced. To illustrate the model, rich descriptions of how these families related, interacted and communicated were provided. It was in the themes and the relationships among the themes that the research provided something new by expanding on the extant literature. The themes will be discussed regarding there significance and how they relate to other research findings.

**Overarching Beliefs**

The families in this study depicted a distinctive set of beliefs related to family, clear organizational hierarchy, strong sense of group identity, an ethic of shared responsibilities, sense of mutual support, believing in functional support, dependence on emotional support, expecting community support and relying on one’s religious faith. These characteristics were quite similar to specific characteristics described in the research literature that are associated with positive functioning in low-income African American families. These specific characteristics are a reliance on family relationships, social support, religious/spiritual beliefs, determination, and self efficacy (Todd & Worell, 2000; Jarrett, Jefferson, & Kelly, 2010).

Similar to previous research findings, the families in this study demonstrated strong beliefs in the value of close family relationships, the value of mutual functional and emotional support from kin and neighbors and strong religious/spiritual beliefs. Close family relationships have been found to play a pivotal role in the lives of African American families. These types of family relationships are seen as a major means of
support stemming back to slavery (Lynch & Hanson, 1998). This family support is seen as a source of strength for individual family members (Waites, 2009). Social support is seen as mutual emotional and economic support provided by church, neighbors and friends that make up a kinship network (Boyd-Franklin, 2003; Lynch & Hanson, 1998). This kinship network has been described by Boyd-Franklin (2003) as “the process of helping each other and exchanging and sharing support as well as goods and services” which is a key aspect in the lives of many African Americans.

Religious beliefs have also been reported to characterize African American values and responsibilities (Waites, 2008; Boyd-Franklin, 2003; Lynch & Hanson, 1998). According to Boyd-Franklin (2003) researchers have “consistently found that African Americans report higher levels of religious and church involvement than the general population” (p. 126). Furthermore, African American women report much higher levels of religious affiliation, and church attendance, and are more likely to believe that the church can improve their lives (Griffin-Fennell & Williams, 2006). Denby (1996) reported that, among African Americans, religion “can be manifested in a belief structure of perpetual optimism and the ability to recover from adversity” (p. 153). The current study offered additional support regarding the importance of the above mentioned factors in addition to finding these factors in low-income African American families caring for a member with a developmental disability.

Although the findings of this study are supported by existing research, they provide much greater detail as to the specific ways in which such families respond to the challenges of having a family member with a developmental disability. The study findings revealed a level of family closeness that was exceptional. For the study
participants family was not just a word that implied support and assistance, it was a way of life and a way to identify oneself. It went beyond support and assistance, to individual members identifying themselves in relation to their family. When speaking to Danielle, sister to Terence, about the role of her family in her life she stated, “There is no me without them.” The study participants could not define who they were without defining family.

This level of identification with the family appeared to be enhanced with the addition of a family member with a developmental disability. When speaking with Alesha, mother to Terence, about the role her family plays in the care of Terence, Alesha stated: “Family is all I need to make things work. I would not be able to do it without my kids.” There was a belief that without family certain aspects of life would not be manageable. In the H family, Betty stated “family is how we do it. We can’t do it without each other”. Family was all encompassing and assisted with describing the individual and how the families function and view the world. The support that each member felt spoke volumes. Georgette stated it best “The love and support of the family, that’s what kind of keeps you going”.

Qualitative researchers have frequently described the powerful types of supports provided to each other by members of low-income African American communities. Such community members often provide resources among households and assist with childcare and other domestic tasks to promote positive family functioning and well-being (Dominguez & Watkins, 2003; Jarrett, 1994; Newman, 1999; Roy and Burton, 2007).

Although, this study found similar results it expands on what was previously known with a shift from a deficit based lens when researching low-income families to a more
strength based focus. The families that participated in this study appeared to be thriving in spite of their low-income status. The support network they had developed and the level of support they received from their family and community appeared to be what made them thrive in spite of financial constraints.

Although financial constraints were evident by their poverty status and their living conditions, financial concerns were rarely discussed among the family members in the research interviews. Instead, the families highlighted the immense level of support offered by their neighborhood and the community. Both participating families resided in neighborhoods that were miles outside of the nearest town. The nearest towns were considered rural, with limited resources and amenities. The neighborhoods could be described as exclusively low-income African American neighborhoods. Many of these rural residents had been established for generations in their homes. This allowed for longstanding relationships with fellow residents. These families appeared to view their neighborhood and community as an extension of their family. They seemed to have a level of trust that members of their neighborhood community not only knew their family member with a disability but would care for them if necessary. This allowed the family additional support outside of their home. There was a strong reliance on these supports and the prevailing belief that anything can be accomplished with support.

The current study expands previous literature by focusing on the beliefs held by low-income African American families caring for a young adult with mild mental retardation. Although some research has been conducted with low-income families sharing similar cultural characteristics, limited information has been available on families who have a member with a developmental disability. These families appeared to grow
from their experiences and magnify the helping characteristics of their beliefs. These beliefs are not highlighted in the dominating deficit based lens through which these families are generally seen. The deficit models focus on the lack of support and resources these families face. When you shift to exploration of what assists these families you do not find support of the deficit models but you find their unwavering belief in family, responsibility, support, and faith which has allowed them to thrive.

**Collaborative Communication**

Froma Walsh (1998, 2002, 2006) described a particular style of family communication characterizing families who demonstrate resilience. This communication style is characterized by communication clarity; open emotional expression; and collaborative problem solving. Communication clarity entails clear, consistent, explicit communication. Open emotional expression involves the ability to share and take responsibility for a variety of emotions and to empathize with other family members’ views. Lastly, collaborative problem-solving is characterized by shared decision making, brainstorming, goal focusing, and a proactive stance.

Although family resilience researchers have not looked specifically at low-income African American families caring for a member with a developmental disability, the three aspects of communication described by Walsh were demonstrated by the families who were interviewed in this study. The style of communication used by these families appeared to play a key role in building relationships, maintaining bonds, and persevering during difficult times. In both of the participating families there were a set of shared meanings that had been developed regarding the nature of the family members with a disability and the roles family members played. There was not much disagreement among family members when they shared particular insights or
experiences. To the contrary there was an overwhelming sense of agreement. It was a
though each family shared one story which all the members had created together.
There were no different stories or different perspectives among the different members.
Instead there was one perspective and one story that each member embraced.

Fivush, Bohanek, Robertson, and Duke (2003) discussed the importance of family
communication on children’s emotional well-being, coping skills and resilience.
Although their report focused on family communication style and its impact on children’s
emotional well-being, the findings can be extrapolated to this study about the
communication styles of low-income African American families. Their communication
appeared to go beyond the retelling of stories to forming, clarifying and defining
individual identities and family relationships. This was clearly seen in the B family and H
family. For the B family when discussing troubling situations Calvin stated, “My momma
always want to know what we think. We figure it out as family.” Not only was
communication sought out by family members but it was something that fostered
competence and self-reliance. Family members seemed to assume life events could
and would be encountered and managed because there was open communication
among family members. This level of communication may positively impact individual
and familial life. Communication was something that kept these families together,
strengthened their relationships and built family bonds.

Positive Meaning Making

Although the stories and narratives shared by these families generally had to do
with emotionally negative and stressful events, they frequently reframed these negative
or stressful experiences more positively by emphasizing how they grew and what they
gained from their experiences. These positive reframes were demonstrated in the
conversations that family members had with one another and the meanings that they made from those experiences.

Froma Walsh (1998, 2002, 2003) described family resilience as the ability to recover from adversity stronger and more resourceful. Resilience is not an achieved outcome or incident-specific response, but a lifelong way of being. According to Froma Walsh, making positive meaning out of adversity is a central characteristic of families who are resilient and have the ability to bounce back” when experiencing adverse life events.

It might be assumed that a low-income African American family caring for a family member with a disability would not be viewed as resilient. However, these families clearly possessed many of the characteristics of a resilient family. Despite the many hardships they encountered they developed both internal and external resources to account for these hardships. The transformative power of their experiences in creating advocacy skills in the individual and family is a credit to their resilience and strength. This was seen through the stories shared by the families.

The positive effects of family communication where seen in the B family and H family especially when they were discussing past stressors. It allowed the family members to reminisce while at the same time heal from those difficult times and acknowledge resources and strengths otherwise unnoticed. Generally speaking a difficult or stressful time in the past was often explained as assisting them in developing their current positive views. As you will recall Danielle provided a rich description of this when she stated: “I mean I used to be jealous of my friends, thinkin’ that they had it easier and they didn’t have to worry about a brother. But I mean they also don’t know
what it’s like to have a brother like Terence. I mean I love Terence and I don’t mind helpin’ and takin’ care of him. You know when you meet Terence he is just so happy and it makes you feel good. Terence’s always got nice things to say…I mean…he just…I feel blessed and I thank Jesus for Terence and my family. And I mean I be seein’ other families and they fightin’ and it don’t never end…my family is not like that”. This negative life experience was reframed as how life has been enhanced.

Hawley and DeHann (1996) described family resilience as the path followed as families adapt and prosper in the face of stress, both in the present and over time. They believed resilient families responded optimistically to stressful conditions in unique ways. Low-income African American families caring for a young adult with mild mental retardation had not been researched through a strength based resilience lens. However it is apparent that the families in this study possessed certain unique qualities and strengths that could be hidden by an emphasis only on looking at their deficits.

Limitations

There are some limitations identified in the design of the current study. Qualitative research of this variety is limited in its transferability, although transferability is not the main focus of qualitative research. The participants had certain qualities that were not characteristic of the general population which limit the transferability of the findings. However, the findings of the current study can be confirmed through replication of the research with families facing similar circumstances.

The sole form of data collection used in this study was that of interviews. In order to enhance trustworthiness, multiple methods of data collection should be utilized (Echevarria-Doan & Tubbs, 2005). There were two families that participated in the research with three family members participating from each family allowing for multiple
perspectives. Although there were multiple interviews that enhanced opportunities for
data collection about each family, there was only one mode of data collection of
interviews. Triangulation was met through corroborating evidence gained from different
family members and from both individual and family group interviews (Creswell, 2008).
However, there was not the methodological triangulation of the data with other data
collection sources thereby limiting the trustworthiness of the study.

Only two families participated in the study. The small sample size may be the
result of the recruitment methods used. This researcher only recruited participants by
contacting Waiver Support Coordinators who worked with individuals enrolled in the
Medicaid Waiver program. This may have hindered families’ willingness to participate as
Medicaid Waiver is a government assisted program. The families may have felt that
there could be potential negative repercussions regarding the services they receive.
Additionally, many families may not want a "government" official asking personal and
descriptive questions regarding their family. In the end there were only three families
who stated an interest in participating in the research and met the research
requirements. However one of those families chose not to participate which resulted in
only two families comprising the stuffy sample. This researcher did not attempt to recruit
participants through other sources.

Being a White researcher may also have been a limitation to the current study.
Due to historical experiences and events, the study participants may not have felt
comfortable fully disclosing their family interaction or history. In addition, although this
researcher took special care to develop rapport with participants, the researcher may
not have understood subtle cultural differences in verbal and nonverbal interactions thereby limiting my understanding and interpretation.

According to Gibson and Abrams (2003), White qualitative researchers interviewing African American individuals may have difficulty gaining access to participants and building trust. However, these researchers also noted that the African American study participants tended to make an extra effort to assist the White researchers in understanding what they were trying to communicate, possibly believing that they need to “teach” the White researchers given the inherent cultural differences. In contrast, the researchers reported that when African American participants were being interviewed by African American researchers, the study participants may assume that the researcher already understands their experiences and as a result do not feel the need to explain, which could lead to limited information and a false interpretation of the data supplied. As a result, these two authors concluded that White researchers may have more difficulty than African American researchers in the beginning, once the White researchers gain access their African American study participants may be more open and detailed oriented.

These observations about the influence of researcher ethnicity made by Gibson and Abrams (2003) appeared to have played a significant role in the current study. Access to the participants was made through my previous employment as a Waiver Support Coordinator working as a case manager providing services to individuals with developmental disabilities. Access was made easier due to this researcher’s pre-existing relationships with the Medicaid Waiver program staff and clients. This researcher had a previous working relationship with the H family to whom this
researcher provided case management services for 5 years. The B family and this researcher had no prior relationship and became acquainted through this study. What this researcher observed during the interviewing process was that the B family was much more descriptive in their communication and appeared to go to great lengths to make sure this researcher understood their experiences. Members of the B family were also more likely to provide rich and thick descriptions with minimal prompts. In contrast, the H family provided limited information in response to my questions and required numerous prompts to expand on their stories. This lack of richer descriptions by the H family may in part be due to the researcher's previous relationship with the family and their belief that the researcher was already aware of their experiences given our long history together.

There may also be a limitation resulting from the amount of interviews completed by family members in the two families. Although the H family completed both family group interviews and the individual member interviews, in the B family, one of the participants Calvin was not available for the final group family interview. However, Calvin did attend the initial family group interview, individual member interviews and volunteered to be available for follow up telephone questions as needed. The aim was for all participants to be involved in every individual and family interview, however due to work and family constraints, this was not possible.

Finally, although measures were taken to limit researcher biases through the use of memos, peer debriefing and triangulation, the researcher was the primary investigator, and thus her subjectivity did influence the data analysis process. For example, there were times during the interview process when the researcher did not
pursue certain topics (e.g. future planning and financial support for the disabled member) in response to felt resistance from the families regarding these topics. This may have been this researcher’s interpretation of the situation rather than the reality of what was being offered by the participants.

Implications

Practice

The findings of the study have important practice implications for counselors, clinicians and other service providers working with low-income African American families having a member with a developmental disability. While interviewing these families, it was evident that their unique qualities were not always appropriately recognized by the professionals involved. The family member’s perception of their disabled member’s needs did not appear to be consistent with the needs perceived by the professionals. This often left the families feeling “unheard” and “pushed into doing things” for their family member with a disability because they felt they “had to do what the doctor” recommended. As a result, the study participants had ended their relationship with helping professionals and appeared to be opposed to seeking additional professional assistance.

This underscores the need for professionals to listen to and acknowledge family members’ perspectives. Professionals working closely with the families need to place themselves in an advocacy role to account for the discrepancy between what these families are receiving from professionals and what these families actually need. Due to the voiced “one down” position of these families, they may not feel they have a strong voice. Professionals need to encourage families to make their voices heard and to
assist the family in advocating for their disabled member. On a larger scale this could influence the implementation of policies, laws and research.

Both of the families involved in this study described a disagreement between their perceptions of the needs of their disabled family member and the needs perceived by professional providers. This disagreement might have been attributed to the lack of cultural sensitivity through which the professional was approaching the family. This might have lead to ineffective treatment or service recommendations. In order for interventions to have real value, they need to be based in the context of the family.

Hence, it is incumbent upon the clinician or social worker to ensure that families’ voices are heard with respect to the needs of the young adult with mild mental retardation. They need to advocate for their low-income, culturally diverse families who may be experiencing distress in their interactions with professionals. They need to advocate for an environment which focuses on the strengths and resources these families bring rather than preconceived ideas regarding what low-income diverse families should do in caring for a family member with mild mental retardation. The deficit models which have dominated the disability and low-income African American research literature need to be replaced with strength-based awareness of African American families and their culture. The resources that are gained through exploring family and community support may turn out to be more powerful than paid supports.

This study provided insight as to possible sources of resistance that low-income African American individuals demonstrate when approaching professional helpers. These family members shared that they often felt that they were not being heard and were generally given advice and recommendations for their family member with a
disability that went against their own family rules and values. Because of this
discrepancy in what the families want and what professionals felt they needed, family
members tended to shy away from professional supports that could provide an
enormous amount of assistance. If professionals were aware of this resistance and the
reason for a family’s reluctance, they could approach the family in a fashion that would
allow for rapport building and genuine understanding. The professional could then offer
supports that fit with beliefs and values of the family with whom they were working.
Additionally, professionals could support the family in voicing their needs and wants.
They could model straightforward, open communication that focuses on assisting the
family member with a developmental disability.

Past research on low-income African American families and disability have
focused on identifying individual deficits in order to respond with corrective
interventions. However these interventions often fail to incorporate the innate strengths
of these families which tend to lead to minimal change. This researcher heard from the
families’ stories of counselors, doctors and services providers “forcing” interventions on
them that went against their beliefs and values for their family. A main concern was
having the family member with a disability placed into a group home. The professionals
involved focused on group home placement in response to the families' low-income
status and perceived limited resources. What professionals failed to do was explore
family’s strengths on which interventions could be based.

There is a need for appropriate interventions when working with culturally diverse
populations. These interventions need to recognize and affirm cultural identities of low-
income culturally diverse populations caring for a family member with a developmental

disability. Rather than viewing these individuals and their families as deficient, professionals need to view these families’ cultural orientation and background as important resources to be utilized in treatment and service identification. Professionals need to understand the benefit of culturally responsive practices and how they positively impact low-income, culturally diverse clients caring for a family member with a developmental disability.

Because these families in the study stated feeling in a “one down” position in relation to professionals, it is the responsibility of the professionals to acknowledge and address this unbalanced relationship. The services and recommendations being offered did not match what the families stated they needed. If professionals were equipped with a better understanding of the beliefs, resources, and unique needs of the families served as well as the cultural considerations, this would allow for implementation of more effective practices in the home and community.

Preparation

There needs to be a focus in professional training programs on cultural considerations when working with diverse families. Special care should be emphasized when approaching clients who come from cultural environments that are not the same as the professional. Recognizing personal biases and judgments should be an important aspect of such training programs. For example, this researcher came from a culture where individualistic goals were stressed instead of collectivist goals. This bias needed to be addressed prior to engaging the families. The families involved in this study focused on collectivistic over individualistic goals. It is important for training programs to stress cultural awareness when working with families from culturally diverse populations. Professionals need to raise their cultural awareness regarding their
own biases and how this may be at odds with low-income, culturally diverse families’
home culture. The families involved in this research provided clear descriptions of how
they avoided professionals due to inconsistencies in needs which may be due to culture
differences not being acknowledged and supported.

Professionals must obtain a better understanding of the ways that relationships
are developed with diverse families. Professionals must make every effort to become
familiar with African American culture and the realities that face African American
families (West-Olatunji, Shure, Garrett, Conwill, & Torres-Rivera, 2008). This may mean
moving out of their comfort zone and becoming involved in communities that are
culturally diverse. The best way to understand a culturally diverse family is to become
intimately involved with that family. It is necessary to look beyond serving these families
on the professional’s terms and engage the family on their terms. Going into the home,
the schools and the day programs are ways to immerse oneself in the culture of the
families they serve and become more aware of one’s biases and judgments. Enhancing
the professional’s understanding of what is important to the families and what they offer
will lead to appropriate and effective interventions. Low-income African American
families caring for a young adult with mild mental retardation need their experiences to
be legitimized by professionals who are well trained in cultural considerations.

Because professionals would need to engage in a variety of roles when working
with families, they must be further equipped to perform these roles. Training programs
need to equip future professionals with the ability to apply a variety of roles to their work
with families and how to assess which roles are necessary for the family. When
interviewing the families it became apparent that a needed role for the families is
advocacy. This advocacy needed by the families involved in this research would take the form of resource identification, service recommendations, policy and research implementations. Even so, many professionals’ may hesitate in engaging in alternative roles. They may not feel comfortable with the role of advocate, feeling that it goes beyond their scope of involvement with families.

Counselors need to change how they work with low-income African American individuals caring for a young adult family member to use a strength-based, culture-centered framework. Using a strength-based lens will allow counselors to focus on ways that African American families have persevered despite personal and historical constraints. Both of the families involved in this research demonstrated signs of strength in the face of adversity. They were confronted with poverty, disability and minority status yet they were thriving in their environments and viewed themselves as resilient and resourceful. There needs to be a focus on resiliency factors in these families that address the strengths they possess in order to effectively assist these families.

**Recommendations for Future Research**

In this study a theory was postulated. This theory augments existing resilience research as well as provides a unique understanding of low-income African American families’ caring for a young adult with mild mental retardation and their abilities to cope in the face of ongoing adjustment and adversity. Although the tenets of this theory are consistent with findings from other resilience research, these tenets need further explication. Further studies examining low-income African American families’ perspectives on caring for a family member with a developmental disability are needed. The ability of the families in this study to transform adverse life experiences into stories of resilience and adaptability was most impressive. Studying the abilities of low-income
African Americans to overcome and transform trying experiences would be of great use to the helping professions when working with these families and formulating interventions focused on strengths.

When interviewing these families it is imperative for future researchers to demonstrate an open and genuine stance. It was apparent that the relationships that were built between this researcher and the study participants played a key role in the level of disclosure provided. Future researchers need to identify their potential biases, recognize judgments and employ a nonjudgmental learning attitude. Researchers would benefit from entering the environment of study participants with an open mind and an ability to embrace differences.

Furthermore, future research studies should focus on how family life is impacted by culture and by socioeconomic status. There needs to be a clearer understanding of the impacts on family life of both these aspects. Due to the majority of research continuing to focus on individual deficits, it is important to separate the challenges faced when focusing on culture and when focusing on socioeconomic status.

The current research participants were caring for a young adult with mild mental retardation. The families reported that they were not currently facing any critical life events. Both families described facing many challenges during the infancy and the school years of the family member with the disability yet find that at the current life stage of their family member, life had become more stable. This was a unique perspective because it allowed the families to look back and possibly reframe their life experiences given the stability they were currently facing. However, it would be useful to interview these families while they are in the midst of a major life transition to see if the same
ways of functioning as a family found in this research study are found during other critical life events. Focusing on infancy or other developmental stages would allow for a broader understanding of the abilities and strengths these families possess.

Additionally, there were aspects of this research study that this researcher would design differently. For example, it would be interesting to focus more intensively on family history and multigenerational issues. Although this was touched on by each family it would be important for future research to understand how each generation informed the next. The history of African Americans is rich in personal stories and accounts. In order to get a better understanding of the family it would be helpful to know more about their families of origin.

Another area that future research might address would be the ways the family engaged in future planning. The participants in this study appeared to resist engaging in future focused conversations. They tended to be more concrete in their thinking and focused on the here and now. When this researcher pushed for discussions related to the future and what the future may hold, both families were quick to say that the family would figure things out. When pressed further with how they were certain about this they were again quick to respond with “that’s just how it is”. This resistance might be a function of culture rather than resistance. This should be explored further. Other areas that this researcher found difficult to address with the families but would be beneficial for future research had to do with conversations related to a male presence in the home and to financial support. Possible future researchers may want to take additional time to build relationships with participants in order to discuss topics that they are resistant to or find difficult to discuss.
This researcher felt that some of the hesitation in discussing certain topics demonstrated by the study participants may in part be due to the process of recruitment. The participants were found through the use of Waiver Support Coordinators who worked for Medicaid Waiver. The family may have felt resistant to disclose some information due to the role that the Waiver Support Coordinator played in their life. The Waiver Support Coordinator is in charge of providing resources and services to the family member with a developmental disability. In addition, a Waiver Support Coordinator has direct involvement with the Department of Children and Families. Both families expressed some distrust in government agencies. They may have felt that this researcher would report back to government agencies and get them “in trouble.” If this researcher were to conduct the research again alternative methods for recruitment would be sought. This could be done by recruiting through schools or day programs. There should be a clear separation from government officials and the research.

Lastly, instead of using interviews as the main means of data collection, it would be useful to use focus groups. This would allow for multiple family members from similar demographic backgrounds to discuss experiences with other families that are experiencing similar life events. This would allow for further rich and thick descriptions. It may also allow the participants a certain level of comfort and camaraderie exploring sensitive topics with families from similar demographic environments.

**Conclusion**

The findings of this study have proposed a theoretical model that describes the lived experiences of low-income African American families caring for a young adult with mild mental retardation and how these experiences are used to facilitate growth and connection. The model depicts how family structure, beliefs, communication and
approaches to reframing adversity appear to be linked to resilience and strength in family outcomes. These findings are particularly important given the documented stress and strain that these families face. Therefore, the results of this study exemplify the need for professionals to learn about the resources possessed by low-income African American families caring for a young adult with mild mental retardation and to use those resources in planning a course of treatment.
APPENDIX A
POSSIBLE INTERVIEW QUESTIONS

**Goals for Interview One:** Develop rapport with family, conduct individual interviews focusing on history, life events and experiences that have brought them to present day.

**Family Group Questions:**
1. How do you describe your families’ composition? Who is considered family and how do you go about determining who is family?
2. What supports, networks and/or resources do you and your family have available? Describe your current financial situation.
3. What is mental retardation? How do you describe mental retardation? How would your family describe mental retardation? What words do you use to talk about mental retardation?

**Questions for Individual Family Members:**
1. When was the first time you heard about mental retardation? When did you first determine that the child in your family had mild mental retardation? What were your expectations of a child with mild mental retardation?
2. Tell me about your family member with mental retardation?
3. What is it like to live in a family with a young adult with mild mental retardation? Describe your relationship with other members of the family.
4. Describe the positive and/or negative effects of mental retardation on your family life? Effects on your personal life?
Goals for Interview Two: Conduct individual interviews focusing on current events of the family surrounding their experiences with having a young adult family member with mild mental retardation. Focus on lives past and present as well as experiences with strengths and resilience.

1. What sorts of things do you celebrate as a family together?

2. What is the best part about being in this family? What’s the worse?

3. Tell about times when things have gone really well in your family. What helps things go well?

4. Tell about times that have been especially tough in your family. What are the things that usually create tough times? Are there any positives that come out of the tough times?

5. What makes the difference between something working well and something not working well in your family?

6. Does religion or spirituality play a role in your life or the life of your family? If so, please explain what it means to you.

7. What makes a family caring for a young adult with mild mental retardation different from a family without?

Goals for Interview Three: The participating family members will be involved in a family group interview.

Family Group Interview Questions:

To conclude the family interview, the members will be asked the following:

1. What does the family want for the young adult with mild mental retardation in the long term?
2. What kinds of things have helped your family manage mental retardation?

3. What do you know about mental retardation that teachers, counselors, relatives and neighbors don’t know?

4. What do other families, professionals, service providers need to know from you?

5. Is there anything you would like to be sure I know?
Dear Parent/Caregiver,

I am a doctoral student in the Department of Counselor Education at the University of Florida. I am conducting research on resilience in low-income African American families’ with a young adult family member with mild mental retardation. I am hoping that the results of this study will help practitioners, counselors, community agencies, direct and non-direct service delivery providers with appropriately understanding these families in order to adequately address resources, supports and family-centered services needed.

Families who choose to participate will be interviewed three times, for about an hour each time. The interviews will comprise of family and individual discussions as well as family activities. I can do the interviews in your home or another location that is comfortable for you. I will tape record the interviews in order to transcribe them later. I will ask several questions about your experiences as well as your family’s experiences with having a family member with mild mental retardation. You will not be required to answer questions you do not choose to answer. These interviews are not mental health or family therapy. I will only be learning from you and your family regarding your experiences with having a family member with mild mental retardation.

To protect you and your family’s privacy, the interviews will not be identified by name nor will any information that could be used to identify you be shared. Your confidence will be protected as provided for under the law. I will use your answers when
writing my dissertation, and possibly in journal articles, but will not use your name or
other identifying information.

Participation in this study is completely voluntary. There are no known risks or
immediate benefits known to participants. There is compensation for participation. After
the first interview, you will receive a $20 gift card from a grocery store; then 20$ for the
second and $30 for the third interviews.

You may request group results of the study if you wish. You may withdraw your
consent at any time. If you have any questions about the research, you may contact me
at 352-XXX-XXXX. Questions about your rights as a research participant may be
directed to the UFIRB Office, Box 112250 Gainesville FL 32611, or call 352-392-0433.

Thank you,

Mary C. McCue
LIST OF REFERENCES


BIOGRAPHICAL SKETCH

Mary Catherine McCue pursued her Bachelors of Arts in psychology from the State University of New York at Oswego, graduating in 2000. After graduating from SUNY Oswego, Mary moved to Florida and spent two years working as a counselor and case manager for culturally diverse low-income individuals with a developmental disability. Her experiences as a case manager led her to pursue graduate studies in the Department of Counselor Education at the University of Florida where she was granted entry into the PhD program. In 2005, Mary received her Masters of Education and Specialist in Educations degrees in marriage and family therapy while also continuing her work as a fulltime case manager. Mary decided to pursue her doctorate in marriage and family therapy while completing the necessary requirements for licensure in marriage and family therapy. In March 2010, Mary became a Licensed Marriage and Family Therapist. Her research agenda is focused on identifying and exploring resilience and strength factors in low-income, culturally diverse individuals and their families where there is a family member with a developmental disability.