ABSTRACT

Title of dissertation: "AND STILL WE RISE": A QUALITATIVE STUDY OF THE STRENGTHS, CHALLENGES, AND NEEDS OF AFRICAN AMERICAN FATHERS PARENTING CHILDREN WITH SPECIAL NEEDS

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An ecological systems/risk-resiliency framework (Bronfenbrenner, 1986) was used to examine selected issues that have the potential for informing the development of culturally sensitive family interventions that focus on the strengths, challenges, and needs of African American fathers of children with special needs. This study attempted to fill gaps in the literature by examining strengths and resiliency within these fathers, and their involvement with and parenting of young children with special needs. This qualitative study included 30 African American fathers who regularly attended a male caregivers' support group at a pediatric hospital for children with special needs in Washington, DC. Four focus groups and nine face-to-face, follow-up interviews were conducted to validate and refine study themes. Verbatim transcript data were analyzed using qualitative software (N6/NUD*IST) to code and generate recurring themes.

Results indicated recurring themes for *strengths* (redefined by the men as *rewards*) including: pride in children's accomplishments; increased knowledge about and ways to promote children's development; social fathering (i.e., serving in roles to complement or substitute for biological fathers); and generative fathering (i.e., making sacrifices and giving back to their children to ensure family connections). Fathers' *challenges* included: relationship difficulties with partners, friends, and community

members; unemployment; negotiating health care systems; and dealing with issues that disproportionately affect African Americans (poverty, substance abuse, and HIV/AIDS). Finally, fathers reported on concrete *needs* that (if satisfied) would improve the quality of their own lives and the lives of children with special needs, including the need for male caregivers' support groups; referrals/linkages to services; improved partner relationships; and culturally competent interventions, programs, and services. Several trans-system themes (i.e., themes that cut across ecological levels) were also identified, including *personal development, generative fathering, social support,* and *advocacy*.

Results have implications for developing model interventions to strengthen family systems and address African American fathers' needs in parenting children with special needs. Findings were used to draw implications for future theory-based research, family policies, and culturally specific interventions to improve services to African American fathers of children with special needs and their families.

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by

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DEDICATION

To my brother Reginald LeConte Bridgers, whose special needs inspired me to conduct this study.

To my wife Kym, my sons Brandon, Bradford, and Braxton, and niece Sky; you are the sunshine that infinitely brightens my day. Thank you for your unwavering fortitude as I pursued my doctoral degree.

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CHAPTER 1: INTRODUCTION

This study explored parenting strengths, challenges, and needs of African American fathers and male caregivers of children with special needs. Previous research has shown that parents play an important role in shaping their children's behavior and promoting positive developmental outcomes (e.g., Maccoby & Martin, 1983; McGroder, 2000; Rutter, 2000; Slater & Power, 1987). On the basis of such research, a number of evidence-based interventions have been designed for parents of children age 18 or younger that seek to strengthen parenting practices and family processes in order to improve child and family outcomes.

The current study recognized the importance of examining cultural contexts that affect individual and family functioning (Garcia-Coll et al., 1996; Ogbu, 1981), and which may have implications for developing parenting programs, particularly among racial-ethnic minority families. For example, Garcia-Coll and her colleagues argue for the importance of developing culturally-sensitive, integrative ecological models that consider the effects of macrosystem influences such as racism, discrimination, and oppression experienced by individuals and families of color. Ogbu's cultural ecology model emphasizes the importance of considering a group's unique cultural and historical roots. African Americans, for example, often function as members of extended families or larger kin networks, and these systems affect parents' ability to nurture, advocate for, and provide for their children.

This study has a special focus on a neglected group within this broader cultural and family context—African American fathers parenting a child with special needs. Data show that African American children are disproportionately represented among the

nation's population of children with special needs (Gabor & Farnham, 1996), and a review of parenting studies reveals that their fathers are rarely the focus of research or programmatic initiatives.

In this study, the term "children with special needs" includes children with developmental disabilities (e.g., Sickle Cell Anemia, Epilepsy, HIV/AIDS, Down's Syndrome, Attention Deficit Disorder (ADD), Attention Deficit Hyperactivity Disorder (ADHD), and Cerebral Palsy). The Developmental Disabilities Act of 2000 (*P.L. 106-402; 42 USC 15062)* defines a *developmental disability* as "a severe, chronic disability or illness that is attributable to a mental or physical impairment or combination of mental and physical impairments that is manifested before age 22 and is likely to continue indefinitely" (Health Resources and Services Administration, HRSA, 2002). In addition, the National Dissemination Center for Children with Disabilities (NICHCY, 2006) identifies 13 disabilities in children and youth age 3 to 21 that include Autism, Emotional Disturbance, Mental Retardation, and Traumatic Brain Injury. Although there are a growing number of children in this group, research on parenting has rarely focused on the strengths, challenges, and needs of fathers in families with children with special needs (Booth & Kelly, 1998). Family researchers also typically use quantitative measures, focus their assessments on negative caregiver outcomes (e.g., burden or stress), and seldom focus on the positive aspects of parenting a child with special needs (Berg-Weger, Rubio, & Tebb, 2001).

Consequently, there have been few strengths-based practices or evidence-based interventions designed for caregivers of children with special needs. In reviewing literature for this study, no studies were found that focused on the unique context for

fathering African American children with developmental disabilities. African American families are likely to live in families that reside in poor, inner city, urban environments that present additional risks and vulnerabilities for these children and their families. More than one in five African American adults (22.5%) and one in three African American children (34.1%) live below the official federal poverty line (U.S. Bureau of the Census, 2004).

There is a growing body of literature giving attention to resilience among African American families in general and low-income African American families with children in particular (e.g., McLoyd, Hill, & Dodge, 2005; Murry, Bynum, Brody, Willert, & Stephens, 2001). Although increasing attention has been paid to the roles of African American mothers, only a small number of studies focus on the roles of fathers and other male caregivers in African American families (e.g., Roy, 2005; Zuberi, 1998).

Historically, Black fathers have had strong roles in nurturing and providing moral and economic support for their families (Poussaint, 1996). Despite tremendous odds, Black fathers' roles have included acting as economic providers, caregivers, teachers, role models, monitors, disciplinarians, protectors, physical and emotional supporters, and providers of linkages to extended and fictive family members (Bowman & Forman, 1997; Jarrett, Roy, & Burton, 2002; Whitehead, 1994). Recent studies have indicated a limited number of factors that support fathers in their parenting and family roles, including: developing positive social orientation and networking with other fathers (Darling & Gallagher, 2004; May, 1997); elevating self-esteem (Grimm-Thomas & Perry-Jenkins, 1994; Hough et al., 2003); strengthening family ties (Ceballo & McLoyd, 2002); improving paternal relationship quality (Jordan & Lewis, 2005); and developing effective

strategies for parenting (Harris, 2000). Although some of these studies included African American fathers, there is still a gap in our understanding of the nature of their parenting and other family roles (Jarrett et al., 2002). Little data are provided on the positive (strengths) or negative (challenges) aspects of parenting; and there exists a critical need to provide information about the needs of African American fathers of children with special needs and their families (Dutra et al., 2000).

Research on the social and economic history of African American men has both aided and distorted our understanding of their roles in family life. A large volume of this research has been conducted from a deficit perspective and, as noted, rarely addresses African American men's roles as fathers (Zuberi, 1998). There is an urgent need for additional research on both African American fathering and paternal involvement in children's activities, including studies of residential and non-residential fathers. Existing studies of Black fathers also tend to focus on parenting of elementary age and adolescent children, rather than young children or children with special needs. To fill these gaps, a qualitative study was implemented with African American fathers and male caregivers of the Health Services for Children with Special Needs (HSCSN), Male Caregivers Advocacy Support Group (MCASG) to examine their strengths, challenges, and needs in parenting a child with special needs. The HSCSN was established in 2005 as a Health Care Finance Administration (HCFA) and District of Columbia Medical Assistance Administration demonstration project within the HSC Pediatric Center (formerly Hospital for Sick Children) health care system to provide services for Supplemental Security Income (SSI) recipients who had developmental disabilities or complex medical and psychosocial health care needs. The MCASG was organized later in 2005 as an outreach

program specifically for men who were part of HSCSN's Parent Advocate Leaders Support group (PALS). PALS provides support to men and women who are parents of children with special needs; however, male group members requested a separate group within the agency that would focus on the parenting strengths, challenges, and needs of fathers or male caregivers of children with special needs. MCASG also provides personalized coordination of outreach services (e.g., health screenings), training, and empowerment opportunities for low-income male caregivers of children with special needs ages 0-22. The MCASG is a community-based peer-to-peer, parent led volunteer program that is structured to increase the capacity of male caregivers to navigate through health care and educational systems within Washington, D. C. Finally, MCASG provides information to fathers, male caregivers, grandfathers, stepfathers, social fathers (i.e., nonbiological fathers), and uncles of children with special needs on how to access support services for personal development, housing, transportation, and other needs.

Following is an overview of the theoretical framework guiding this study and a literature review. This review is based on the large literature on maternal parenting and African American families in general and the limited, available literature on African American fathers and caregivers of children with special needs. After this review, the key research issues that were examined in this study with fathers/caregivers are presented, followed by a presentation of the qualitative methods, study limitations, and analytic plans. Results (recurring themes reported by fathers) in focus groups and interviews are presented, and finally implications of the study are discussed.

CHAPTER 2: REVIEW OF RELATED RESEARCH

Theoretical Framework

Family science researchers have offered several theories to explain certain phenomena that occur within African American families, (McAdoo & McAdoo, 1994). Among these, use of a human ecology theory may facilitate understanding the variety of roles (e.g., provider, caregiver, and teacher) and may take into account the intersection of race, class, and social inequality that African American men undertake in their families (Allen & Connor, 1997; Livingston, 2006; McAdoo, 1998). This study used an ecological systems/risk-resiliency framework to study the parental strengths, challenges, and needs of African American fathers or caregivers of children with special needs. The framework (Bronfenbrenner, 1986; 1990) posits that an individual's development is influenced by the differential and interactive effects of risk and resilience at various levels in one's environment--specifically, at the individual (microsystem), family (mesosystem), community (exosystem), larger societal (macrosystem) levels, and across life transitions (chronosystem). *Risk* factors pose challenges to healthy individual development (e.g., caregiver burden) and family functioning (e.g., poor parenting). In contrast, r*esilience* refers to the ability of the individual or family system to recover from negative experiences (McCubbin & McCubbin, 1996; Murray et al., 2001). Protective factors promote this resilience.

Ecological/Risk-resilience framework

Bronfenbrenner's (1990) ecological theory provides a framework for examining risk factors that may negatively affect protective factors that promote resiliency. Early studies on risk and resiliency in families attempted to correlate parental stress and childhood illness (Garmezy & Rutter, 1983). Recent studies on risk and resilience have indicated that stress, coping and adjustment to childhood illnesses influence individual, family, and community- level positive and negative outcomes (Hough, Brumitt, Templin, Saltz, & Mood, 2003).

Previous research using a risk-resiliency framework has focused on infants and younger children. Studies now include issues concerning adolescents and children with special needs and factors that place them at risk due to such factors as parental conflict, lack of family support, and community violence. Garmezy (1983) suggests that future research using a risk-resiliency framework examine processes that focus less on problems experienced by individuals and their families, but rather focus on factors that build on cultural lessons from family elders that teach effectively coping with adversity. In this study, this perspective guided the inclusion of a focus on strengths of fathers in a particular cultural context, African American family life in an urban community.

Garmezy (1983) also states that resilience is not invulnerability, but rather, the ability to bounce back under adversity and is often erroneously equated with "invulnerability" or lack of "self-sufficiency." The risk-resilience framework was an appropriate framework to use in this study to examine risk or protective factors at various ecological levels that decrease risks (i.e., the likelihood of negative outcomes) and increase protective factors and processes (i.e., specific circumstances and behaviors that

enable positive outcomes to occur despite stressful conditions; Garmezy, 1983; Jarrett, 1995; Masten et al., 1999; Rutter, 1987).

The various system levels have different effects on development depending on the individual's life stage and context. Thus, for men who are fathers, the family system or community may have a dominant influence on parenting. At the family system level, the quality of a father's interactions with the child's mother or his level of involvement in family activities might be related to the quality and frequency of his interaction with the child with special needs. At the community system level, the father's involvement in support groups or church activities might promote a higher quality of father involvement with the child or family (Bennett, Deleuca, & Allen, 1995). Thus, this study applies the ecological systems/risk-resiliency framework to broaden the traditional perspective of studying family functioning from the limited view of the individual and family levels (Barnes et al., 2005) by including aspects of the larger community context that might also influence positive family functioning (Murray et al., 2001).

It was assumed that within each of the four levels of the ecological systems theory there are risk and protective factors that interact with each other (Reis, Barbera-Stein, & Bennett, 1986). For example, at the individual level, a father's positive feelings about fathering a child with special needs might impact his interactions with the child, the child's mother, or other family members (at the mesosystem level); with medical personnel, child care providers, support groups, or other community members (at the exosystem level); with involvement in advocacy efforts to change policies affecting children with special needs and their families (at the macrosystem level); and with the transition and care of their child with special needs over the course of the father's and

child's life (chronosystem). The ecological systems framework permitted me to examine risk and protective factors at various levels in terms of fathers' strengths, challenges, and needs related to parenting a child with special needs.

At the core of this system is the microsystem, which in this study is focused on the father. (It should be noted that ecological models often start with the child at the core). The microsystem, then, contains the structures (e.g., fathering roles) that have the greatest influence on the individual father. This level of the ecological model might encompass relationships with others that may influence parental practices and interaction (Bronfenbrenner, 1986). These parental practices or relationships have bi-directional influences to and away from the parent. For example, a father's behavior and how he copes with the child's disability might influence his perceptions of the strengths and challenges of parenting a child with special needs. In turn, according to Bronfenbrenner (1986), bi-directional influences are strongest at the microsystem level (i.e., have the greatest influence), and thus the child's perception of his or her disability might also influence fathers' parenting behaviors or perceptions of his own strengths, challenges, and needs. The next level within the ecological system is the mesosystem. This level incorporates and connects individual, family, and community structures. This connection between systems might also influence strengths, challenges, and needs of fathers who have children with special needs. For example, a father who parents a child with special needs and who is involved in activities at the site where the child is enrolled for long-term care might have relationships with care providers and mechanisms in place to assist with the child's health care that may alleviate concerns that he has about his child's development.

Using the father as the microsystem, the exosystem is defined by the larger community system in which a parent is involved but that has implications for the child's functioning (Berk, 2000). This level, might involve a father's workplace, which provides insurance or family medical leave, or the pediatric care setting, which provides health care to the child as well as supportive services for the father. For example, a father's employer might have family support programs that assist with extended leave, if needed, or support groups might provide access to resources to further support the father or his family. On the other hand, some workplaces might place demands on fathers that put them in the position of having to choose between keeping their job or being more involved in their child's care. The macrosystem is the outermost layer of the father's environment and is made-up of the larger societal features such as cultural values, customs, and laws/policies (Bronfenbrenner, 1990). The effects experienced by parents within this system have influences throughout and across other levels and can impact parenting and associated needs. For example, there might be societal stigma attached to children with special needs such that some fathers may not want to be seen in public with their child. In comparison, some communities might be more responsive to the needs of families with children with special needs and provide an abundance of supportive services for families. Some health care policies may create challenges for families. The lack of access to quality care or the cost of child care may pose financial challenges if, by law, these costs have to be paid out-of-pocket (DeNavas-Walt, Proctor, & Mills, 2004). Then again, other policies provide needed supplemental assistance (e.g., Supplemental Security Income/SSI or Title XVI).

Finally, Bronfenbrenner (1990) describes the chronosystem as a level within the ecological system that is affected by life events and time. Within the context of events and time, a father's parenting environment may be affected by social, physiological or developmental changes in the parent or child. Fathers of children with special needs may experience challenges (obtaining vocational or life skill training for their growing child) or needs (transitional medical services from pediatrics to continuing health care as an adult) during their child's life course. Elder (1998) also indicates that the life course of one's development may help to contextualize or frame people's lives and may occur across generations or through social networks. Figure 1 depicts an ecological model of African American fathers of children with special needs with the father at the core of the model.

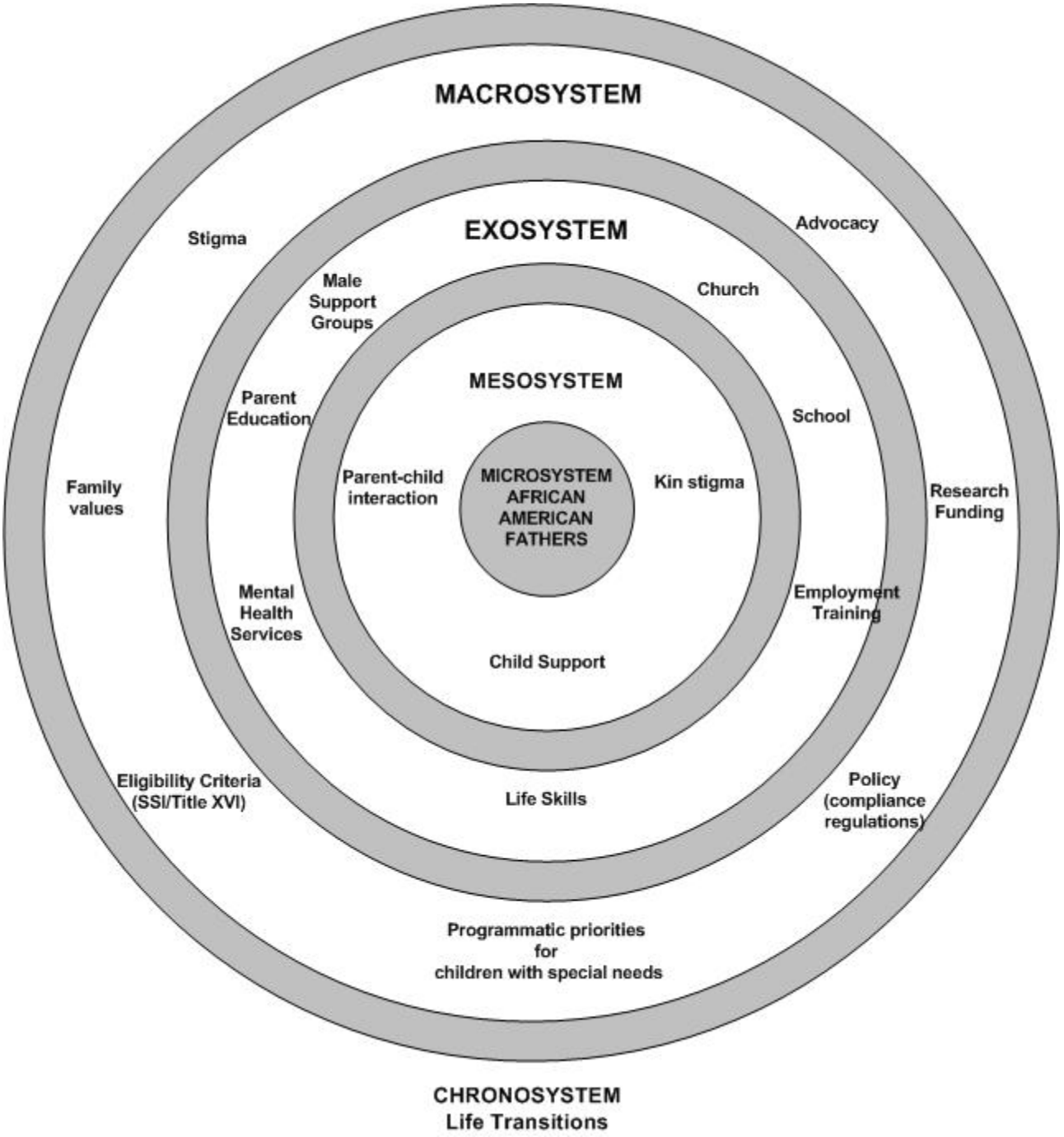

Figure 1. Ecological model of African American fathers parenting a child with special needs (adapted from Bronfenbrenner, 1990)

While there are many risk and protective factors likely to influence parent, child, and family functioning and outcomes in families with children who have special needs (King, King, Rosenbaum, & Goffin, 1999), this study's attention will be directed toward factors related to fathering since there is limited focus on these men in existing research (Darling & Gallagher, 2004). Specifically, this study focused on both positive and negative aspects of caregiving for a child with special needs by utilizing qualitative approaches to hear African American fathers' stories about their strengths, challenges, and needs of fathering children with special needs. These issues were selected because of their potential for generating data for proactive intervention to promote resiliency in families from a specific cultural background. After hearing fathers' stories, an ecological systems/risk-resiliency framework was used in a modified grounded theory approach to organize and summarize recurring themes.

These findings have implications for refining theory and developing culturally specific interventions for fathers or other male caregivers of children with special needs. Studies on Black families also include Afrocentric concepts in order to enhance our understanding of the common history, experiences, and culture that is shared by people of African descent. Understanding how Afrocentricity is incorporated into culturally specific interventions or studies on families allows the researcher to illustrate the meaning of Black culture rather than compare it to middle class Whites in America (Asante, 1980; Johnson & Staples, 2004; Nobles, 1972). Afrocentric quotes, proverbs, and sayings are used to add cultural meaning and introduce each theme explored in my study. These quotes or proverbs illustrate cultural expressions and highlight individual, family, and community level sayings shared by participants during our discussions. The

remaining sections of this chapter present an overview of literature related to African American families, men as caregivers, African American fathers as caregivers, strengths related to African American fathering, and challenges to Black masculinity, and summarize literature related to parenting strengths, challenges, and needs.

African American families

The contemporary study of African American family life views family organization and dynamics as adaptations to the broader context within which the family is situated (McLoyd et al., 2005). Greater recognition has been given to the multiple roles of Black men as fathers, whether they live with their families/children or participate in other ways in their lives. Some of these roles include what has been referred to as "social fathers," who take on the role of fathering when biological fathers are absent from the family. Thus, recent studies on Black families have now shifted from the exclusive or predominant focus on family roles of Black mothers to the inclusion of roles of Black men/fathers. This shift in the research paradigm recognizes that men of all ages find fulfillment in the roles in which they nurture and support their children, wives, relatives, and friends (Harrison, 1985; Taylor, Jackson & Chatters, 1997).

Men as caregivers

Talley and Crews (2007) suggest that caregiving within the context of public health is an emergent issue regarding fluctuating roles and responsibilities. Furthermore, previous studies on the roles of caregiving focused on women who typically did not work outside of the home and who cared for their children and their parents (Talley & Crews, 2007). However, according to Kramer (2002), studies on the impact of male caregiving have been neglected and marginalized. Most studies on men as caregivers have been

overshadowed by studies of females who are often viewed as principal caregivers of their spouse, child, or parent. Men comprise 30% of all caregivers and may have unique experiences and needs as a caregiver (Kramer & Thompson, 2002). Many of these caregivers' experiences are not acknowledged or studied. For example, 41 to 53% of caregivers to persons with HIV/AIDS are young men whose responsibilities go unnoticed (Kramer, 2002).

The body of literature on caregiving is beginning to examine challenges and rewards of how men accept the obligation to care for a child, spouse, or parent as well as attend to their personal needs. The role of male caregiver will need to take into consideration trends in the family, kinship roles, social environment, and policies that are likely to increase or decrease the strain or burden of caregiving (Kramer, 2002; Thompson, 2002). Cultural expectations of male caregiving may also influence the level of male caregiving. These cultural expectations may include individual, family, and community influences (e.g., stigma, racism, and discrimination). Life changes may also influence aspects of male caregiving. These life changes may include, for example, life transitions such as developmental changes in children with disabilities, role changes for fathers, social arrangements for families, and internal shifts in personal perceptions of one's life (Cowan, 1991).

Family research has also largely neglected fathers as caregivers of children with developmental disabilities (Essex, Seltzer, & Krauss, 2006). More attention is given to mothers who function as the primary caregiver of children with special needs. Children with developmental disabilities are often less responsive and may be more difficult to teach and interact with as compared to child with normal development (Essex et al.,

2006). These children are also less likely to respond to normative child rearing processes (e.g., toileting or play). Male caregivers of children with developmental disabilities may not receive as much support from friends, family, self-help groups, and other professionals as mothers receive (Davis & May, 1991). In a study of fathers of children with mental retardation, men were perceived to have more difficulties with parental competence than fathers of children with normal development (Roach, Orsmond, & Barratt, 1999). Essex et al., (2002) also indicated in their study of male caregivers that fathers of children with mental retardation had challenges with their children transitioning to adulthood and being placed in residential or out of home care settings (i.e., a shift to a formal care setting). Another challenge for male caregivers of children with developmental disabilities is developing support systems that will provide for their child due to death or incapacitation of one or both parents (Gordon, Seltzer, & Krauss, 1997; Thompson, 2006). Thus, a greater understanding is needed of various aspects of African American fathers as caregivers of children with special needs and how these parenting experiences may alter one's approach to parenting their child. In particular, what strengths do fathers bring to these experiences? What aspects of these experiences are considered challenging, and for what aspects of caregiving do they need support?

African American fathers as caregivers

According to the U.S. Census Bureau (2000), roughly 60% of Black men are between ages 18 and 64, with over 40% of them marrying or entering into a partnership that may have children. African American men are also likely to nurture and participate in the socialization (i.e., teaching cultural values) of their children. Unfortunately, within the context of the African American family, many of these households will be headed by

a female with 9% of Black fathers either supporting their family as a single parent or nonresidential dad (Livingston & McAdoo, 2007). Contemporary views of Black fathers in society today are still connected with the White middle-class view of residential breadwinner and head of household (Connor & White, 2006). Once again, much of this view negates the fact that Black fathers who live outside the home may also have a significant impact on their child and community. Studies on Black fathers and child development or family life mostly view them as invisible, or portray them as deadbeat dads or financially irresponsible fathers; Coley 2001; Connor & White, 2006). However, many of these fathers are visible in their community (e.g., in the corner barber shops and on neighborhood porches) and seen in other supportive roles (e.g., as social fathers such as "Big Daddy" or "Uncle Jeff"). Coley (2001) defines social fathering as men who perform in the role of a biological father or caregiver; the role encompasses a significant degree of nurturance, moral and ethical guidance, companionship, and emotional support. Connor and White (2006) cited a study in which African American low-income, adolescent girls were asked to identify or name the man who was "most like" a father to them; 24% responded and named a nonbiological father. Thomas (1997) noted in an earlier study that a similar response pattern was reported for 26 African American boys aged 13 years to 15 years who shared rich relationships with nonbiological fathers.

The literature seems to present major discrepancies in negative absent father images versus positive Black fathering images often described in structured interviews, narratives, and community-based observations (Connor & White, 2006). Finally, qualitative approaches often indicate that these fathers' voices are seldom heard, but

Black men have always risen to assume individual, family, and community level responsibilities (Hutchinson, 1995; Wade-Gayles, 1997).

Strengths of African American fathering

Caldwell and White (2006) suggest that generative fathering is one aspect of male caregiving that recognizes the dynamic nature of parenting by African American fathers. Generative parenting or fathering is an Eriksonian concept of psychosocial development where individuals are actively involved in contributing to the welfare of their children by teaching (parenting) or through social activism (Allen & Connor, 1997; Erickson, 1959). Through the generative fathering process, Black fathers are committed to participate in the life-span of their children's lives to ensure that they remain connected with their culture and community (Caldwell & White, 2006; Huchinson, 1995). Allen and Connor also define generative fathering from an Afrocentric perspective where developmental patterns (e.g., involvement, interaction, availability, and responsibility) reinforce family structure and enhance community involvement. Brotherson, Dollahite, and Hawkins (2005) describe generative fathering as a concept of generational ethics, the place of men's responsibilities and capabilities as fathers to be caregivers and nurturers of their children. Fathers, who were primarily White and participated in their focus groups and interviews, expressed a need to "give back to their children."

Black masculinity

According to Franklin (1994), images of Black masculinity in mainstream America may suggest that Black men are fearsome, threatening, unemployed, and generally socially pathological. Positive aspects of black male masculinity are often missing in these portrayals. This is unlike mainstream perceptions of Black femininity,

where Black females are more likely to be assured their gender identity as a birthright, provided that they follow the traditional roles of marriage and child bearing (Cazenave, 1979). Some have argued that Black masculinity has to be proven on a day-to-day basis and is a lifelong quest for gender identity among Black men (Cazenave, 1979; Turner, 1970). African American men still seek to achieve, accomplish, have, and provide for themselves and their family.

Franklin (1994) identified three sources of group socialization that influence Black male masculinity. These sources consist of: (1) a primary group that provides mixed messages regarding the meaning of Black masculinity; (2) a peer group that teaches innovative Black masculine traits; and (3) a mainstream society group that sends mixed messages regarding competitiveness, aggressiveness, passivity, inferiority, and invisibility (Franklin, 1994; Majors & Gordon, 1994). The primary peer groups attempt to provide societal norms and values that are usually from a community perspective. The Black male peer group may be the most influential component of the masculinity process. It is the place in a Black man's life where he is vulnerable to both negative and positive influences and directives from others (Franklin, 1994).

Cazenave (1979) conducted a study of 54 Black male letter carriers' perceptions of masculinity. Approximately 41% of the respondents indicated that being a man meant being responsible. Other important views of masculinity in the study included hard work and firm principles. Respondents also viewed masculinity as a complex process that was demanding, changing, and a means to provide economic support to their families. It was also found that it is within the peer support process that men begin to bond with other males and discover opportunities to nurture their identity. Finally, the mainstream society

group is the link between the Black male primary group and the Black male peer group, which is a teaching component of masculinity that is directed by what men should or should not do in society. For example, lessons are learned in informal settings such as street corners versus formal settings such as a classroom or school. Black men may seek individual and community level support in order to meet the challenges such as stress management and job placement in caring for their child with special needs (Cazenave, 1979).

The following is a discussion of fathering strengths, challenges and needs in general, which are relevant for understanding these aspects in African American fathers of children with special needs. This review is followed by a brief description of the current study and its significance.

Fathering Strengths

"Children are the reward of life" Zairian Proverb

In order to understand the range of parenting strengths that might be expressed by African American fathers, it is important to note how Black families have been studied in the past and the recent shift in research on African American family life. Models of Black families in general have undergone a tremendous shift in demographic and social transformation during the past 30 years (Taylor, Jackson, & Chatters, 1997). Traditional research that focused on race differences in family structure showed that Black families were organized in positively functioning ways that were in contradiction to the ideal white, middle class norms that had been previously assumed by scholars as the preferred model (Dilworth-Anderson & McAdoo, 1988; Taylor et al., 1997). For example, even though African American families were predominantly two-parent families until the latter

part of the 20th century (Gutman, 1976), they were historically represented as single mother families. A large body of literature was produced on Black motherhood (Staples, 1999), leaving a void of information on Black fathering. In addition, earlier research overlooked or rarely referenced other African American family formations such as "augmented families," defined as nuclear families with non-relatives (e.g., boarders) who functioned as family members (Billingsley, 1988, 1999) and "fictive" kin defined as unrelated "uncles" and "aunts," who are deeply involved in the child's life (Stack, 1974).

Parenting strengths

Hough et al., (2003) indicate that parental coping strategies lead to strength and resilience in families of children with HIV/AIDS. They examined pathways by which the HIV-positive status of mothers affects their uninfected school age-child. Predictor variables for the study were family sociodempgraphic characteristics, social support, and quality parent-child relationships. Data were collected from 147 mother-child pairs living in the Detroit, MI metropolitan area. Women who participated in the study were recruited from community-based AIDS service organizations, case management agencies, and medical clinics. Selection criteria for the study also identified participants based on their status as being HIV-positive (participants' status was confirmed by agency records); having at least one child ages 7-14 who was not HIV-positive; and having contact with their child at least once a week. Due to various living arrangements of the HIV-positive mother, grandmothers, aunts, and social mothers were eligible to participate in the study. Results from the study indicated that the level of mother's HIV-related stress (e.g., frequent visits to clinic) had a significant effect on their child's adjustment to stress; the higher the level of stress, the higher child adjustment problems were reported by the

mother or caregiver (Hough et al., 2003). However, the study did show that mothers exhibit strengths through their coping behavior which mediated positive adjustment (i.e., effectively coping with her symptoms by using tension reducing behaviors such as crying or daydreaming).

Ray and Ritchie (1993) examined individual coping perceptions in 29 parents of chronically ill children who lived with their parents. Studies on current caregiving trends have challenged parents to find ways to be resilient and cope with multiple demands in their homes (Ray & Ritchie, 1993). Furthermore, little is known regarding the impact of caregiving factors associated with coping and parenting strengths in African American fathers of children who are chronically ill (Anderson, 1990). Parents in their study were mothers (in all but one of the 29 families) of children ages 3 months to 16 years who received gastro-intestinal medications, dialysis, apnea monitoring, and oxygen care in their home. Results from the study indicated that mothers were in a unique situation that was characterized by care and commitment for the child with special needs. Mothers found strengths in having strong support systems and maintaining a positive outlook. The importance of family support was evident in the strength of associations involving the family subscale of the Coping-Health Inventory for Parents (CHIP) and in the frequency in which family cooperation outnumbered descriptions of the absence of support from spousal or family members. Ray and Ritchie also indicated that mothers in the study emphasized that positive parenting was associated with a reassurance and support that health care professionals had their child's health in their best interest. Wallander and Varni (1989) also found that parents report social support as a strength.

Conventional portrayals of African American men, husbands, and caregivers have reflected negative aspects of parenting. For example, Black males are stereotypically viewed as residents of poor housing, financially irresponsible, uninvolved in their children's lives, adolescent fathers, street corner men/criminals, sexual partners with limited household responsibilities, and marginal participants of extended family networks (Taylor, Johnson, & Chatters, 1997). These characterizations fail to consider the environmental diversity and strengths of parental and other roles that African American men experience (e.g., Roy, 2004, 2005; Whitehead, 1994).

Contrary to the conventional roles of African American fathers, more recent studies have portrayed Black men as exhibiting a high level of family life satisfaction, happiness, and well-being (Broman, 1988). For example, in Broman's review of family satisfaction among African American men and women across socioeconomic levels and age groups, both men and women associated older age, being married, and parenting younger children with positive aspects of family life, or higher levels of family satisfaction. Broman also found that Black men and women had equally high levels of family satisfaction when they assisted with routine household activities such as cooking and cleaning. Family satisfaction has also been shown to be generational. Taylor et al. (1997) found in their analysis of three-generation Black families (i.e., grandparent, child, and grandchild) that members of the grandparent generation expressed the highest levels of family satisfaction followed by the parent and the child generation. However, research has not been conducted to examine the indicators of family satisfaction and well-being specifically among Black men who are sole caregivers of their children (Taylor et al., 1997).

In the present study some caregivers were grandparents of children with special needs who are serving in the father role. Eight percent of children nationally live in kincare-headed households (Crewe & Stowell-Ritter, 2003; U.S. Census Bureau, 2000). Caregiving is defined as type of care given to one person by another that includes time, volume, intensity, and duration of support provided (Barer & Johnson, 1990; Maleonebeach & Zarit, 1991).

Caregiving plays a key role in long-term supportive services and is an emerging public health concern. The National Alliance for Caregiving (NAC) and the American Association for Retired Persons (AARP) estimate that 21% of Americans provide unpaid care for family members and friends above age 17; thousands more care for children with special needs and chronic illnesses who will require life-long personal and professional assistance (Crewe & Stowell-Ritter, 2003; National Alliance for Caregiving, 2004). While studies indicate that the majority of caregivers are women, recent studies indicate that nearly 39% of these caregivers are men (National Alliance for Caregiving, 2004). The number of male caregivers reported included fathers caring for children with special needs. These fathers or caregivers vary based on their relationship to the target child (i.e., biological fathers, other father figures such as uncles, brothers, grandfathers, and other male relatives or family friends). In this study, other male caregivers are expected to be sole or primary caregivers for their children. Thus, this study has the potential to shed light on African American men's roles as single fathers and grandparents raising grandchildren.

According to Hovey (2005), fathering roles influence child behavior and can include caregiver, protector, communicator, and teacher. However, the dynamics of these

fathering roles that are associated with positive aspects of parenting children with special needs (e.g., physical, emotional, or social adaptation to the child's needs) warrant further study. It has long been noted that it is important to study not only the child and the impact of the illness, but also the impact that the illness or condition has on the family as a whole and on various family members (von Bertalanffy, 1968). Since the late 1990's, several studies have examined such impacts on mothers (Ray & Ritchie, 1993); including a few that have included African American mothers (Staples, 1999; May, 1997). Yet, few studies have focused on fathers and how their roles impact the family of a child with special needs. No studies were found for this review examining these role impacts for African American fathers of a child with special needs. Therefore, studies of fathering in general were consulted for additional information about fathering strengths. This additional review indicated that father's work experiences and family structure are other important factors that might enhance or interfere with perceiving strengths or receiving rewards in the fathering role.

Work Experiences

Grimm-Thomas and Perry-Jenkins (1994) demonstrated that fathers can form close, affectionate bonds with their children and can influence their child's social, emotional, and intellectual development. The goal of their study was to examine how working class White fathers' job experiences affected their self-esteem and fathering style and determined how fathers' self-esteem may serve to intervene in work-parenting relationships with their children. Dimensions of fathers' work (i.e., level of work autonomy, innovation, and control) and the experiences fathers shared with co-workers, supervisors, and employees were studied in relation to parenting styles and well-being.

The study sample consisted of 59 White, working-class, residential fathers and their biological child between the ages of 8 and 12 years. Working-class was defined as factory workers, service workers, non-farm workers, mechanics, and electricians. The measures used assessed fathers' work experience, fathers' self esteem, fathers' and children's reports of fathers' parenting, as well as fathers' time spent with children over a 5-day period. The analyses assessed relationships between father's work, self-esteem, and parenting. Path analyses indicated that the more positive fathers' work experience, the higher his self-esteem, which predicted more accepting parenting styles for caregiving. Grimm-Thomas and Perry-Jenkins (1994) also found that fathers who reported higher amounts of autonomy, clarity of job role, involvement in their child's life, supervisor support, and physical comfort with their work also reported higher levels of self-esteem. They noted that these findings were consistent with studies that have documented the relationship with men's employment experiences and well-being. This study has implications for understanding how rewarding fathering roles and job satisfaction may impact parent–child relationships and developmental outcomes of children with special needs.

Additional research is needed to explore African American fathers' involvement with children of various ages and abilities as well as how their involvement in settings outside the home (e.g., work) affect this relationship. Such research would provide the basis for future studies examining the relationship between father's parenting and the socioemotional functioning of African American children. Father's confidence in parenting a child with special needs might improve their mental health as well as their overall involvement with the target child in particular and the family as a whole. Thus,

the strengths of parenting a child with special needs will be one focus of this qualitative study, and fathers will be asked briefly about their employment status to provide a context for their responses in discussions about their strengths, challenges, and needs.

Family Structure

Family structure may also influence strengths associated with parenting children with special needs. As noted earlier, African American fathers are typically discussed in research as absent members of their community (Zuberi, 1998). Consequently, research on Black men is predominated by a focus on young men or young fathers, reflecting concerns over such issues as teenage parenting and mother-only families (Taylor et al., 1997). Moreover, this focus leads to a failure by researchers to see structural diversity in familial systems where African American men dynamically exist (Hunter & Davis, 1992; Tucker & James, 2005). Family systems where fathers are involved in the lives of their child are viewed as benefits that increase the quality of parent-child relationships (Hofferth, Pleck, Stueve, Bianchi, & Sayer, 2002). Studies also indicate that part of child learning occurs through interaction with and observations of parents (Hofferth et al., 2002). While this study did not focus on family components *per se* (e.g., single parent versus two parents), it should be noted that a primary focus of the study was to better understand African American fathers' experiences with children, the roles that they play in children's lives, parenting strengths and challenges, and the resources these fathers need to support positive parenting. An additional aim was to capture the variations in family structure that provide the context for their involvement with their child with special needs. For example, the demographic shifts in Black family forms noted above might be seen in this group and, therefore, will need to be illuminated if we are to

develop more appropriate interventions. These shifts include: increases in "never marrieds," more couple cohabitation, declining teenage births, diverse living arrangements for children, fewer children in the family, older persons living alone, and increased racial-ethnic diversity among Blacks due to immigration (Tucker & James, 2005).

Reviews by Brodsky (1999) and Murry et al. (2001) also caution that the studies on African American family structure should move away from the deficit model and consider the variation in family structures as noted above. Brodsky reviewed literature on family structures and concluded that most studies on African American single mothers were based on a cultural deficit model and did not closely examine the strengths of how these mothers succeeded in the midst of adversity. Murry et al. (2001) note that involvement of fathers and other adults such as extended kin also contribute to the family processes for which family structure promotes positive psychosocial outcomes of African American children. They further indicate that African American families are not limited to a nuclear family form which consist of father, mother, and children; nor to one finite household; nor to blood relatives (Murry et al., 2001). As indicated earlier, this study will aim to capture this diversity in family structure in order to better understand how family level factors pose strengths and challenges to fathers or create needs for added support.

Fathering Challenges

> *"I am invisible. I am invisible understand, simply because people refuse to see me. When they approach me they see only my surroundings, themselves, or figments of their imagination-indeed, everything and anything except me."*
> *Ralph Ellison*

In general, Black families and other racial-ethnic minorities socialize their children under conditions that are in contrast to the American creed of "life, liberty, and the pursuit of happiness" (Staples & Johnson, 1993, p.170). Despite moderate changes in social and economic advances, Black families are still faced with challenges that limit their access to advances in education and healthcare. Staples and Johnson noted that Black parents are also faced with challenges in establishing relationships with their children, overcoming discrimination, and coping with other negative life circumstances (e.g., poverty and lack of equal employment opportunities). For many Black families less value is placed on overcoming economic challenges and more emphasis is placed on parenting challenges such as nurturing their children and obtaining a high level of well being for them (Peters, 1997; Staples & Johnson, 1993).

Raising a child with special needs may pose special challenges for fathers or male caregivers. For example, in a recent study focused on the challenges of fathers parenting chronically ill children, Hovey (2005) examined how fathers of chronically ill children dealt with their own concerns and perceived their wives' coping strategies. This descriptive study used a mail survey to gather data from White fathers of children with chronic conditions on the impact of childhood diseases on parental adaptations and perceptions of parenting challenges and needs. Questionnaires were mailed to a convenience sample of 113 fathers who were identified at the immunology, oncology, and pulmonary clinics of children's hospitals in the Midwest United States. According to

Hovey (2005), other studies (e.g., Britton & Moore, 2002) have been conducted on the impact of chronic conditions on mothers, fathers, and grandparents; however, none have been published that focus on the child's illness and the parents' perceptions of the impact of that illness on their partner.

Findings from Hovey's study indicated that fathers perceived their wives/mothers as more concerned than fathers about being "worn out" with the responsibility of caring for the family. Fathers reported that mothers were the primary caregivers in the families and took responsibility for the general childcare as well as doctors' appointments and other health maintenance issues. Results from the study also indicated that mothers were perceived by fathers as more worried than fathers about their own fatigue and the practical challenges of caring for their child with a chronic illness. Fathers' daily concerns were related to having the ability to do family activities, making their family happy, and having fun together. Many fathers also expressed concern about their sexual relationship with their wife and not having time alone with their spouse due to the significant amount of time spent caring for their child. On a practical note, Hovey suggested that fathering roles be strengthened through resources external to the family in order to promote family resiliency and support fathers' adaptations to their children's illnesses.

Neil-Urban and Jones (2002) examined the parenting challenges of fathers of children diagnosed with cancer. Ten men were recruited from a hospital-based medical program and inclusion criteria were that participants had a "fathering" relationship and live in the home with their child. A phenomenologic qualitative design using open-ended questions was employed to examine fathers' challenges and coping strategies with health

care providers. Fathers reported that they experienced work-related tension and emotional pain that was associated with their child's illness. These fathers also reported that they felt the need to always be vigilant, and they struggled to maintain control while still feeling vulnerable. The fathers who participated in the study also expressed concern regarding their family as a whole and how challenging it was to manage finances, marital relationships, and living arrangements in order to accommodate their child's illness. However, the findings also indicated that these fathers found that everyday stressors (e.g., work, marriage, and family activities) became less important when they considered their child's condition. In the current study, African American fathers or male caregivers were asked about their strengths, their challenges, what they do to deal with challenges, and their perceptions of what is needed to deal with these challenges.

Fathering Needs

"It takes a village to raise a child."
African Proverb

The above review suggests that although fathers experience various strengths from parenting a child with special needs, there are also several challenges. Many of these challenges potentially relate to the needs fathers might have for assistance with parenting as well as their own personal adaptation to the child's illness (Hovey, 2005). A large literature shows that social support from sources within the immediate family (e.g., a partner or spouse) or external to the family (e.g., a kin network, faith-based involvement, or community groups) can also address the mental and physical health needs of parents in general as well as when there is a child with special needs in the family (Hoard & Anderson 2004; Rogers-Dulan, 1998; Tannila, Jarvelin, & Kokkonen,

1999; Wannamaker & Glenwick, 1998). Hoard and Anderson (2004), in their study of noncustodial fathers who participated in the State of Maryland Young Fathers or Responsible Fathers of Program (YF/RF) examined factors related to depression. The program was developed to assist fathers to become economically sufficient and responsible parents. Participants in the study consisted of 127 predominantly African American, noncustodial fathers including 96 fathers living in urban settings and 31 fathers living in rural settings. There were no significant differences in age, marital status, education level, employment status, and number of children under age 18 of fathers residing in urban and rural settings. Findings indicated that depression was positively related to life stress (i.e., unemployment, crime, health, substance abuse, transient housing, parenting conflict, and lack of transportation) and is inversely related to highly levels of reported social support. Studies on depression experienced by men in urban settings was lower among fathers experiencing higher levels of reported social support and may aid in understanding how levels of stress (e.g., high, medium, and low) may present barriers to caregiving among African American fathers who have children with special needs.

Another study (Slaughter & Dilworth-Anderson, 1988) examined how social support is perceived by primary caregivers of children with Sickle Cell Disease when fathers are present in the household compared to when fathers are absent. They also examined patterns of caregivers over time. Sickle Cell Disease is a chronic illness that constricts blood flow and causes extreme pain in leg joints and ankles. There is also no know cure for Sickle Cell Disease and it occurs frequently in Black children. Slaughter and Dilworth-Anderson (1988) recruited 34 families from patient lists of children at one

public and one private hospital in metropolitan Chicago, IL. These patient lists consisted of children ages 5 years to 12 years who were diagnosed with Sickle Cell Disease. Families of children who were recruited for the study were contacted via telephone. Slaughter and Dilworth-Anderson found that black mothers as primary caregivers to children with Sickle Cell Disease received emotional support and assistance for example, help with chores, baby sitting, transportation and money from extended kin networks, despite father's home status (i.e., noncustodial versus custodial). Maternal grandmothers and aunts were identified and primary supporters to mothers in the study when fathers were absent in the home. This study shows the average level of extended family participation or perceived life satisfaction of the child's mother is not significantly different if the father is present or absent in the family. Again, this literature is primarily based on studies of mothering and mother-child relationships and does not examine caregiver satisfaction levels for fathers of children with special needs.

Other literature has shown that men in general and Black men in particular have a range of unmet needs indicating that researchers and practitioners must better understand this range in order to develop interventions that address personal and parenting concerns (Brotherson et al., 2005; Cooper & Allred, 1992; Crowley & Taylor, 1994; Ellerton, Stewart, Ritchie, & Hirth, 1996). For example, recent studies have established that father-child relationships and the needs of fathers of children with special needs in particular can also benefit from social support. In their study, Brotherson et al. (2005) interviewed 16 primarily White Mormon fathers (1 Black, 1 Chinese), who had at least two children in early to middle childhood (including one child with special needs). Fathers were asked about parenting needs, specifically connecting to their child. While

fathers connect with their children through a variety of activities (spiritual, spending leisure time together, and helping children with developmental tasks), they also report the need for assistance in improving their parenting roles in these contexts. In the present study, the range of needs among African American fathers was expected to be wider than in extant literature. These needs extend beyond connecting with their children, such as those needs that focus on the fathers personally (e.g., assistance with dealing with daily stressors at work or coping), their family roles (e.g., marital concerns, parenting the target child, maintaining their family), and community roles (interacting with family supportive services and others in their situations). Therefore, in order to collect data to inform improved practices for the target population, fathers were asked about individual and family strengths in caregiving for a child with special needs (Berg-Weger, 2001).

Summary

Studies examining the individual strengths or resiliency of African American fathers are very limited. Studies about Black fathers' family involvement, while increasing, rarely focus on parenting of young children in general; and there is almost no literature on Black fathers parenting a child with special needs. The limited literature on fathers/caregivers of children with special needs suggests that fathers do find strengths in parenting, despite several challenges and a wide range of unmet needs. A strengths-based perspective grounded in the sociocultural context of the families under study is needed to further highlight the strengths and needs of fathers in African American families raising a child with special needs. This study was intended to generate new knowledge to fill these gaps and to guide the development of theories and interventions to

strengthen family systems and address African American fathers' particular needs in parenting children with special needs.

The Present Study

This study used a modified grounded theory approach (LaRossa, 2005) to explore the strengths, challenges, and needs of African American fathers and male caregivers of children with special needs. The following research questions were addressed in interviews with African American fathers and male caregivers of a child with special needs:

1. What are the strengths experienced in parenting a child with special needs?
2. What are the challenges faced in parenting a child with special needs? and
3. What are the needs fathers or male caregivers have in parenting their child with special needs?

Qualitative research methods were used in data collection, management, and analyses. The approach was built on grounded theory but is referred to as "modified" because an existing conceptual framework, the ecological systems/risk-resiliency model, was used to guide interview discussions and organization of the themes that emerged during data analyses. This conceptual framework was used along with qualitative analytic approaches to discover themes that could inform future research and theoretical developments that relate to African American fathers or male caregivers of children with special needs.

Significance

This study expands the available information on and resources for enhancing the role of fathers and other male caregivers in African American families. Moreover, findings from the study are expected to add to the limited understanding of risk and protective factors for African American fathers with children with special needs. It is also anticipated that findings will suggest culturally specific parenting strategies and highlight factors in the sociocultural context of African American fathers that should be considered (and measured) in future research and programming. Thus, findings of this study are expected to inform practitioners and researchers about ecologically valid issues related to family functioning for male caregivers in African American families. The results will also provide a foundation for developing interventions and family policies that address specific needs of African American fathers or caregivers of children with special needs. Finally, this study yielded information about a range of potential risk and protective factors that should be examined in future research on this selected set of African American fathers and their families to reduce disabilities-related health disparities (The Health Resources and Services Administration, 2002).

CHAPTER 3: METHODS AND RESEARCH DESIGN

Approach

This study used grounded theory methodology (LaRossa, 2005; Lincoln & Guba, 1985; Strauss & Corbin, 1998), a qualitative approach, to examine risk and protective factors for African American fathers raising a chronically ill child. Grounded theory entails deriving theory from systematically gathered and analyzed data. The central feature of this method is that rather than beginning with some preconceived theory, the researcher begins with an inductive exploration into an issue and allows theories to emerge through constant questioning and re-analysis throughout the data collection and analysis processes. This study used a modified grounded theory approach in that the issues of interest were derived from an ecological/risk-resiliency framework which shaped the development of the data collection instrument (i.e., focus group and interview guides) and analysis strategy. In that regard, there is a preliminary theoretical framework that directs the data collection and analysis, whereas in grounded theory, the theory emerges from the data. However, the data gathering process was modified on the basis of ongoing analysis, as comparisons were made within and across individual cases (focus groups and interviews). Consequently, patterns that are related to some phenomenon (e.g., in this case, a father's involvement in raising his child with special needs) were uncovered. For example, patterns in themes developed from pilot interviews, study discussions and interviews guided the refinement of the sampling strategy, the data collection process, and subsequent analyses.

The grounded theory process also included the notion of "theoretical sensitivity" (Strauss & Corbin, 1998), which refers to personal qualities as well as personal or life

situational experiences that enhance the meaning of the data. The methods used in this study were designed to capitalize on one's own personal and life situations. I am an African American father of school age children and the caregiver of my great-niece. My theoretical sensitivity was sharpened by observations of the target population in weekly support groups over an 18-month period, my personal experiences as an African American father, my life experiences as an African American male who was raised in Washington, DC, and my own childhood family situation in which I was raised with a brother with special needs. My status as a doctoral candidate in family studies, an interdisciplinary field, also enhanced my process for giving meaning to the variables of interest in the high risk population I studied.

Rationale

There are numerous reasons why modified grounded theory methods were appropriate for this study of African American fathers of children with special needs. First, the qualitative design allowed me to explore a topic for which little is known (Padgett, 1998). There is a scarcity of research that explores the experiences of African American fathers of children with special needs. Second, through qualitative study I derived meaning from the actual experience as described from the point of view of those living it—the fathers and male caregivers (Maxwell, 1996; Padgett, 1998). Not only did this qualitative study serve as a vehicle through which fathers and male caregivers who are participants described their experiences, it also permitted me to understand what meaning these fathers give to these experiences (e.g., what experiences were viewed as strengths or challenges).

Third, qualitative research permitted me to explore the context within which participants' experiences take place and how this context influences their behavior (Maxwell, 1996). It is critical in this study of African American fathers/male caregivers that their experiences are properly placed within the sociocultural context within which they occur in order to fully understand them. Murry et al. (2001) noted that the qualitative approach could also be viewed as a culturally sensitive approach; however, few studies examining African American single fathers have used this approach. Only a small number of investigators have adopted the qualitative method with African Americans. Moreover, during my initial contact with the MCASG, I was informed that members "were tired of questionnaires" and asked what made me "different from other researchers" who were interested in Black men. Thus, in this study qualitative methods permitted me to use a culturally sensitive approach, based on initial feedback from gatekeepers, to examine the sociocultural contexts of African American fathers with a child who had special needs. For this study, gatekeepers included hospital/agency administrators and staff, male caregivers support group leaders, and support group members.

Institutional Review Board

Approval to conduct the study was requested and received from the University of Maryland, College Park Institutional Review Board (IRB). Departmental/university IRB was received on August 17, 2006 and is attached as an appendix to this dissertation. Data collection began in late August 2006 during weekly MCASG meetings at the HSC Pediatric Center (a hospital and health care setting for children with special needs) located in Northeast Washington, D.C.

Research Relationship with Participants

Steps Taken to Gain Entry

Maxwell (1996) cautions that in designing a qualitative study, the researcher should negotiate the research relationship on an ongoing basis. Since November 2004, I have been meeting on a bi-weekly basis with agency staff and members of the prospective target population through an agreement with the sponsoring agency, the Outreach Department of the HSC Pediatric Center of Health Services for Children with Special Needs, Inc. (HSCSN), a pediatric hospital in Washington, DC. As the investigator, I attended regularly scheduled, three-hour (i.e., 6:00 to 9:00 p.m.) support group meetings sponsored by the Male Caregivers Advocacy Support Group (MCASG) as an observer, as well as held periodic meetings with agency administrators to brief them on observations and plans for this research. In addition, I provided administrators with progress reports that aided in participant recruitment strategies.

Following the recommendations of Creswell (2003), a brief synopsis of the study was developed and shared with the administrators (i.e., gatekeepers) of the HSCSN and HSC Pediatric Center, the cooperating site in this study. A pilot group session in August 2006 included a discussion that addressed anticipated issues such as how results would be reported and how "gatekeepers" would benefit from the study. Gatekeepers included hospital/agency administrators and staff, male caregivers support group leaders, and support group members.

Ethical Considerations

Several ethical issues were considered while conducting this qualitative research: (1) informed consent, (2) distress and emotional harm, and (3) confidentiality (Ambert,

Adler, Adler, & Detzner, 1995; Padgett, 1998). An informed consent form was developed and approved for the study as part of the IRB application (see Appendix A). The informed consent form was read by participants (or read to them) and signed by the participants and witnessed by a study team member prior to engaging in focus group discussions or individual interviews. This strategy ensured that all consent and participant information forms were collected and protected participants' rights during the course of data collection. Focus groups and individual interviews were conducted in a private room on site at the HSC Pediatric Center for the initial focus group and at the southeast DC location for the other groups. The individual interviews were conducted in a private space in a dedicate office provided by HSCSN at the southeast site, except for one interview which was conducted n the participant's home in a private space. In the agency settings, an experienced social worker was provided by the HSCSN and available on-site to make any necessary referrals, should any difficult emotions have arisen as a result of the focus groups or face-to-face interviews. The in-home interviewee was also provided access to the agency social worker.

Code numbers and pseudonyms were used in managing and reporting data so that only my peer research assistant and I knew respondents' identities. These codes are considered "tags" or "labels" for assigning meaning to descriptive information gathered (Miles & Huberman, 1994). Once the open coding process was completed, I created a Microsoft Excel spreadsheet to identify preliminary axial codes or sub-themes noted during review of data transcripts. No names or other identifiers (other than a code number for each group or interview) appeared on these spreadsheets. A code book was then developed using qualitative software (i.e., the Non-numerical Unstructured Data by

Process of Indexing Searching and Theory-building [NUD*IST/N6] application version 6) in order to document and quality assure the list of codes used in the study.

Consideration was also given to sensitive issues (e.g., parental status, living arrangements, unemployment and spanking) in the African American community. Darling and Gallagher (2004) suggest that presenting an understanding that such issues may be sensitive among African Americans will enable the participants to feel more comfortable with sharing candid information during the focus groups and face-to-face interviews. For example, African American parents' approaches to discipline may be more direct and physical under stressful conditions (Peters, 1997). This is even more likely to be so for socio-economically disadvantaged African American fathers of children with special needs (Hill, 1999). Livingston and McAdoo (2007) suggest that the authoritarian parenting style (i.e., a strong emphasis is placed on discipline and control) may serve as a protective factor for Black children living in-low income areas plagued by crime and violence. As noted later, most fathers lived in southeast Washington DC, an area of the city marked by high rates of violent crime. It was also anticipated that fathers would have children who are bullied and stigmatized at school because of their special need. The procedures for training on and conducting the group discussions and interviews included instructions for handling these sensitive discussion topics.

Sampling Decisions

Type of Sampling Strategy

Three sampling strategies were used in this study: (1) purposive sampling (selecting participants for their ability to provide information about the topic being explored), (2) snowball sampling (generating additional participants for selection through

nominations by other participants), and (3) theoretical sampling (selecting participants based on emerging themes and concepts). For purposive sampling, rather than talking to various individuals about African American fathers, African American fathers of children with special needs themselves were chosen to participate in focus groups and interviews. In this way, I was able to acquire an insider's perspective regarding areas of interests or concern prior to data collection. Fathers were identified with assistance of the HSCSN which provides public assisted health care for Washington, D.C.'s population of children with physical and medical disabilities and other chronic conditions. No data were collected on participants' socioeconomic status or location of their home residences. However, the male caregivers advocacy support group (MCASG) of HSCSN (which was formerly located in northeast DC near Catholic University) relocated to Martin Luther King, Jr. Avenue in southeast Washington, D.C. (political Ward 8) in order to better serve its clients. Washington, D.C. is geographically divided by four quadrants (i.e., Northwest, Northeast, Southwest, and Southeast). Each quadrant has sub-sections or Wards and there are eight Wards throughout the city. Most (97%) fathers in this study resided in southeast Washington, DC, and three were from nearby Prince George's County, Maryland a suburb of the District of Columbia. Residents of Ward 8 are disproportionately Black and low income. According to the U.S. Census Bureau (2000), 60% of residents in DC are Black and 32% of all residents fall below poverty level. In southeast DC, 93% of residents are Black, and 47% fall below poverty level. The demographics of study participants and the special needs of their children are presented later in the section, "Participant Characteristics."

The second strategy, snowball sampling, occurred as the study progressed (Padgett, 1998). For instance, fathers who participated in the focus groups in the initial period of the study led me to others (e.g., friends, members of other support groups) who were eligible to participate in the study as well. For example, three fathers, who resided in Prince George's County, Maryland, were identified through fathers who resided in DC and participated in the initial focus group. Other fathers and male caregivers were identified through other programs at HSCSN and its partner agencies.

The third strategy, "theoretical sampling," involved choosing individuals based on emerging themes or concepts (Strauss & Corbin, 1998). Throughout the process of focus group discussions and face-to-face interviewing, participants brought up factors that they thought were important in raising a child with special needs. For example, one focus group member talked about his experience navigating through the judicial system and ensuring that his child support payments were used to benefit his child's health care needs. I then considered who else should be selected for subsequent interviews to further explore fathering challenges in negotiating community systems. Inclusion and exclusion criteria were added as the study progressed, and documented as part of a journaling process throughout the study. For example, a journal entry dated October 12, 2006, indicated that participant screening techniques needed to be revised in order to better select fathers or caregivers dealing with parenting a child with special needs versus fathers or caregivers who were simply seeking resources such as diapers, milk, or other resources for their child from the HSC Pediatric Center (a sister organization of the HSCSN). Journal entries were also used in preparing the methods section for the dissertation.

African American fathers were recruited from a variety of sources. These included, but are not limited to, the male caregivers support groups organized by HSCSN and their partner agencies, The United Planning Organization of Greater Washington and Parents Anonymous® of Washington, D.C. Padgett (1998) recommends providing an incentive (e.g., a small amount of money) in order to facilitate the recruitment and retention of participants. Following this recommendation, participants received $25 for their participation in the focus groups and interviews. Participants who participated in any form of discussion (e.g., focus group, individual interview or member-checking activities (described below) also received a $25 payment for their participation in these aspects of the study. Incentive payments were made possible through a dissertation grant from the University of Maryland, College Park Graduate School and Department of Family Studies (FMST), and through a grant from the Kaiser Family Foundation to HSCSN.

Sample Size

In qualitative studies, it is not often possible to know before one begins the number of participants needed for an adequate sample size. Some qualitative researchers have suggested that sample sizes might range from a case study of one individual to as many participants as are needed by the researcher for "saturation" (Miles & Huberman, 1994; Padgett, 1998; Strauss & Corbin 1998). Kvale (1996) suggests 10 to 25 cases. A discussion of saturation is presented later in this section.

For this qualitative study, sample sizes in published literature were used as a guide. In two studies of African American single mothers, Brodsky (1999) found theoretical saturation in a sample size of ten. Brotherson et al. (2005) in a qualitative

study of primarily white fathers collected interview data on 16 men who had a child with special needs. In a large national study, Tubbs et al. (2005) collected data on 61 mothers of diverse racial/ethnic backgrounds using more involved qualitative (ethnographic) methods. In the current study, 30 African American fathers or caregivers of children with special needs constituted the sample. All of these fathers participated in focus group discussions (four groups ranging from 4 to 12 men) and 9 of these men also participated in face-to-face interviews after the focus groups. The fathers in the interview sample volunteered to talk one-on-one about their experiences caring for children with special needs and their data were used to enhance and expand on the development of themes. Face-to-face interviews were also used to confirm trustworthiness of data collected from focus groups.

Table 1 presents the demographic characteristics of the sample. These data include means and standard deviations for fathers or male caregivers age, fathers or male caregivers marital status, age of first child with special needs, and age of second child with special needs. Also, the frequencies and percentages for marital status of fathers or male caregivers, residential and non-residential fathers or male caregivers, and male caregiver group participant status are provided.

Demographic information for study participants is included in Table 1. All of the fathers who participated in the study were African American. The average age of participants in the study was age 45 with MCASG members and non-members ranging in age from 21 to 71. Eight men (28.6%) reported that they were single and never married. Thirteen (46.4%) participants reported that they were married, and three (10.7%) indicated that they partnered or living with their partner. One (3.6%) participant reported

that he was separated and two (7.1%) participants indicated that they were divorced. One (3.6%) study group member stated that he was widowed. Fathers who participated in the study self-reported on their child's special needs. A majority of the fathers (46.4%) in the study were married and had a child with special needs whose age ranged between 2 to 25 years.

Table 1

Demographic Characteristics of the Sample

Demographic Characteristics	Fathers/Male Caregivers (*N*=30)	Range
Fathers/ Male Caregivers	*M* (*SD*)	
Age of participant in years	45.28 (12.16)	21-71
Age of first child with special needs	11.96 (6.46)	2-25
Age of second child with special needs	15.50 (.707)	15-16
	n (Percentage)	
Marital Status of Fathers/Male Caregivers		
Single, never married	8 (26.7%)	
Married	13 (43.3%)	
Partnered living with partner	3 (10.0%)	
Separated	1 (3.3%)	
Divorced	2 (6.7%)	
Widowed	1 (3.3%)	
Missing Information	2 (6.7%)	
Residential Status of Fathers/Male Caregivers		
Residential Father/Male Caregivers	16 (53.3%)	
Non-residential Father/Male Caregivers	10 (33.3%)	
Missing Information	4 (13.3%)	
Male Caregiver Group Participant Status		
Member of MCASG	19 (63.3%)	
Non-Member of MCASG	8 (26.7%)	
Missing Information	3 (1%)	

Table 2 illustrates the type and percentage of fathers or male caregivers for the reported child's special needs. One (3.3%) child was reported to have an Emotional Behavioral Disability. Two (6.7%) children were reported to have Attention Deficit Hyperactivity Disorder (ADHD). Two (6.7%) children were reported to have Attention Deficit Disorder (ADD). One (3.3%) child was reported to have Down's Syndrome. Two (6.7%) children were reported to have Sickle Cell Anemia. One (3.3%) child was reported to have HIV/AIDS. Two (6.7%) children were reported to be Developmentally Delayed/Slow. Two (6.7%) children were reported to have Autism. Three (10%) children were reported to have a Learning Disability. One (3.3%) child was reported to have a Speech/Motor/Mental special need. One (3.3%) child was reported to have Cerebral Palsy. One (3.3%) child was reported to have Epilepsy. One (3.3%) was reported to have a Traumatic Brain Injury. One (3.3%) child was reported to have an Orthopedic special need and Psoriasis. One (3.3%) child was reported to have Mental Retardation. Eight (26%) fathers or male caregivers who participated in the study did not specify the type of special need for their child.

Table 2

Reported Type and Percentage of Child's Special Needs

Type and Percentage of Child's Special Needs	*n* (%)
Emotional Behavioral Disability	1 (3.3)
ADHD	2 (6.7)
ADD	2 (6.7)
Down Syndrome	1 (3.3)
Sickle Cell Anemia	2 (6.7)
HIV/AIDS	1 (3.3)
Developmentally Delayed	2 (6.7)
Autism	2 (6.7)
Learning Disabilities	3 (10.0)
Speech/Motor/Mental	1 (3.3)
Cerebral Palsy	1 (3.3)
Epilepsy	1 (3.3)
Traumatic Brain Injury	1 (3.3)
Orthopedic; Psoriasis	1 (3.3)
Mental Retardation	1 (3.3)
Not Reported	8 (26.6)

Regarding "saturation," qualitative studies focus on quality rather than quantity and richness as opposed to representativeness. Therefore, sampling is considered complete at the point of "saturation"—i.e., when no new information seems to emerge during coding (Strauss & Corbin, 1998). Like sample size, the point of saturation cannot be determined ahead of time (Lincoln & Guba, 1985); however, some endpoint is needed for data collection. Once saturation seemed to have been achieved based on a redundancy of initial themes of strengths, challenges, and needs, I decided through peer debriefings to stop or continue by conducting an additional focus group or re-interviewing some participants on an emergent theme (Miles & Huberman, 1994). Data collection stopped when no additional themes were developed. Saturation was achieved after the third group discussion. However, an additional focus group was conducted based on

recruitment concerns that developed after peer debriefing of the transcript for the second discussion. As a result, peer debriefings with research advisors and member checking (see below) indicated that two participants' in one group might represent an extreme instance due to "negative case." because they did not responds to themes concerning strengths, challenges, or needs of fathers or caregivers of who had children special needs but talked about their experiences with incarceration or community violence.

Participant Characteristics

Demographic characteristics of the participants are discussed above in the section on sample selection. As mentioned previously, criteria for inclusion and exclusion were altered as the study progressed and particular factors emerged as important. These criteria were documented throughout the research process. For example, desired study participants were fathers or male caregivers of children with special needs. Fathers, grandfathers, stepfathers, uncles, cousins, and other men who take care of children with disabilities and chronic illness can participate in MCASG sessions. The purpose of the MCASG is to provide fathers and male caregivers support that may alleviate day-to-day challenges that they experience while caring for their child with special needs. MCASG is a multi-cultural forum open for discussion to all father or male caregivers of children with special needs in the District of Columbia. Some fathers of these children may reside in nearby suburban communities. Some men who were not MCASG members were recruited through snowball sampling. The following is a discussion of the inclusion criteria for the target population, which included being African American and a father or male caregiver of a child with special needs.

African American

In accordance with the definition used by the U.S. Census Bureau (2004), African American will refer to those fathers who self identify as African American, Black, or Negro. In addition, men are expected to be English-speaking, even if multi-lingual. Men who self identify as Afro-Caribbean or African who have been living in the United States since the birth of the target child will also be eligible for participation. The 30 African American fathers or caregivers who served as respondents were drawn from participants in the MCASG or similar support groups of HSCSN partner agencies.

Father/caregiver of Child with Special Needs

Participants had at least one child between the ages of two and 21 years old enrolled as a client/patient at the HSC Pediatric Center in the Washington, DC metropolitan area. Some participants were biological fathers of their children; however, other father figures such as uncles, grandfathers, and other male relatives or family friends who are also currently participating in the MCASG in the role of "father" for the target child participated in the study. These "fathers" were retained in the sample because of the importance of extended kin in raising African American children (Billingsley, 1999). Fathers/caregivers of both boys and girls were also included. Caregivers varied with respect to their living arrangements with the child's mother; some were married or living with their partner, while others did not co-reside with the child or his/her mother. During the screening process and the focus group or interview the "father" or "caregiver" was asked about his perception of himself as sharing or bearing the sole responsibility for

parenting or caring for a child with special needs. The process for screening eligible fathers was tested in a pilot study of three "fathers" prior to full recruitment.

Data Collection

This study involved a partnership between University of Maryland, College Park researchers and HSCSN program staff and fathers or male caregivers who participated in the MCASG. The Director of Community Outreach and MCASG program coordinator invited fathers or male caregivers (hereafter referred to as "fathers") to participate in the study through oral presentations at two support group meetings and was followed up by a letter distributed during weekly group meetings at HSCSN and telephone calls to participants. HSCSN and MCASG maintain a sign-in or contact sheet that is updated weekly during meetings. This contact sheet was used to assist with participant recruitment and follow-up. The study convened four focus groups and nine face-to-face interviews and explored strengths, challenges, and needs of African American fathers or caregivers of children with special needs.

Focus Groups

This study involved four focus groups with a total of 30 participants. Group one consisted of nine members; group two consisted of five members; group three consisted of 12 members; and group four consisted of four members. All of the focus groups were composed of African American fathers of children with special needs who regularly attended MCASG meetings or who lived in the Washington, D. C. area. A case summary table of focus group participants' pseudonym, age, child's special need, group or interview assignment and reflective note is provided in Appendix G.A pilot group discussion was convened with three MCASG members to determine trustworthiness of

study questions. It was determined after the group discussion that participants were not comfortable with responding to questions on parenting "strengths" and thought that "rewards" was a better term use in asking questions concerning the positive aspects of how they felt about caring for a child with special needs. The focus group moderator's guide was changed to reflect this input from the men.

A focus group moderator's guide (Appendix B) using standard focus group methodology (Morgan, 2001) was developed to direct the collection of data for this study. The moderator's guide included ground rules for the discussion (e.g., there are no silly answers, everyone's opinion is to be respected; try not to debate each other; do not use your full name; and use only your first name or nickname). A preamble that provided an overview of the study and discussion topics was also created and provided a synopsis for the study.

Focus groups were conducted after securing informed consent protecting the rights of the fathers or male caregivers who participated in the study. Confidentiality and participant privacy were paramount in the information gathering process. All participants were given a detailed explanation of the study procedures and signed the informed consent prior to joining the focus groups. Aside from the initial recruitment and sign-in forms, participants were also instructed to use only their first names during the groups. In addition, they were reminded that information discussed during the focus groups was not to be shared outside of the group. The University of Maryland, College Park Institutional Review Board (IRB), approved all forms and instruments associated with this data collection effort. This approval included permission to audiotape the discussions and interviews with participants' consent.

The focus group moderator convened each focus group at its designated time. At the beginning of each session, the moderator briefly reviewed the focus group process and guidelines. After the focus groups were completed, the audio and handwritten records were used to analyze the content of the discussion. All handwritten notes were analyzed and the audiotapes were used as a reference. A content analysis of the focus group notes was conducted to generate general themes for each of the four focus groups. These themes were synthesized to determine if similarities and differences between or among groups emerged.

Face-to-face interviews

Nine fathers who participated in focus group discussions also completed a semi-structured face-to-face interview conducted by me in order to provide credibility for stories shared during data collection and to determine if saturation occurred where no additional themes were recorded. The interviews were scheduled for 90-minutes; however, four of the nine interviews lasted less than 90 minutes. Some of the participants provided short responses and chose not to elaborate when probes for additional information were asked. Demographic data that included family background items as well as discussion topics for the issues of interest were discussed during the interviews (Russell, 1994). This information was gathered by way of items included at the beginning of the interview guide that was developed by me and peer debriefers. These items targeted information about the respondents such as age of the father, residency status (with child and mother), marital status, age and gender of target child, developmental disability of target child, number of children, sexes of other children, ages

of other children, developmental disability status of other children, and father's employment status and education level.

Nine face-to-face interviews were conducted with MCASG members to verify and expand on themes noted during focus group discussions. A summary of participant demographic information and their discussion by session one through nine is provided below. As previously stated, all men who participated in the interviews were African American fathers or male caregivers of children with special needs.

Face-to-face Interview Participant Demographic; Session 1

Session 1 was held on Sunday, November 19, 2006 from 6 – 7:30 p.m. at the home of Mr. K. Mr. K is 43 years old and was born in Washington, D.C. in 1964 and has lived in Washington all his life. He currently works with parents who have children with special needs. He also aids parents with understanding their child's Individualized Educational Plan (IEP), the special education process, and any resources and information that parents may need in order for them to succeed or to make their life comfortable with their child. He is the biological father of four boys and three girls. The majority of Mr. K's training was paid for by Health Services for Children with Special Needs (HSCSN) Outreach Department. In addition, Mr. K received special training on services provided to children with special needs under the Individuals with Disabilities Education Act (IDEA), training from Parents Anonymous, DC, Children's Trust Fund, Fatherhood Initiatives, and Catholic Charities. He also recently became a certified parent educator. Mr. K is divorced and currently lives with his new partner. He has four boys (ages 9-17) and three girls (ages 2-6); all of the boys and one girl currently live with him. Two of Mr.

K's boys have special needs; specifically, one has been diagnosed with Attention Deficit Hyperactivity Disorder (ADHD)/Attention Deficit Disorder (ADD), and the other with ADHD/ADD and emotional disturbance.

Face-to-face Interview Participant Demographic; Session 2

Session 2 was held on Friday, December 1, 2006 from 11 a.m. – 12:30 p.m. at HSCSN's Martin Luther King, Jr. site. The interview was conducted with Mr. V who is 50 years old and was born in Greenville, North Carolina, and is one of 13 children raised by his mother. Mr. V's family moved to Washington, D.C. when he was in his pre-teens. Mr. V received his Bachelor of Science (BS) degree from the University of the District of Columbia (UDC). He is worked at Safeway (a supermarket chain) for 20 years, but took a hiatus from work, and went into training for computer repair in nearby Tysons Corner, VA. Mr. V is the biological father of an 18-year-old son who has a traumatic brain injury suffered as the result of a severe motor vehicle injury and now has developmental disabilities.

Face-to-face Interview Participant Demographic; Session 3

Session 3 was held on Wednesday, December 6, 2006 from 6 – 6:45 p.m. at HSCSN's Martin Luther King, Jr. site. Mr. O is 45 years and has lived in Washington, D.C. his entire life. He works full-time for the DC Housing Authority and has an 11th grade education from the D.C. Public School System. Mr. O is married, but does not live with his child with special needs or the child's mother. However, he does have weekend

visitation rights. Mr. O has a three-year-old daughter and an 11-year-old son with emotional disturbance and anger management concerns, who also has trouble in school.

Face-to-face Interview Participant Demographic; Session 4

Session 4 was held on Wednesday, December 6, 2006 from 6:50– 8:15 p.m. at HSCSN's Martin Luther King, Jr. site. Mr. AA is a 63-year-old, life long resident of Washington, D.C. who was raised in the Northeast DC area. He attended DC Public Schools through high school, but did not finish; he dropped out and joined the United States Army. Mr. AA served six years in the Army and then joined the Air Force for two years and eight months. Mr. AA currently works in at the Mayflower Hotel in DC as a house cleaner. He is the biological father of three daughters (ages 10 -17) and four boys (ages 7 to 17). Mr. AA has a nine-year-old autistic son who is a member of HSCSN.

Face-to-face Interview Participant Demographic; Session 5

Session 5 was held on Wednesday, December 6, 2006 from 8:20 – 9:30 p.m. at HSCSN's Martin Luther King, Jr. site. Mr. X is a 53 year old and was born in North Carolina. Mr. X graduated from high school and college and is a certified public manager and paralegal specialist by trade. He is also a certified substance abuse counselor. Mr. X is married and has three children. He is the biological father of a 21-year-old daughter, 14-year-old foster son with ADHD, and uncle of a 17-year-old autistic nephew.

Face-to-face Interview Participant Demographic; Session 6

Session 6 was held on Wednesday, December 13, 2006 from 6:00 – 7:30 p.m. at HSCSN's Martin Luther King, Jr. site. Mr. GG did not state his age during the time of his interview but indicated that he is a married man of 26 years. He relocated from New Jersey to the Washington, D.C. in 1965. Mr. GG is currently unemployed. He and his wife have eight children, two sons (ages 12 and 18) and six daughters (ages 8 to 22). Mr. GG's 12-year-old son is a child with special needs who receives services from HSCSN.

Face-to-face Interview Participant Demographic; Session 7

Session 7 was held on Wednesday, December 13, 2006 from 7:30 – 8:30 p.m. at HSCSN's Martin Luther King, Jr. site. Mr. R is 47 years old and is a life long resident of Washington, D.C. He attended public schools in Washington, D.C. until the 7th grade. Mr. R previously stocked soda machines until 1983, when he started doing something different (in his own words, "working with my hands") and painting until 2004. He has been married for six years and has 13 children ages 19 -27. He has a 27-year-old daughter who is mentally retarded.

Face-to-face Interview Participant Demographic; Session 8

Session 8 was held on Wednesday, December 13, 2006 from 8:30 – 9:30 p.m. at HSCSN's Martin Luther King, Jr. site. Mr. N is 45 years old and a life long resident of Washington, D.C. He attended public schools in Washington, D.C. until the 10th grade. Mr. N. is currently unemployed due to a disability. He is married and has a son (age 16)

and a daughter (age 15), both of whom have been diagnosed with autism. His son and daughter are clients at HSCSN.

Face-to-face Interview Participant Demographic; Session 9

Session 9 was held on Wednesday, December 13, 2006 from 8:30 – 9:30 p.m. at HSCSN's Martin Luther King, Jr. site. Mr. I is 41 years old and was born in Athens, Georgia; he moved to Washington, D.C. when he was 12 years old. Mr. I completed the 11th grade and works full-time for a messenger service. He is married and has three children ages four months, 15 years and 25 years. Mr. I's 15-year-old son is a client at HSCSN and was diagnosed as ADD, ADHD, having a Learning Disability (LD), and as Emotionally Disturbed (ED).

A protocol was also developed and guided questions asked during interviews (see Appendix C). The questions/discussion topics posed in the interviews explored the three primary issues under investigation in the study: fathering strengths (rewards), challenges, and needs of male caregivers of a child with special needs. Discussion topics focused on the fathers' perceptions about the positive (rewards and strengths) and negative (challenges and needs) aspects of their experiences in caring for a child with special needs. The HSC Pediatric Center is a hospital setting and hospital staff provided a space with privacy to conduct interviews during a wide range of hours (day and evening; weekdays and weekends) to accommodate fathers' schedules.

An African American male colleague and I conducted all discussion groups and interviews. The dissertation chair trained us initially during the pilot study; during the pilot, HSCSN administrative staff observed three (3) interviews, which were held in one

of the hospital rooms. The dissertation chair and hospital staff provided feedback regarding verbal and nonverbal behavior, particularly to guard against leading questions, researcher bias, and reactivity (see below). Suggestions were also made by these peer debriefers during the pilot test to improve the interview protocol and field note template.

Following training, one focus group was conducted, followed by a round of member checking (discussed below) using a small group discussion with 5 persons—comprised of some group members who did not participate, but who have children with special needs or are male volunteers of HSCSN.

Data Recording

I manually recorded the focus groups and interviews, with audiotaping of participants provided by permission during the informed consent process for the interviewer to audiotape the session. All transcripts were labeled with the group or interview number sequence as it occurred (e.g., FG1, FG2…FG4; I1, I2….I9).

Transcription of Focus Groups and Interviews

Following the recommendation of Padgett (1998), transcription of focus group data and interviews began early. For quality assurance, Strauss and Corbin (1998) suggest listening to the audiotaped interview while reading the transcription within one week of conducting the interview. However, a two-week turnaround period for quality assurance occurred in this study, as a transcription service was used to ensure that member checking occurred in a timely manner. Basic rules for transcription were established and monitored throughout the study. For example, instructions on how to handle non-verbal behaviors and vocal utterances were provided to the transcription service. In addition, HSCSN staff was asked to monitor room dynamics in the event participants experienced any

discomfort with any questions asked during the group discussions. Interview sessions did not present any major emotional challenges as most men felt more comfortable during face-to-face, individual discussion than in focus group discussions.

Quality assurance of the transcripts included peer debriefers and me reviewing the transcripts while listening to the audiotape. The dissertation advisor randomly selected two focus group tapes and two interview tapes (one after each member checking session) for additional quality assurance using the same procedures--reviewing the transcript while listening to the audiotape. My dissertation advisor and I noted revisions based on field notes. Revisions were made by colleagues/research assistants and transcripts were saved to Word text files prior to entry into NUD*IST/N6, the computer-based analysis program.

Field Notes

Taking field notes is an important task for the qualitative researcher (Padgett, 1998). Creswell (2003) recommends using a protocol that includes "descriptive notes" and "reflective notes." Descriptive notes included information such as the time, date, and location of the interview, and memorable quotes. In this study, the date of the event, number of participants, quality of data, place/location, name of moderator and recorder, and start/end time of the session were also captured on each transcript.

Reflective notes included my initial impressions of the participants' perceptions, quality of the data, or other topics of interest. For example, my field notes from November 15, 2006 during a MCASG meeting included the following:

> Men in the group began a discussion on proposed legislation for establishing a "Disability Rights Protection Act of 2006." Then, newly elected Council Member Harry Thomas, Jr. stopped by the meeting unannounced. All of the men were so interested in more about the proposed legislation and how it would impact them and their child. And I thought how much energy group members provided to the discussion. Council Member Thomas offered to give one of the men's son a job just as soon as his administration was organized.

The field note template used in this study appears in Appendix D.

Data Management

To facilitate data management the following strategies were implemented in this study: (1) the date, time, and place were recorded on all focus group notes, field notes, interview notes, transcripts, and memos, and (2) a separate folder was kept on each group and individual discussion. All audiotapes were marked with the group's or participant's unique numeric identifier (e.g., FG1, FG2, FG3, etc.), and labeled as tape "1 of 1" or "1 of 2," and so on. A separate file was maintained by me with the date and time of interview, code numbers, and number of tapes per group/respondent in a locked file cabinet. Text files of the transcripts served as the data for this study. These files were stored in electronic (NUD*IST) files for use in coding and analysis and backed up on CD-ROM. All files were password protected. Audiotapes will be maintained in a locked file cabinet until I destroy them. I will destroy audiotapes upon completion of the study (i.e., after filing of approved dissertation with the graduate school) under supervision of my dissertation advisor.

Data Coding and Analysis

Coding in qualitative research involves organizing data into categories so that comparisons can be made of data within and between these categories. Such categorization assists in the development of theoretical concepts related to the phenomenon under study (Maxwell, 1996). Strauss and Corbin's (1998) systematic steps for coding in the grounded theory method were followed: open coding, axial coding, and selective coding. Open coding is the process through which initial concepts were noted and categorized (Creswell, 2003; Miles & Huberman, 1994; Strauss & Corbin, 1998). For example, text units were marked (tagged) with descriptive coding using NUD*IST tools to indicate that they reflected information relevant to family (e.g., marital status) or individual (employment status) characteristics or to constructs of interest—fathers' strengths, challenges, and needs. Open coding for focus group and interview data were tagged on 350 pages of transcripts. For example, descriptive notes from preliminary open coding on strengths/rewards identified making my child happy, praise for my child's drawings, playing an active role in my child's life, and being part of the support group as sub-themes. Once these codes were tagged they were transferred to a Microsoft Excel spreadsheet for additional analysis and axial coding. Several reviews of transcript data and notes were conducted during open coding in order to theoretically saturate concepts and themes in the study.

Axial coding deepens the theoretical framework underlying the analysis through building new connections within categories. Axial coding involved relating the categories identified in open coding to their subcategories. For example, I tagged text units to indicate subcategories of rewards (parenting, marital) and challenges (financial,

role strain), or to identify variations in types of need (e.g., instrumental versus emotional). I used the ecological/risk-resiliency framework to explore connections between categories and discover patterns in the data. For example, subcategories of rewards were also described at various levels within an ecological framework at the individual level (e.g., child making progress), family level (e.g., spending time together through family routines), and at the community level (e.g., participating in MCASG).

Textual memos were also created for each preliminary theme coded in my study. These textual memos permitted me to think intuitively about how to assign names and meaning to my data. Daly (2007) suggests that writing memos is a good way to think through data analyses. For example, I would write memos to the HSCSN's Outreach Director discussing preliminary findings during my open and axial coding. I also used my memos as part of my member checking process to confirm the validity or trustworthiness of my findings.

Selective coding is "the process of integrating and refining the theory" (Strauss & Corbin, 1998). The goal is to weave a story from the interconnections of the categories (Creswell, 2003). For example, using the modified grounded theory approach of this study, I began to analyze text units using concepts such as risk and protective factors operating at various ecological levels (individual, family, and community). During this coding stage, I attempted to explore an emerging theme from an ecological/risk-resiliency perspective about the individual, family, and community level factors related to African American fathers parenting of children with special needs. In addition, I reviewed the existing themes and began to develop additional emergent themes from a culturally specific perspective. The ecological/risk-resiliency framework was used as a starting

point. For example, fathers' needs for pre-employment training (computer literacy) or employment-seeking assistance were coded at the individual level, but linked to the culturally specific data documenting Black men's low computer literacy and high unemployment rates. Once all of the "dots" were connected during the coding process, analysis of the data and peer debriefings led to the discovery of new core variables or processes related to patterns of fathering children with special needs in African American families. These analyses also led to identifying additional strengths of Black families related to raising a child with special needs. For example, in discussions with my peer debriefers themes were identified which cut across all of the ecological levels. For example, although social support was originally coded at the community level, during the selective coding and debriefing processes it was noted that father's expressed needs for social support at all levels: e.g., for themselves (which was then tagged as an individual level code), for improving their parenting (later coded at the family level), and for increasing resources for their male caregivers support group (coded at the community level).

Threats to Validity or Trustworthiness

Three types of bias are common in qualitative studies: (1) respondent, (2) reactivity, and (3) researcher (Lincoln & Guba, 1985; Padgett, 1998).

Respondent Bias

Respondent bias typically occurs when participants want to be seen in a particular way (e.g., socially desirable, extremely negative or positive, or contrary to their real life situation). For example, an African American father may respond in a way that shows he is doing very well with raising his son when in fact he is having great difficulty.

Participants in this study were asked about both ideal and actual experiences in raising a child with special needs. I tried to be aware of body language and other nonverbal behavior so as not to convey that a participant's response was viewed as socially desirable or undesirable. Introductions/transitions to discussion items also suggested that I was interested in the respondent's personal experiences as well as perceptions about parents in general in situations like theirs (e.g., "Some fathers have indicated that they have problems parenting a child with special needs when it comes to disciplining an autistic child. "How do you spank a child with autism?").

Reactivity

Reactivity refers to how the researcher's presence is changing things. Maxwell (1996) pointed out that this threat is more serious with regard to face-to-face interviews than it is for observations or group discussions. Although it is not a meaningful goal for qualitative research (per Maxwell), it is important to consider the degree to which my presence had an effect. I used the following strategies to reduce threats in this study: (1) prolonged engagement, (2) triangulation, (3) member checking, and (4) avoiding the use of leading questions. The first three of these strategies are discussed in detail below among strategies to reduce threats to validity. Leading questions were addressed during my interviewing technique training with my research advisor.

Researcher Bias

Ambert et al. (1995) suggest "researcher bias occurs when the researcher is unable to see the truth in the data, owing to preconceived notions" (p. 886). This might be the result of the researcher's experiences, disciplinary training, or research perspective (e.g., focus on deficits vs. strengths). For instance, during my observations of the

MCASG support groups, some MCASG members expressed their dislike of surveys in general and they particularly frowned upon reports of negative findings about African American men. Research in this study focused specifically on experiences with fathering or caring for children with special needs and the discussion probed for both rewards and problems (e.g., problems caregivers may experience with social services and support mechanisms they receive from such services that strengthen family ties).

Strategies to Increase Validity

Utilizing several strategies can increase validity or "trustworthiness" in a qualitative study. These include: (1) prolonged engagement, (2) persistent observation, (3) triangulation, (4) peer debriefing, (5) member checking, (6) negative case analysis, (7) journaling, and (8) an audit trail (Lincoln & Guba, 1985). A brief discussion follows describing how these strategies were implemented in my study.

Prolonged Engagement

Prolonged engagement has to do with how long the researcher was involved in a situation and whether it was long enough. This strategy typically applies to qualitative approaches such as ethnographic studies or repeated interviewing, but has utility for the one-time interviews in this study as well. There is no specific time period; however, as mentioned previously the goal is that I reached the point of saturation (i.e., no longer observing or hearing anything new). I had already been in the target site for more than a year and a half observing participant activities that are not part of the qualitative approach. Data collection began in late August 2006 and continued through December 2006. Sample recruitment began upon IRB approval in August 2006. As noted earlier,

four focus groups and 9 father interviews were conducted to validate and gather more in-depth data on themes based on a preliminary review of verbatim transcripts for this study.

Persistent Observation

Persistent observation (Creswell, 2003) involves constant questioning. Persistent observation can be facilitated through the use of a journal. I maintained a journal on the observations noted during the study and decisions made during qualitative data coding. For example, a journal entry dated July 7, 2006 read:

> Discussions during this session focused on understanding health disparities for children with special needs or developmental disabilities. "We need to have more presenters discuss diversity and disparity issues with male caregivers who have children with special needs."

Triangulation

Triangulation allows for the addition of different perspectives and comparison of emergent themes across these diverse perspectives. There are several types of triangulation—e.g., theory, methodological, observer, data, and interdisciplinary (Padgett, 1998). Data triangulation was used in this study (i.e., the use of more than one data source to make comparisons). MCASG information packages (e.g., group agendas, flyers from referral organizations) were used as secondary data to explore additional needs for study members. In addition to transcripts, notes from peer debriefings and member checking with MCASG confirmed themes and were used to explore interconnections between categories.

Peer Debriefing

To enhance the study's rigor, I identified "peer debriefers" to review and ask questions about the study to test whether my synthesis or observations made sense to other people. The peers in this sense are dissertation committee members. Following the recommendations of Padgett (1998), peer debriefing occurred throughout a four-month period with dissertation committee members who fulfilled this role.

Member Checking

Member checking ensures that the researcher is on track by subjecting data to review by participants or other members of the target population (Padgett, 1998). Erlander (1993) recommends that member checking occurs on a continuous basis, but because of the short duration of this study, I only conducted two rounds of member checking. The strategies in this study included: (1) reviewing summaries of focus group and interview data and discussing preliminary findings with MCASG after the first three focus groups (2) repeating this process after the second interview with a second group of MCASG members during a weekly meeting; and (3) at both times sharing preliminary findings with other group members who did not participate in the study and persons who work with African American fathers (e.g., agency staff).

Negative Case Analysis

Negative case analysis involves identifying cases that are outliers—i.e., they do not fit the emerging theories or interconnections. It is expected that such cases might be identified by my observation or during peer debriefing and member checking (as

described above). Two journal entries identified negative cases that did not fit or were not connected to my study. For example, one entry dated August 16, 2006 notes:

> One male participant in today's focus group was not a father or male caregiver of a child with special needs. He is, however, a young man (age 21) who recently transitioned from adolescence to young adulthood. He is also a member of the MCASG who shares his experiences as a child with special needs and increases the cultural awareness of the group by helping participants understand what their child might be going through.

Another journal entry dated October 11, 2006 noted:

> Two male focus group participants were also recruited by a HSCSN member agency. However, these respondents did not know if their child had special needs as they were nonresidential fathers. Responses for these cases were further examined to determine if they were applicable to the study.

Journaling

Several qualitative researchers recommend the use of a journal throughout the qualitative research study (Roy, April 8, 2005; personal communication). Journals include but are not limited to the following: documentation of planned versus actual events, circumstances that occur and influence the study's progress, feelings and thoughts, ideas about patterns in the data which emerge during the study, and selection criteria of participants throughout the study. I kept a journal and maintained written notes on sheets of paper or on the back of MCASG agendas for the duration of this study. In addition, NUD*IST tools for journaling were used to document ideas and justifications for codes and quality assure data while coding electronically.

Audit Trail

Padgett (1998) explains that an audit trail provides a way to track concepts and decision-making to their basis in the data. The audit trail in the study included such components as: raw data (e.g., field notes, small group discussion notes, transcripts from focus groups and face-to-face interviews, MCASG weekly agendas), the journal, notes from the member checking and peer debriefing sessions, the codebook with journal entries in NUD*IST, and details of analysis strategies and their rationale.

Limitations

There are several aspects of this project that will limit the generalizability of the findings and the utility of the data in interventions for implementation with populations of African American fathers or other male caregivers of children with special needs. Notwithstanding their multiple family roles, participants were expected to participate in the study in addition to the regular schedule of activities for their MCASG, which resulted in competing demands on fathers' time. Two fathers or caregivers who participated in the study had children who were patients of HSCSN, but fell outside of the targeted age range of 2 to 18 during data collection. These fathers or caregivers' responses were also included in the study given that their children were within range at the onset of the study. In addition, some fathers felt left out because they were unable to participate in the study, because their children fell outside of the 2 to 18 year-old age range for a target child. However, some members participated in the member checking and/or triangulation processes of the study; and they will also receive reports on the findings of the study along with participating members.

Qualitative approaches used in this study have not been used extensively in the literature with fathers and have limited use with African American families. A pilot test of three fathers, journaling, and an audit trail were used to determine the effectiveness of focus groups and face-to-face interviews.

Attrition was likely to be a problem between enrollment and the actual focus groups or interviews. However, fathers had very good attendance at the weekly MCASG meetings (averaging 10-15 members per session) where they signed up for the study. Agency members and support staff conducted recruitment of male participants. The primary goal of MCASG is to provide a forum for men to openly talk about challenges they experience while caring for a child with special needs; so it was an appropriate forum for identifying men who met the selection and inclusion criteria. During the referral process, some participants were unsure if they had a child with special needs but wanted to participate in MCASG or benefit from the services (e.g., child care and transportation) that are provided for group members. Better recruitment strategies could have been used in order to ensure that only fathers, male caregivers, uncles, grandfather, or other male relatives participate in future studies. Focus group and interview times were based on fathers' arrival to group meetings. Some fathers had competing priorities beyond the MCASG, since they are in families that are likely to have additional problems with family functioning, personal and family finances, child development, health care issues, and other demands. The MCASG staff placed reminder calls to fathers the day before their scheduled focus group or interview. HSCSN provided on-site child care for children who needed to attend with their fathers and as mentioned earlier fathers received a $25 monetary incentive provided by HSCSN. HSCSN also provided assistance with

transportation to the extent available, and the timing of the focus groups and interviews were flexible to accommodate job schedules and fathers' other commitments. Nonetheless, some fathers who committed to attend focus groups or interviews did not participate. This group of fathers might have had challenges and needs beyond those expressed by fathers who were able to get to the group or individual discussions.

The MCASG has a small population (n=50) from which to draw the needed sample, so the eventual sample size was small. MCASG program staff worked with me to identify male caregivers in other support groups at agencies that have clients who are also HSC patients. HSC is the Medicaid service provider for Temporary Assistance for Needy Families (TANF) families in DC, but there were moderate problems in identifying a large pool of prospective participants. This pool was restricted in racial/ethnic diversity (largely African American followed by Latinos) and income range (poor families). Future research is needed that includes a larger sample in this community with wider racial-ethnic and socioeconomic diversity to further investigate the interrelationships among the risk and protective factors. For example, fathering issues could be examined among Latino families and working class, middle class, and upper class families.

Only qualitative measures were used in this study. Although many of the issues that fathers discussed lend themselves to standard measurement (e.g., physical or mental health needs), most of these measures have been developed on mothers. Also, fathers were not asked to report on child behaviors that are often linked to parenting in the present study. Even though parents could report on their children's behaviors, the range of special needs among the children in the target population is not known, and some of their developmental needs might be difficult to untangle from behaviors that are often

assessed in the field. For example, it would be difficult to know if a father's report of his child's behavior problems is the result of poor parenting, the nature of the child's special needs, or parents' inaccurate perceptions of the child's behavior. Fathers also shared that their children are often misdiagnosed by public school health educators and are therefore placed in school settings that are not developmentally appropriate for their child.

Additional research on the role of African American male caregivers is needed to examine other potential protective and risk factors for families who often operate within stressful environments. While fathers were asked to provide feedback during member checking experiences, future research might include focus groups or individual interviews about barriers and facilitators to their participation, other topics they would like to see included, suggestions for intervention design and implementation, and contextual factors that might influence their parenting of a child with special needs.

Personal Biography

I am an African American father of school age children. My status as a doctoral candidate in family studies, an interdisciplinary field, enabled me to understand and give meaning to the variables of interest in a high risk population as well as the potential for additional culturally sensitive studies that may generate theory-driven approaches to research, programming, and policy development. My theoretical sensitivity has been and will continue to be sharpened by observations of the target populations in weekly MCASG meetings, and my personal experiences as an African American father, my life experiences as an African American male who was raised in Washington, DC, and my own childhood family situation in which I was raised with a brother with special needs. Finally, my research aspirations include expanding qualitative research and informing

interventions that enhance resiliency among African American men who may face potential economic, mental health, or family functioning concerns.

CHAPTER 4: RESULTS

This chapter presents the results of my findings from data collected with African American fathers and other male caregivers of children with special needs. Four focus groups and nine face-to-face interviews were held from August 2006 to December 2006 with 30 fathers or male caregivers. The nine interviews were conducted to validate themes that were emerging from the focus groups. My study focused on exploring the strengths, challenges, and needs of African American fathers/caregivers who have a child with special needs. However, as noted above in Chapter 3, I determined after the pilot group discussion that participants were not comfortable with responding to questions on parenting "strengths" and thought that it was better to ask about the "rewards" of parenting a child with special needs. Therefore, my presentation of the findings from my focus groups and interviews are framed and organized around three sensitizing concepts related to caregiving themes for fathers and male caregivers of children with special needs: rewards, challenges, and needs. Fathering a child with special needs was the central phenomenon for this exploratory study. Father or male caregivers' expressed rewards, challenges, and needs in response to the study questions. After open coding and axial coding, these expressions were subjected to further analyses and four overarching concepts emerged from the data--i.e., personal development, generative fathering, social support, and advocacy. These concepts were used to organize the findings. Figure 2 provides an overview of my findings organized by the initial and emergent concepts.

Core Concept:
Fathering
Context:
African American Family with a Child with Special Needs in Urban Environment

	Personal Development	Generative Fathering	Social support	Advocacy
Rewards	■"Being there"/Pride in being an active father ■Pride related to child's achievements ■Social fathering ■Spiritual awareness	■Being a responsible father/ "giving back" ■Teaching/socializing child with special needs ■Establishing family routines	■Being a member of a male caregivers peer support group ■Receiving support from community agencies	■Successful procurement of educational, health, and financial resources for my child
Challenges	■Emotional adjustment to diagnosis of child's special need(s) ■Continuing mental health problems ■Role strain	■ Relationship difficulties with mother and kin ■Problems in parenting siblings ■Adjusting developmental expectations for child with special needs	■Family stigma resulting in reduced support ■Dismissive attitudes of health providers/"invisibility" ■Lack of community service coordination	■Pessimism about ability to influence health care and educational system ■Inadequate access to high quality educational and recreational equipment
Needs	■Individual mental health assistance ■Job assistance ■Housing assistance	■Parenting and caregiving education ■Strategies for parenting siblings of child with special needs ■Assistance in understanding and addressing child's health/medical needs	■Strategies for educating family members and friends about child's special needs and abilities ■Greater support from family, friends, and churches	■ Financial resources for health care expenses ■ Educational resources for individual instruction of child ■Training in understanding and getting services defined by IEP's ■Social marketing and resources for father support groups ■Inter-agency collaborations ■Programs sensitive to the culture of the disabilities community

Figure 2. Organizational framework of fathers' expressions of rewards, challenges, and needs: Personal development, generative fathering, social support, and advocacy

Strauss and Corbin (1998) and Lincoln and Guba (1985) suggest that using multiple data gathering processes increases the credibility of the findings. Verbatim transcripts from the four focus groups (with the exception of two negative cases) and from all nine interviews provided credible data. These data include the stories fathers shared during data collection and their validity (trustworthiness) was established and confirmed through prolonged engagement, member checks, and peer debriefings.

In this chapter, I present the data analyses for each major research question using the organizing framework in Figure 2 above—i.e., within the section for each research question (on rewards, challenges, needs), I present the findings for the cross-cutting concepts (personal development, generative fathering, social support, and advocacy). Appendix H summarizes for each sensitizing concept (Rewards, Challenges, and Needs) the working definitions for the initial themes and presents examples for the cross-cutting concepts that emerged from the coding. Below are the working definitions for the cross-cutting concepts.

First, I tagged text units with tags for both the ecological levels (individual, family, community) and later through constant comparison I tagged them with the emergent concepts (personal development, generative fathering, social support, and advocacy). Next, I provide working definitions to illustrate how the ecological levels were merged with the cross-cutting concepts to identify themes for cells in Figure 2. *Personal development* reflected themes at the individual level and included those that were father-focused and involved the father reflecting on his own developmental accomplishments or shortfalls, reflecting on his positive or negative feelings when he observed his child's accomplishments or shortfalls, or on his pride or disappointment in

being able to serve in the role of father. *Generative fathering* reflected parent-child/family level themes and involved those in which fathers were (reward) or could not be (challenge) involved in shared activities with their child with special needs or other children and immediate family members (e.g., spouse/partner), connecting moments in which the father and the target child or his other children and immediate family, expressed responsibility for his child/children's well-being, pride or challenges in being able to give back or pass on skills and values, and positive or negative feelings about his relationships with the child's siblings and interactions with the child's mother.

Social support and *advocacy* were the two crosscutting concepts used to organize text units that reflected community level themes. *Social support* reflected rewards, challenges, and needs related to establishing or maintaining relationships at the community level (i.e., receiving or providing informal support from kin and peers outside of the immediate family and receiving formal support from agencies and institutions). Finally, for *advocacy*, I was guided by Palfrey's (2006) definition of advocacy which suggests that advocacy is an act of "speaking out" or "speaking for" effective interventions and quality health care for parents and children who share the same risks, concerns, and life circumstances. Thus, for *advocacy*, themes were tagged that reflected rewards, challenges, and needs related to father's involvement in efforts to engage agencies to provide better services, efforts to change laws or policies, and expressions of ways fathers were involved in improving services for the broader community (i.e., of fathers, families as well as children with special needs).

Data Analyses

Focus group discussion topics explored fathers' perceptions about the positive (rewards) and negative (challenges and needs) aspects of their experiences in caring for a child with special needs. Participants were asked to describe what it is like being the father/caregiver of a child with special needs, the rewards (such as what makes them feel proud about parenting a child with special needs), challenges to their parenting role, and needs (their own as well as those of their children, and the broader community of fathers of children with special needs). Using modified grounded theory methods (e.g., Soulliere, Britt, & Maines, 2001) allowed me to view fathers' responses from an ecological point of view where a father/caregiver's involvement with his child might be influenced by environmental factors across multiple levels including the individual (father), family (child, parent-child), and community (school, church, health agency, and policy) levels. The following sections report the results of data analyses for each major research question and data are organized within each major section using the crosscutting concepts as subheadings.

Fathering Rewards

Research Question 1: What are the strengths experienced in parenting a child with special needs?

Overall participants expressed a number of rewards associated with caring for a child with special needs. These rewarding experiences were also described at various levels within an ecological framework—i.e., at the individual level (e.g., seeing child make progress), family level (e.g., spending time together), and at the community level

(e.g., participating in MCASG). In this section, I present the findings in summary and in fathers' own voices using quotes (text units) from the verbatim transcripts which were tagged in NUD*IST. The organizing framework was utilized to summarize these findings.

Personal Development

Fathers' rewards included expressions of pride in being an active father ("being there"), seeing their child's achievements, their role as social father, and their spiritual awareness. Father's pride in "being there" was related to times when they were happy to just be physically present and have an opportunity to share in family routines. Family routines are defined as observable, repetitive behaviors that involve two or more family members and occur with predictable regularity in the life of the family (Jensen, James, Boyce, & Hartnett, 1983). In addition, these patterned, family practices are thought to organize daily family life and define members' roles and responsibilities (Wolin, Bennett, & Jacobs, 1988), as well as provide a sense of structure and stability over time (Imber-Black & Roberts, 1992; Wolin & Bennett, 1984).

These routines, while incorporating the notion of family time, are distinguished by their predictable and regular pattern. Examples of such family routines include fathers' expression of being rewarded by simple situations such as one father who expressed that it was rewarding just to "wake up with my family." Other family routines and "being there" moments included: attending weekly peer group meetings where provisions are made for them to be accompanied by their child with special needs, having evening meals together with their child, and attending church services.

Several fathers talked about the personal reward in seeing their sons develop or do certain things/tasks while spending family time with their child. Family time is defined as specific, uninterrupted time spent with children, spouses, or friends where activities are planned to increase the quality of parental involvement. Family time includes time spent connecting with children through shared activities for fun, teaching, or fulfilling family functions such as grocery shopping or attending worship services (Brotherson et al., 2005).

Examples of text units that were tagged with this coded included fathers' references to "spending time" with their child with special needs or other children, "teaching the child" a developmental activity, and "going to (events or outings) as a family." Family time is defined as specific, uninterrupted time spent with children, spouses, or friends where activities are planned to increase the quality of parental involvement. Family time includes time spent connecting with children through shared activities for fun, teaching, or fulfilling family functions such as grocery shopping or attending worship services (Brotherson et al., 2005).

Examples of text units that were tagged with this coded included fathers' references to "spending time" with their child with special needs or other children, "teaching the child" a developmental activity, and "going to (events or outings) as a family." Spending time together provides a context in which fathers could observe children's small achievements they also indicated gave them pride. Mr. W, a 50 year-old father of a child with developmental disabilities, talked about how rewarding it was for him to watch his son do certain things:"

> "I'm tickled every day when I see him do certain things or say certain t things. It's just another part of his growing."

Mr. W also indicated that when it comes to spending time with his son, he:

> "Loves every day that I wake up and I see Tony doing different things. I mean, he is respectful and everything. He has got his little ways, but to me, that's a normal child. Because watching him do things that normal kids do, but as long as it took him to do it – I am proud to see that. I mean, even if it's just climbing a ladder and I love to watch him on the ladder. You definitely have got to watch him – because I will tell you, he might go up the ladder and then fall back off of it. But it was because he wasn't taught – I didn't teach him to ride a bike or catch the ball. I had neighbors, friends and his brothers, they taught him. I missed out on all of that because of my disability. But anyway, those are proud moments and when you see that, it's like a scrapbook."

Two fathers talked about the pride that came from observing a school bus experience. Mr. C, a 23 year-old father of a child with developmental disabilities, expressed joy in seeing a smile on his daughter's face as she gets off of the school bus:

"…she has a big smile on her face every time she gets off the school bus." Mr. I, a 41-year-old father of a child with ADD, shared how he also enjoys seeing a smile on his daughter's face as she gets off the bus to go into school:

> "she has a big smile on her face every time she gets off the school bus. I know that she is going to go and enjoy herself."

Some fathers also found joy in observing others during a special time with the child. One of the men, who served in the role of caregiver, shared his personal reward in observing others in a special moment with their child with special needs. Mr. Y, a 53 year-old caregiver and family friend of a child with autism, talked about how rewarding it was to see the joy that his friends expressed when their child embraced them:

> "…I had been working with a family who, the child had autism and they were really, really hurt because the child wasn't cuddling. It wasn't responding to their wanting to hug the child and the child to be warm or whatever with them. We kept applying sort of techniques and kept applying those techniques and kept

> helping the family to say even though the child isn't responding, I'm going to keep doing it, going to keep doing it, going to keep doing it. I remember feeling real, real good because of the feeling that the father and the mother had when that child actually embraced them, like in a group. It was kind of in a group hug and they had been trying to years, just trying to get the child to accept hugs on a regular basis. The child wouldn't accept them, he just wouldn't do it. And then all of a sudden, they kept trying, they kept trying and it's part of that patience that we talked about earlier, routine, that kind of thing. And when the child actually did a group hug with them, man, you should have seen the glow on the parents' faces….

Social fathering.

One of the men, an uncle caregiver, talked about being a social father and how he was not in an excuse mode when it comes to parenting a child with special needs. Mr. AA, a 55 year-old uncle of a child with a severe skin disorder, talked about community level challenges that he has faced and his efforts to stay proactive in his role. He stated that:

> "I'm not in the excuse mode; I'm in the proactive mode of saying how do I help? How can play a role a greater role in my niece's life? But I'm a proactive role player."

These statements were also tagged for their reflection of Mr. AA's role as an advocate his niece.

Spiritual.

Spiritual aspects of parenting a child with special needs was not coded as an initial theme for rewards, but emerged during selective coding. One father shared that his parenting reward was in knowing that God saved his daughter's life. Mr. D, age 25 years old, thought that God was responsible for saving his daughter's life when she experienced complications from sickle cell anemia.

> "My daughter was having issues regarding her sickle cell and the ambulance had to rush her to Greater Southeast Hospital, and I got the call from work that she

> was dead on arrival (DOA) but by the grace of God, He brought her back. She was DOA for an hour, but He brought her back. She's doing good, and she just turned six. She was DOA for an hour, but if He wanted to go home, she wouldn't have stayed on here (on Earth)."

Another father talked about being blessed to be a family and to have his personal and family needs guided by spiritual awareness. Mr. L, age 43, indicated that his family is blessed, stating:

> "Well, pretty much so I can say that we are blessed." We all have our needs (met)."

In addition, Mr. Y also described the observation as a spiritual experience:

> "… it's like they were born again. Unbelievable stuff – it's unbelievable."

Generative Fathering

Generative parenting or fathering is an Eriksonian concept of psychosocial development where individuals are actively involved in contributing to the welfare of their children by teaching (parenting) or through social activism (Allen & Connor, 1997; Erickson, 1959). Allen and Connor (1997) also defined generative fathering from an Afrocentric perspective where developmental patterns (e.g., involvement, interaction, availability, and responsibility) reinforce family structure and enhance community involvement. Brotherson et al. (2005) describe generative fathering as a concept of generational ethics, where men take pride it the responsibilities and capabilities of being fathers, caregivers, and nurturers of their children. Fathers who participated in the focus group and interviews expressed a need to "give back to their children," a theme consistent with generative fathering. Specific examples of text units tagged as generative fathering include responsible fatherhood ("being a responsible parent"),

teaching/socializing children ("teaching my child how to use computers"), and establishing family routines ("we are always going to school every morning").

Responsible fatherhood.

One father talked about how he wanted to give back to his family and child with special needs. This concept of "giving back" to your child is a dimension of generative fathering that reflects that father involvement stabilizes the structure of the family. Mr. T, 48 years old, father of a child with Down's Syndrome talked about how he wanted to give back to his son and make sure the his son was able to do what other children could do:

> "I want this child to do what other kids do, and that is the whole thing. Don't put any limitations on yourself. I mean, this is something that – just like my son, this is something that I have to relate to him each day. Each day if you learn something different – in other words, you want to keep his horizons as broad as possible."

One father, who was able to grasp the concept of "strengths," indicated that it was important for him to be a "responsible" parent for his child. Mr. Z, age 54, and father of a daughter with Down's Syndrome said:

> "I think the primary strength simply comes from the responsibility of being a parent. The child didn't ask to be here, I brought her here. And it is my responsibility and it is my duty as a parent to make sure that every avenue is available to her. We actually made some changes in life just for her because there was a need. And I think my adaptability or ability just to change in the middle of the stream, so to speak, so that now she can have what she needs is the greatest strength I've got."

Mr. J. indicated that his son's special need (epilepsy) makes him accountable for being a responsible father:

> "Listening to your child, identifying when they are right, as well as when they are wrong over a period of time in my situation makes my son stand me up straight."

Mr. CC (mentioned above), in reflecting on his role as an advocate for his child, provided a statement that is very indicative of generative fathering concepts (i.e., commitment and making sacrifices):

> "…I think the fact that I am fully committed to it and I make the sacrifices and adjustments that are needed to be made is something that makes me a strong parent, too."

Teaching/Socialization.

Several fathers talked about their child's performance of developmental tasks and their role in facilitating the child's development. Socialization is a process by which parents (or other caregivers) facilitate the development of children's skills, behaviors, knowledge, and learning about customs, attitudes and values that help the children to become productive members of society (Brotherson et al., 2005; Livingston & McAdoo, 2007). Socialization includes parenting practices (negative and positive) for assisting or interfering with development as well as disciplinary strategies such as praise, spanking, or ignoring used to teach a value or skill or control behavior. Socialization is essential for the development of individuals who participate and function within their societies, and ensures that cultural features of their family will be carried on through future generations. Finally, socialization is most strongly enforced by family, school, and peer groups and continues throughout an individual's lifetime. In the case of parents of children with special needs, the socialization processes might vary from those of normative development, but parents, nonetheless, are engaged in socialization activities. Examples of text units that were tagged as "socialization" included: "helping a child climb a ladder" and "praising a child for tying her shoes."

Mr. EE, age 68, whose son is autistic, said that he is proud that his son had a special need, and proud to say that his son knew more than he (the father) does when it comes to using computers:

> "Like on the computer, I don't know A from Z and he's autistic, but he knows computers better than me and I'm proud of that."

Mr. EE, the 68-year-old biological father (just mentioned above) of a son with autism, also said that:

> "…you have to praise your child for doing little things…sometimes you've got to give him praise when he does well, say, you did a job well."

Mr. Y, a 53 year-old biological father of a child with ADHD, talked about the reward of teaching his son social skills. He also shared with the group how his son thought that he wanted to be a policeman. Mr. Y told his son that:

> "…being a policeman was a rewarding career, but that involves a variety of a lot of things and then about several months ago, he got a chance to go to this cadet for civil air and it was a new experience for his son he said, "WOW"! I was thinking I could be a policeman, but now maybe I can work on airplanes. In other words, the sky is the limit. He says sometimes I have trouble remembering today what I said yesterday. I said, well give it time and you do fine."

Mr. Y is also an uncle caregiver for his nephew, a child with autism. Mr. Y shared his story about the joys of spending time as he teaches his nephew the importance of keeping his room cleaned (socialization/developmental task):

> "When I ask him to clean up his room and I come back, clothes in the middle of the floor. He fixed his bed. At first, I'm saying, well there is no need in me getting upset, so I just said, "OK, stop"! "What does it mean to you? Explain to him, clean your room, what does it mean to you?" He said that means fix the bed and put my shoes away. I said, "what about the clothes in the middle"? He said, "Oh, I didn't know what that meant". When I was growing up, when they say clean your room up, that means the entire room. So that's why I say you can't assume anything. That was a learning experience for me. It means that you have to have a little patience and you have to look at things a little different and smile."

*Family Routines***.**

Fathers talked about how rewarding it was to establish and maintain family routines. As I noted earlier, these expressions were usually voiced when reporting about the time they spend with their child. Several of these experiences involve school contexts. Mr. R, age 47, who described his daughter as "mentally retarded," spoke specifically about how good it was to regularly spend time with her after school:

> "We don't do too much, because we are always going to school every morning and the only time I see her is when she is coming home in the evening. We would sit out and talk, or she would come in the room with me and talk to me for a while and we will just reminisce for a little bit and I enjoy the time that we spend together."

One father talked about how rewarding it was for him to visit his daughter's school and check in progress given her special need (i.e., ADHD). Mr. L indicated:

> "It makes me and my wife feel very proud when we go to my daughter's school and teachers are expressing to us how wonderful and a good job that we are doing. So I'm just happy, you know. That makes me proud to be able to go to school with her and see how she's doing in school."

Fathers also report on family outings to public places and find these experiences rewarding. Mr. R also shared how good it was to spend time with his family going on outings to a theme park. He indicated that family time was great for him:

> "We're going out to Six Flags, chill, just me and my family. She's happy and I surprised her when she got off the bus today, I said I got a surprise, you ain't going to school Friday, she say "why?" I said, "I got a big surprise for you". She was happy, jovial. It's a good thing. Yeah, you know and she gotta a big smile on her face and I know she gonna enjoy herself."

Social Support

Peer Support Group.

A prominent theme for rewards was being part of the peer support group from which the participants were drawn. Examples of peer support included family interactions with spouse/partner or kin, family structure as suggested by references to a spouse/partner or kin, family satisfaction, spending family time with members other than children or spouse/partner, influences from or involvement of the child's mother maternal influences, and informal support from family, friends, church. These examples of social support are considered social capital within the context of caring for children with special needs. Social capital is defined as the advantage of having access to resources created by a person's location in a structure of individual, family, or community relationships. It also refers to the collective value that social networks and kinships have on one's environment (Brisson & Usher, 2007).

Fathers talked about how good it was for them to have a formal support group and be part of the MCASG. This support seems to come from a shared experience of fathering a child with special needs and having similar backgrounds. Mr. K, a 43-year old father of multiple children with special needs, states:

> "So again, to be honest with you, this group is one of the biggest drives, inspirational, because we all are fathers here. We all are men here. We come from pretty much the same backgrounds, some with and some without. So that's my take on my driving force, why I'm here."

Receiving support from community agency.

Fathers also expressed that they rely on social support from a variety of community agencies and programs. Several also reported on the rewards of training they

received from MCASG (e.g., parent education) and other services. Mr. K, the 43-year-old father of multiple children with special needs (above), was also homeless at one time. He describes his children as having "ADD/ADHD/ED". Mr. K said that being part of MCASG has allowed him to make a positive change in his life and in his family's life:

> "Everything has been set for me is in a circle. It was almost as if everything, all the right people and the right organizations were doing their job at the time for the same time for at that particular time in my life -- here, UPO, Salvation Army, even DC Village. These are all places that at the time they all did their part, so I can't say that there was no one thing. What I will say for me personally, it was just determination to make something better and being a part of MCASG helped."

Advocacy

Fathers found rewards in several successful procurements of services and resources for their children and families. These advocacy efforts were directed toward procuring educational, health, and financial resources. Fathers or male caregivers were active advocates for addressing issues regarding their child. Moreover, some fathers felt a special commitment to care for and advocate for their child. Five fathers talked about "doing their best" in regards to the health care issues for their child. Mr. CC, a 57-year-old father of a son with developmental disabilities, indicated that:

> **"**I don't just care for my child, I fight for my child and I think that's what makes me a strong parent. I am an advocate, in addition to the advocates that I need for sure to help me, but I also make sure to play a role in being an advocate for them. I think the fact that I am fully committed to it and I make the sacrifices and adjustments that are needed to be made is something that makes me a strong parent, too."

Mr. U, who is 49 years old and has a child with little patience, stated:

> "Mine is a different mindset in more ways than one, especially if you have more than one child and then you have a child with special needs. You can't assume anything. When I say assume – you just have to ask all of the things that you – you really have to ask all of the questions. Because your whole thing is, I want what is best for this child."

One father, who has multiple children with special needs, talked about how rewarding it was for him to advocate on behalf of his children. Mr. K also indicated that his boys were the reason for his active involvement in the DC public school system and developing Individualized Education Plans (IEPs) for his children.

> "…my boys turned me into an advocate for parents and children. So I don't just say I try to advocate for children. I try to provide information and resources to parents as well as the kids."

Summary of "Rewards" Findings

In summary, most of the men who participated in the discussions and interviews felt the fathering or caring for a child with special needs was a rewarding experience. Fathers/caregivers take pride in their child's accomplishments no matter how small (e.g., climbing a ladder or getting off a school bus with a smile). Fathers/caregivers also look for ways to enhance parent-child interactions and increase "normal" development through shared activities with their child. Finally, fathers/caregivers thought that their participation in their peer support group, MCASG, and serving as an advocate in health care and school systems were also rewarding experiences.

Fathering Challenges

Research Question 2: What are the challenges faced in parenting a child with special needs?

Fathers also reported a number of common *challenges*. These *challenges* include: relationship difficulties; role strain; parenting conflicts; employment issues (finding work that will allow for participation in their child's life, including health-related appointments); obtaining adequate health care (insurance issues, negotiating health care

for children with special needs); and environmental/structural challenges that disproportionately affect African American males and their families (poverty, high unemployment, crime, substance abuse, community violence, HIV).

Focus group discussion topics explored fathers' perceptions about these challenging aspects of their experiences in caring for a child with special needs. Participants were asked to describe some of their challenges, and asked to talk about some of the obstacles or barriers faced, if any aspect of fathering a child with special needs was particularly challenging, and how they overcome these challenges. These challenging experiences were also coded for various ecological levels—individual, family and community. This section provides a summary of the findings on challenges that fathers talked about during the focus groups and interview sessions. Again, the organizing framework was utilized to report these challenges.

Personal Development

Several fathers expressed challenges to their personal development. Some of these were emotional challenges related to their learning that their child had a special need (shock, guilt, shame, depression). Other challenges related to their own shortcomings apart from having a child with special needs (i.e., their own continuing mental health problems) and role strain.

Emotional adjustment.

Two fathers talked about the emotions they had when they first became aware of their child's special need. Mr. T, 48-year-old biological father of a child with Down's Syndrome, talked about how shocked he was to learn of his child's special need:

> "I'll start from the back end where you say the moments that you were sorry that you had a special needs child. That would have actually come from the initial shock of learning that my child was born with Down's."

Continuing mental health problems.

One father told of his depression related to having children with special needs. Mr. L, age 43, said that it was depressing for him, at first, to learn about his child's special needs (ADHD/Emotional Disturbance):

> "I have two kids that got ADHD and emotional disturbance. And to me personally I think at first it was depressing. You don't know what's wrong. There was uncertainty. You weren't sure of anything. You didn't know what to do. You don't know. I didn't have any resources because I didn't know where to go. I didn't have no support because I didn't know what kind of support that I needed for the child other than to get him evaluated or what have you."

As indicated in Mr. L's statements, his depressed state was related to the lack of knowledge about where to turn for information or assistance, and the lack of support he felt in general. Some fathers' mental health and other personal problems were coupled with substance abuse. Mr. EE shared his past battle with substance abuse and how it affected his family and his job:

> "I had problems with alcohol, so I found it hard to stay on a job. But I had plenty of opportunities, and I can only blame myself."

This statement also points out how challenges in one area of personal development relate to another area of personal development (employment issues).

Role Strain

Fathers also told stories about the personal adjustments they had to make after their child was born with special needs. Role strain included expressions of problems with managing the multiple roles of father, spouse/partner, provider, caregiver, and friend, where fathers had competing demands for their time and other resources. This

working definition was adapted from Bowman and Forman (1998) and reflects the particularly challenging roles for African American men in urban contexts. Examples of text units that were coded as "role strain" included: always making "adjustments in life," need to have "adaptability," or the "ability to adjust in mid-stream."

Mr. CC, age 57, talked about the personal challenge and role strain of parenting his child who was born chemically dependent.

> "He was born dependent, a substance abuse child, so I had to witness him drying out his first – they said seven days, but it only took five. I took a special interest not knowing what this would bring in his later years. Then at 47 days, I gained physical custody and at nine months I gained legal custody and it was me and my mother's field now. The mother was no longer involved for whatever reason."

Mr. H shared how difficult it was for him to be a single parent with a son who was HIV positive:

> "My son has HIV…what am I going to do, you know what I'm saying? how am I going to deal with this? how am I going to handle it? I guess after we found out the diagnosis and exactly what was going on with him, it became apparent to me that he was going through things that he didn't really realize he was going through. And I think as a dad I just had nowhere to go, no one to talk to, no one to be supportive. Naturally (indiscernible), but the mom dipped out, did whatever she wanted to do."

These examples also highlight some aspects of generative fathering, which is reported next.

Generative fathering

Fathers also indicated challenges associated with several aspects of generative fathering. These themes were related to problematic marital/partner relationships, difficulties in maintaining relationships with kin and friendships with others who do not

have a child with special needs, managing difficult relations with siblings, and adjusting developmental expectations for the child's development.

Relationship difficulties with mother and kin: "Getting on the same page."

I coded text units that reflected problematic marital/partner relationships and difficulties in maintaining friendships or connections to kin in this category. A sample text unit is (in regards to dealing with extended family) is, "getting everybody on the same page." Mr. Q stated that it was challenging for him to get all members of his family "on the same page" regarding his child with special needs:

> "I find the biggest challenge that I have is everybody is not on the same page, and that's a concern. What's the objective here? Everybody wants to put their input without having to go through the challenges or without having to go through the opportunity of saying this is the final objective. I got input, you got input, everybody got their own, and that's how they should do it, without having to say, well, let's go through it. Let's walk through the process."

> "The challenge is saying when you go through the judicial system, they have their input, and the school has their input. I have my input. The other parent has their input. And in most cases, if not all cases, everybody seems to be on a different page. And eventually you lose the product as far as saying, 'well, look, how do we get this child to the final outcome, because eventually the manipulation is starting to take place, and everybody is in disarray emotionally'."

Problems in parenting siblings.

One father related how difficulty it was to dealing with his other children who do not understand the development of his child with special needs. In this category I included those themes that reflected fathers' struggles to manage parenting his child with special needs along with fathering for his other children. A sample text unit is: needing assistant to promote "acceptance of child by younger family members."

Mr. T, a 48-year-old biological father of a child with Down's Syndrome:

> "Still the family piece is a difficult piece for the younger children, the children between 10 and 13, because they are not being brought up in the

> household with us. They're being brought up in their own homes, so the prejudices of the parents show through when you have Thanksgiving and Christmas and all of that, because again they shun her. They go, well, why do you talk that way? Why do you act that way? And why aren't you doing this?"

Adjustments in developmental expectations.

Fathers related how they had to adjust their expectations for the child's development from a normative view to one of uncertainty for the child's future, their expected roles as father, and what would be needed from them to care for and assist their child in developing. For example, Mr. G, age 36, talked about challenges that he experienced while parenting his child with special needs:

> "You know, it was kind of a real shift for us in terms of everything – in terms of expectations and in terms of ideas." It has been one of the biggest things for me to adjust. Like on the personal side, I think just having to shift everything in terms of what you imagined – playing sports with him and helping him with school and all those kinds of things. It's a whole new dynamic because now the questions are like will he ever talk, will he ever walk?"

Social Support

Fathers or male caregivers expressed several challenges to receiving social support at all levels--personal, family, and community. The following are prominent themes I noted under "social support" challenges.

Family stigma resulting in reduced support

At the family level, fathers expressed a lack of support from extended family because of stigma or a lack of knowledge/awareness of their or their child's needs. Mr. I talked about how the lack of his extended family's knowledge regarding parenting a child with special needs presents a barrier in his interactions with kin:

> "I have relatives, friends and things of that nature with children with special needs, which makes me involved, you know? I am involved. And I know that it is very, very, very difficult to deal with them (family), number one, and especially

> if you don't really understand the whole concept of special needs and what that problem is and what it is that they suffer from."

Mr. T stated that family and community level stigma were challenges for him:

> "And lately we've been more fortunate because now she's an accepted part of church. She's somewhat accepted in the community. Definitely accepted at school. She has peers and things like that. Still the family piece is a difficult piece for the younger children, the children between 10 and 13, because they are not being brought up in the household with us."

Mr. T also said that it was challenging for him to deal with family ignorance and stigma concerning his child's special need:

> "And it's not all the school system. It's not all the community. Part of it was my family because when (my child) was born, (my) mother would say, oh, there's nothing wrong with her. And my mother has got 30 years experience in special education. She is a special ed person. And for her to actually sit up and look at me and say, oh, there's really nothing wrong with her. And then for my father, a learned man, to say, ah, she'll grow out of it, that's ignorance."
>
> Mr. T's statement also seems to suggest some denial in his family.

Dismissive attitudes of health providers/"invisibility."

Fathers also face the challenge of being "invisible" to health care providers, and are regularly subjected to dismissive attitudes (i.e., when mothers are present, fathers are ignored by providers when they accompany children to health care visits). In this category, I included access issues such as insurance issues (lack of insurance, underinsurance) and problems negotiating health care systems for children with special needs. Mr. U, age 49, talked about how he felt when he was dismissed (rendered invisible) by a nurse at one his child's visits.

> "I felt something that sticks in my mind still and I feel it's the kind of thing that somewhere down the line, someone should address. Speaking of fathers and caregivers, male caregivers – I don't know for sure if it happens, but because we are Black fathers or fathers in general, but on several occasions now when I've gone with my wife to the hospital for an appointment or whatever, the nurses

> ignore me and just like talk to my wife the whole time. Like we both come in and the subtle stuff of they will just sort of say what is his weight and how he's eating, but they will just look at her. And sometimes it is even more clear when they will be like, 'Now Mom, what's his temperature' and I'm holding him. And I may be reading into it, but I almost feel like they assume that I'm not going to know. They assume that I am not participating. They assume that I am not part of the process, so clearly they don't even bother to ask me. So it's not even like they sit back and see if I'm engaged, they straight up just write me off immediately. Like we will be out in the waiting room and the nurse will come out and be like – I'll be holding him and they will look at her and say to follow them. So does the baby come?--because I'm the one with him." And so for me – not to mention just the emotional part of it, the respect piece. I feel like I don't count by these nurses and stuff, and that gets me upset and that is the stuff I don't like. I'm not appreciated at all, and that is the kind of thing that is not productive."

In Mr. U's statements is also a reference to the lack of respect he feels from health care professionals. He is uncertain whether this lack of respect is due to being a father in general or being Black.

Mr. K, age 43 and father of child with ADD, talked about what he thought were some community level needs:

> "There needs to be education in the classroom and for the professional that deals with the special needs community, and just the community at large. And it's got to go beyond where everyone is right now."

Mr. U, above, also indicated that stigma for him existed at the community level when he visits the hospital with his child:

> "As the brother said, going to the hospital all of the time. They have to deal with the views of other people who deal with their children and how little children talk about their children and make fun of their children, all of the stigma that is surrounding special needs children."

One caregiver, Mr. AA, thought Black men experienced hardships in caring for a child with special needs because they are Black. He stated:

> "We are going through it by natural reasons, we're going through it for job reasons. We're going through it just being a Black man in the United States."

Lack of community service coordination

Fathers expressed the challenges of fulfilling their fathering roles for their children without adequate information or professional advocates (such as case managers/social workers) to assist. One father talked about how challenging it was for him (and his wife) to get information from public health agencies or hospitals regarding his child's special need:

Mr. L, age 43, indicated that:

> "…the other thing I think is that information is lacking. Like once he was born, the hospital was helpful and everything, but we had to really kind of ease into figuring out really what existed. And it was very much this kind of thing of us having to like do our own research and like ask around and the D.C. office that is supposed to help you, the Infant and Toddlers or whatever it is called, some folks got too much work to do, some folks just got a bad attitude, some folks just don't return your calls, who knows why."

Advocacy

Fathers or male caregivers expressed challenges advocating for their child. They noted the challenges of dealing with pessimism in the health care system and inadequate educational and recreational resources for children with special needs. As I further analyzed these themes, I also noted that fathers' data included references to specific policies that were missing or inadequate for men, children with special needs, and their families.

Pessimism in the health care system.

Fathers do not have faith in the health care system. Several fathers expressed their pessimism in the system and their frustrations with dealing with providers in the system who as noted above render them "invisible.". Despite this frustration, fathers and

other male caregivers told how they were active advocates for their child in the context of this unsupportive system.

Mr. Q, a 46-year-old biological father of a child with emotional behavior disorder, talked about his personal challenges in advocating for his son:

> "And in his case, what I feel in my personal case with him is feeling that I am losing a lost cause, losing another black male to the system, another black male to society, to fend for himself."

> "That's the emotional part of feeling how I feel. But the good part is saying that I know where my faults are. I know where his faults are. And at this point, I'm stepping to the plate and not using what's happening then as an excuse for what needs to be happening now. I'm not in the excuse mode; I'm in the proactive mode of saying how do I help?"

Inadequate educational/recreational resources

Another father talked about the challenges at the community level regarding the advocacy required to ensure that his son was placed in the appropriate educational setting. Mr. W stated the following:

> "We didn't want him like (in) a separate class because we knew that he was capable of learning. Like I said, the schools won't tell you this. And then they have advocates out here who will fight for your child, too. Now that is still like an ongoing thing for us now because we said that the school isn't doing their part in providing him with a social worker there at the school or coming to take him out of class for half hour or an hour at a time to learn these things. We would rather see, and they have the programs out there, the county has arranged for his transportation."

Fathers' stories indicated that there are little educational or recreational resources in the low-income community, referred to as "East of the (Anacostia) River," where many of these families and their children with special needs reside. Mr. Y stated:

> **"**There's nothing on this side of the river, it definitely is needy. Just like resources as far as recreation centers, some way that the kids could come and get off the streets and do something constructive, because there are too many kids on the street just doing nothing. They don't have no recreation centers like that, I ain't

> seen not one indoor pool on this side of the river at all. I ain't seen no arts and crafts program, I ain't seen no poetry programs. No after school programs, the only thing that they have on this side of the river is football Again, I work on the weekends, every other weekend, I take care of a house and folks and I take them out to the pools, indoor pools and they got equipment that the children, what their needs are. They may have cerebral palsy, they may have Down's Syndrome, they may have a lot of different needs. But they got equipment for these children to be able to swim in the pool, to experience the pool. They've got equipment to help adjust them so they can push weights and begin the – when their muscles are spastic and it gets tight, they have got equipment that helps them relieve the tension in their muscles and things. We don't have that here for our children."

This lack of resources in the fathers' communities was a recurring theme. As the following statements indicate, fathers are very concerned that there is a need for additional advocates for the special needs community as well as for resources in general for their families. I coded for any expressions of inadequate material resources or sources of instrumental support (e.g., a job, money, housing, food, transportation, child care) related to providing for one's self, care for the father's child with special needs, or family unit. A sample text unit is: needing help with "transportation of child to school."

Mr. CC, age 57, said that the one of major challenges is that the community lacks technologies (e.g., wheelchair lifts in all public schools) that are developmentally appropriate for children with special needs:

> "One of the biggest challenges is that our community, when it comes to the service for special needs children, our community still lacks all of the technology that exists. We don't have those resources. Sometimes we have to do without, not only the resources, but maybe the equipment that a child needs."

Mr. V, age 53 and biological father of a child with traumatic brain injury, also talked about how communities are challenged by a lack of resources and technologies that are typically not afforded to areas of the city that are social or economically disadvantaged:

> "We don't have those resources. Sometimes we have to do without, not only the resources, but maybe the equipment that a child needs. How many times have you gone out into our community and you see people still doing the wheelchairs like that (making a back-and-forth motion as if trying to roll a wheelchair), trying to get them (the wheelchairs) going. You go up to the circle at Dupont (a gentrified part of DC) and everybody is riding the little scooters and riding all around the community. So we are still lacking in resources and we are not getting the resources. So that is something that you want to talk about in terms of challenges. Our community needs more resources to be able to protect and take care of our children also."

These discussions about dealing with inadequate resources also included stories about the lack of other father- and family-focused resources needed in an urban environment. Mr. G, age 36, talked about challenges he experienced while trying to access resources for his child with special needs:

> **"**So we just had to constantly push just to find out that we could get therapists to come to his daycare. Like that was even something that wasn't obvious to us. We were sitting there trying to figure out how we were supposed to go take him out of daycare, from home for the first six months and then when he went into daycare, take him out and drive him over to the hospital seven times a week. How were we supposed to do that and keep jobs?

Mr. K, age 43 and father of a child with ADD, noted the absence of father- and family-focused services:

> "There's not a network of each of those organizations that's there just for the family...I would love to see something similar to the map process, but detailed to service fathers of children with special needs, or to serve fathers. What it does, it almost eliminates, there's no way if you have a proper map meet that you won't meet the child's needs. That's what they did for me and my son. So if it works for a child, how difficult is it to make the services based for fathers?"

Summary of Challenges

In summary, men who participated in the group discussions and interviews experienced individual, family, and community challenges fathering their child with special needs. Fathers/caregivers experienced personal challenges that include feeling shocked to learn that their child has a special need. Fathers also were challenged when

understanding the types/kinds of medicine or treatment for their child need with special needs. Some fathers specifically talked about how challenging it was for them to get additional information about medicine that health care providers prescribed for their child. Fathers also talked about stigma and other challenges at the family and community level regarding their child's special needs. Getting members in the extended family on "the same page" also proves challenging for fathers. Finally, a prominent theme was that in the low-income community, in which fathers were situated, the community lacked developmental advances or technologies (e.g., school equipment or therapeutic pools for recreation) for children with special needs).

Fathering Needs

Research Question 3: What are the needs fathers or male caregivers have in parenting their child with special needs?

Fathers reported on "needs" in response to questions about and requests for examples of personal, familial, and community needs. Fathers/caregivers were also asked to talk about the extent to which their needs were being met and asked to provide suggestions for what could be done to meet their needs. Support group members also talked about a number of needs they experienced when caring for a child. Some of these needs included personal and community resources; professional counseling; community advocacy; money; knowledge; and spiritual inspiration. These needs were described at various levels within an ecological framework: at the individual level (e.g., the need for personal outlets for fathers), at the family level (e.g., receiving support from females; role recognition; or having siblings understand their brother's or sister's special need); and at

the community level (e.g., more community IEP advocates for children with special needs).

Personal development

These themes included the need for specific types of mental health services (i.e., individual versus group-level), substance abuse counseling, and programs to promote self- sufficiency (e.g., job and housing assistance).

Individualized Assistance for Mental Health.

Fathers suggested that programs and services to assist them with mental health needs should be individualized. For example, Mr. K, age 43, indicated that his needs were different from other MCASG members and that each group member's needs should be addressed individually:

> "When you say what the needs are as a dad, that's kind of individual based because what his needs may be for a special needs child, or a situation, or a household may be totally, completely different from mine. His solution to handling the situation is different than mine….it's kind of situational."

Jobs Assistance.

Fathers also suggested that there is a need for programs and services to promote self-sufficiency in terms of securing jobs and housing. I applied this code for text units that included references to needs for resources to assist men with personal development, or to attend to the child's or family's needs—e.g., more literature concerning children with special needs; locating a job or assistance with employment searches; and financial or debt management.

Mr. K, age 43 and father of a child with ADD, suggested:

"There need (for) resources for job assistance."

Mr. CC indicated that:

> "...You cannot receive help until you help yourself."

Housing assistance.

The MCASG was viewed as an important resource for self-sufficiency. Mr. K, who was formerly homeless, talked about his involvement in obtaining housing for himself and providing assistance for other MCASG who are in need of temporary or interim housing.

> "I know they need housing assistance, but we just can't do nothing right now. Why don't you sit right on back over to -- and that's just how it go. There's not a network of each of those organizations that's there just for the family.

Generative fathering

Parenting and caregiving education.

Most of the fathers' needs in this are related to the need for more information (i.e., parenting and caregiving knowledge). Knowledge was also a recurring theme within the previous category, "Challenges"; however, the challenges were largely related to the lack of knowledge among extended family members and community members. In this category ("Needs"), fathers were primarily concerned with their own need for information to improve their parenting and caring for their child's needs, in particular and their need for information to be a better father/caregiver, in general.

Strategies for parenting siblings

Mr. Z, age 54 and father of a child with Down's Syndrome, talked about the need for understanding how children feel about having a brother or sister with special needs:

> "And then, of course, on the sibling side, how do they feel about this child with special needs that's either getting all the attention or getting this or getting that, or that they'll have to possibly care for the rest of their lives? Because that's a situation with my oldest daughter. She's now responsible, if something were to

> happen to my wife and me, she's responsible for my daughter. And does she want that responsibility at 26? I think the sibling issue needs to be considered."

Although not a prominent theme, some men were, as Mr. Z was, concerned with issues related to transition planning (i.e., what will happen to their child as he or she ages) in their stories that related to siblings of children with special needs. Mr. Z also thought that additional questions concerning fathers of children with special needs should focus on how a brother or sister with special needs impacts the well-being of children in the family.

> "I think the issue around siblings really needs to be considered because they play an interesting role in this nurturing of a special needs child, because without siblings, especially when they're in the house, they're such a positive influence because again the child, the special needs child can get the modeling. They can give the nurturing that you would get from, say, a peer. And they're just able to be there because they're closer. It's just like daughters or sisters and brothers and things like that. But I think it's something that actually needs to be considered because siblings just play a huge role in the development and the life of the child.

Assistance in understanding/addressing child's health/medical need

Other men expressed need for assistance in administering medications. Mr. FF, age 71 and grandfather of a granddaughter with developmental disabilities, said that his personal need was to obtain additional information on how to administer various dosages to his granddaughter:

> "I'm still trying to understand meds -- different doses, milligrams, and Clonidine (used to treat ADHD) and Tributerol (used to treat psoriasis or dry skin)"

One father talked about the personal challenges he experienced while caring for his child who had HIV/AIDS. Mr. H, age 40, indicated that it was personally challenging for him to learn and understand the multiple drug therapies that his son required to treat his HIV/AIDS. He shared how challenging it was for him through this expression:

> "I was a father of a child with special needs for eleven years but unfortunately, my son passed last July. But it was hard, man, because at six months old when I got custody of him from his mother, my son was HIV. He got it from her dealing with some other guy when she was pregnant, so I took on that big responsibility. It was rough, it was real hard. I mean, back and forth in the hospital, all different types of medicines. At times, he didn't want to take any medicines, so it was rough. It was rough for eleven years, but the father that I was, I took that responsibility."

Social Support

Fathers also noted social support needs during group and interview discussions. These included the need for support from spouses/partners, other family and kin support, knowledge development for kin, and greater exposure and reach for the MCASG peer support group. I used this category for text units that made reference to father's needs for increased support from their wife or partner, understanding of their equity in caregiving for the child with special needs, role recognition, and a shift to focus on the "needs of Dad."

Strategies for educating family members and friends

Another way in which family members can be more supportive is to increase their understanding of the child's disability and ways to interact with the child. Mr. W, age 50 and father of a child with learning disabilities, stated:

> "As the needs for my family as a whole – again, understanding what his disability is and how it may affect your social life period with his brothers. His brothers have their little friends coming by and Joey might want to sit down while you all are sitting down."

Greater support from family, friends, and churches

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Fathers expressed a need for support from all segments of the community, including his own family. Mr. S talked about a need for family support or more support needed from his spouse:

> "I want to say spousal support. What about the spousal support for dads? We ain't talking about child support. Spousal support. That's what we need to talk about. And it needs to be because whenever you talk about dads and caregiving as well other things. I found out that that is insanely important and very necessary that both parents have a part in it."

Other fathers talked about a need for more family or kin support. Mr. CC, for example, indicated that:

> "There is a saying that it takes a whole tribe to raise one child....they don't always have to be your family, they can see your struggles and just help you. You cannot receive help until you help yourself."

Advocacy

Several fathers or male caregivers also expressed a need for advocacy that includes increasing the amount and quality of resources for fathers and their families. Among the needs mentioned were increased financial resources for fathers and children, resources to increase children's access and success in educational settings, culturally competent programs for children and families, specific policies in school and community settings, improved interagency collaborations, and social marketing for MCASG and similar support programs.

Financial resources for health care expenses

Several fathers talked about family level needs that included monetary resources needed to offset health care expenses that are not covered by Medicaid or other private providers. Mr. G, a 36 year-old father of a child with cerebral palsy, talked about his family's need for financial assistance in order to cover health care costs for his son's therapy:

> "…we're lucky in many cases, but there is even one thing where he gets this physical therapy and occupational therapy and speech therapy which is for eating

> right now at his age. But the there is this other thing called special instruction, which is this integrated thing, and it's a therapy. The woman who does it is trained and that is not covered by the health insurance. The special instruction doesn't fall under like the standard bucket of therapies and so that is not covered. So that right now comes out of our pocket and thankfully, because we have the other things that help us out, we're able to put the money into having that and getting that therapy. But if we couldn't afford that, he just wouldn't get it, it's that simple."

Mr. CC talked about needing to get additional monetary resources for himself and his child:

> **"**What special needs is from the top, it will trickle down to … and my situation is finances. In order to get that just like the health services has the parent advocate, lobbying, the federal council and the governors that govern these finances, we have to unite and bring it forth as an urgency, because it is the right of special needs.

Educational resources for individual instruction

Fathers expressed their need for instructional resources in terms of individualized tutors or other instructors. Mr. N, age 45, indicated that there needs to be additional resources for his child; he believes that these resources will enhance his family:

> "But again it's got to be around education. It's got to be around resources. It's got to be around the things that will enhance the family."

Mr. X, a 53 year-old father of a son with ADHD and nephew with autism, talked about his need to find an instructor who is trained to teach autistic kids sign language:

> "Like I said, my son is not verbal. So right now, my biggest need is whether he can be taught to sign. I think that if he can be taught to sign, then he can be taught anything or he can learn anything. So when school starts, I am going to try to find out who the experts are in that field and see if I can address that. Because if I could ever communicate with him, I am sure the child is intelligent – he just doesn't know, he just doesn't express it the way that I can understand it. But he pretty much knows what he wants and what he doesn't want. I think that maybe he knows why. So if we can ever get on a communication, I think that we will be all right. We are all right anyway, but we will be a lot better off if we could communicate. That was something that they were supposed to be working on, so

> we are still working on it so they can have a device there at school and also one that he can take home so we can work with him verbally. So that is another need, another resource. But tutoring is always – tutoring is a good thing, because I found out – our son, he is very good one-on-one. Large settings, he is not very good, but one-on-one, he can give it back to you. He can give you 95 percent back what you ask him."

Training and understanding in getting services defined by IEPs

Fathers suggested two areas for policy changes in educational settings: educational reform and increased advocacy for IEPs. Mr. M, age 44 and father of child with emotional disabilities shared his thoughts on needed educational reform:

> "I'm thinking that as a society we've actually written some wonderful laws, and we've put a number of wonderful things in place, but we just don't honor them. As far as education is concerned, they say that each child is supposed to have this freedom of public education; that all schools are supposed to be a safe place; that inclusion is supposed to be something that exists and that it is not a quote, unquote, "different curriculum. That's just a huge hurdle, not only in education, but in the social services, in the community, the whole nine yards. If we would just do as we've said we're going to do on paper, that's just where we need to be."

Fathers varied in their understanding of the "power of the IEP," but those who do, expressed how utilizing advocates and increasing their availability are greatly needed. One father talked about this need for more advocacy and the need to better understand how IEPs can assist with ensuring that children receives an appropriate education. Mr. CC indicated:

> "As a single parent advocate fighting for your special needs child….In your struggle, they have created the IEP as an instrument of sheer power to push those people that don't want to do. Force those people that don't want to do. Make some people that do go a little further. Because that IEP is that child's bible through education. As long as you show through your advocate – my son has an advocate, a lawyer and a paralegal. That means the lawyer goes to court, the advocate goes to school and the paralegal does all of the paperwork. Once they see that you can tap into those resources and make them follow that IEP to the – I want this, I want that. As a matter of fact, let's have an on the spot meeting and change the IEP because that is not what I want. Once they see that you understand your power to pull those strings, you will have no problems and your

> problems will be minimum…Once you use that team, that advocate, that lawyer and they are just going to get a paralegal, because they are too busy and somebody needs to do that paperwork. It all goes into motion and those teachers see you do that and follow that IEP, know that IEP."

Social marketing and resources for fathers' support groups

Social marketing was viewed as a tool that could assist in educating the community about children with special needs. One father talked about social marketing as a community level need. Social marketing refers to organizational materials used to promote positive ideas about the benefit of a health innovation (behavioral approach, participation in an educational or supportive group, etc.). I applied this code to text units in which fathers expressed the need for community outreach and materials to promote the benefits of the MCASG.

Mr. K, age 43 and father of child with ADD, talked about why he viewed social marketing as an important community level need:

> "So as far as resources, maybe a social marketing thing. What we need to do and how we need to embrace the special needs community."

Thus, he viewed social marketing as the means to also increase resources for the special needs community.

Another father talked about a need for community outreach and advocacy for MCASG and their children. This outreach was thought to be key to increasing recognition and exposure for MCASG and could be used to also increase resources. Mr. Z shared his thoughts about conducting outreach to fathers who are in similar situations (e.g., with respect to housing assistance, mental health, and parent education):

> "I think that one of the things that need to be addressed the whole notion of outreach. What happens is, I'm looking at these brothers, we've got diversity and

> aid and generation and so on, but I think we lack in outreach. Most communities, most other cultures and groups, they have men's groups and they have where men can talk and share and really begin to learn. We don't have that. Now as the young guy said over there, this is kind of like an organizing tool for our community, this kind of group, but we don't have them in our community. So I think the outreach, outreach for male facilitation, for male support groups be it this or some other support group. But I think that the point that support group, men's support groups, we need to reach out and we need to go after developing them and continuing to develop those."

Inter-agency Collaborations

There was some discussion that services could be improved through agencies collaborating with each other. Interagency collaboration refers to the efforts of organizations to work together to accomplish goals for their target populations. It includes such activities as co-locating services, cross training for staffs, and providing a network of linkages and referrals that allows community service providers to share resources and information to meet the needs of clients/participants. I used this code for fathers' suggestions for improving MCASG's service networking as well as when they specifically mentioned the need for collaboration among community agencies in the DC area.

However, governmental agencies in DC were perceived as "territorial," and that this situation affects families with children who have special needs. Mr. DD, a 58 year-old uncle and caregiver of child with special needs, indicated that:

> "…it got so close to us having some form of success, they disbanded the project, because that's the District of Columbia. And now they went back to another model that they call the Teen Family Meeting that was being used by another agency that was not successful at all because they would come from this meeting, and they would come over to our meeting so that now we could expedite something. And again, it's how do we change the mindset of agencies, service providing agencies to not be so territorial."

Programs sensitive to the culture of the disabilities community

Several fathers or male caregivers expressed the need for increased cultural competency in programs and services. In addition to the statements already reported that reflect men's concerns for whether Black men will be lost to the system or whether the lack of respect they perceive is due to being Black, fathers also reported specifically on the need for improving services through cultural competency training and other program improvements. Some of these needs related to improving interactions with Black men in general, others were more broadly focused on the special needs or disability community. . I used this category for text units that included fathers' suggestions for needed programs or program enhancements. These included, for example, calls for more culturally sensitive school programs for their child with special needs and other children; and cultural competence for programming for the special needs community.

Mr. K, age 43 and father of child with ADD, stated:

> "The cultural competence piece, it's got to go beyond that. It's got to say "cultural competence" and "special needs community." It's got to be included. We can no longer as a society continue to divide because there are so many divisions in our society. There are economic divisions, social, the race. And now we're getting into the cultural piece. That's why we have all the issues that we have now, even religion."

Mr. M, age 44 and father of child with emotional disabilities, also shared his thoughts on needed cultural competencies for community providers:

> "And I think that is just a problem as far as the culture, and when I say "culture," we still as a society do not look at the special needs population as a resource. We miss that close to 52 percent of the working class are special needs individuals that need special accommodations or some type of accommodation. And these things just need to be brought to the forefront. Everyone somehow or another is just ashamed of the special needs community, and we need to break that stigma."

It should be noted that in Mr. M's statement he refers to stigma, a theme that has surfaced in other areas as well.

Summary of Needs

In summary, men who participated in the discussions and interviews expressed individual, family, and community level needs for fathers of children with special needs. Fathers/caregivers expressed a variety of needs including improving their own and their children's well-being through individualized approaches, increased knowledge about caring for children with special needs for fathers, mothers, and other family members; increased understanding of the impact on siblings; increased support from wives/partners and other kin; cultural competency in health care settings; educational reforms to increase access, equipment, and advocacy for IEPs; and use of tools such as social marketing and outreach to increase the community's awareness and provide access to other fathers in similar situations.

CHAPTER 5: DISCUSSION

In the first part of Chapter 5 I summarize the major findings and present a discussion of how they relate to the theoretical framework and methodological approach (i.e., ecological systems/risk resiliency and grounded theory). I discuss how I used the ecological framework and grounded theory to derive meaning out of the men's stories as described in Chapter 4. My summary presents the key findings with respect to the strengths, challenges, and needs of African American fathers of children with special needs. I then compare these findings with relevant literature (past or current) within the contexts of African American families, fathers of children with special needs, and residency in an urban environment. Strengths and limitations of the study are addressed next, followed by a discussion of the implications of this study for research, practice, and policy.

Theoretical Framework

An ecological systems/risk resiliency theory proved to be an appropriate framework for my study. By using an ecological theory I was able to better understand the variety of roles (e.g., provider, caregiver, and teacher) of the fathers or caregivers who participated in the study. It also permitted me to take into account culture, socioeconomic status, and social position in understanding the roles African American men undertake in their families (Allen & Connor, 1997; Livingston, 2006; McAdoo, 1993). The ecological systems/risk-resiliency framework also allowed me to use an alternate strategy to examine themes and sub-themes that emerged from the data. By using a modified grounded theory approach I was able to hear fathers' stories regarding

strengths, challenges, and needs to organize and summarize recurring themes. Subsequently tagging themes with respect to their ecological levels, then permitted me to identify emerging concepts that could be used to organize potential risk and protective factors coded in men's stories. For instance, results from this study highlight that fathers and caregivers experience risk and protective factors for themselves and their children at all levels of the ecological system. Moreover, strengths, challenges, and needs at the individual, family, and community levels seem to interact across the life course of the father and child. Fathers' stories included accounts of rewards or challenges from the child's birth through their current developmental stage (or, in some cases, the child's death) as well as those rewards or challenges related to the men's own aging and growing in their parenting role. These factors may also influence a fathers' ability to parent or care for his child.

This study integrated an ecological and risk/resiliency framework to examine risk and protective factors across various levels within a specific ecological context of fathering African American children with special needs. From this perspective, fathers or caregivers are nested within five subsystems that include the individual, his family, his community, policies that affect his child with special needs, and life transitions for his child. These men's accounts include stories about both the *risks* they and their children experience as well as stories of *resiliency*. *Risk* factors pose challenges to healthy individual (e.g., caregiver burden) and family functioning (e.g., poor parenting). In contrast, r*esilience* refers to the ability of the individual or family system to recover from negative experiences (McCubbin & McCubbin, 1996; Murray et al., 2001). Amidst stories that tell of the risks that disproportionately affect African Americans (poverty,

substance abuse, homelessness, HIV/AIDS, insurance problems, parenting children with special needs), fathers tell stories of amazing personal development, generative fathering, supportive family and community networks, and effective advocacy. For example, I identified an individual level risk (e.g., a father's lack of knowledge about health care systems) and then explored how the protective factor of fathers' in a peer group facilitated his ability to support the child's special needs. These protective factors emerged in the data collection as well as in participants' sharing during the weekly support group meetings.

Summary of Findings

This section presents a summary of key findings based on the three research questions presented in this study. These questions focused on 1) the strengths or rewards experienced in parenting a special needs child; 2) the challenges faced in parenting a child with special needs; and 3) the needs fathers have in parenting their special needs child. During the final phase of my analysis four themes were recurrent in data for each research question. These recurrent themes (emergent concepts) were personal development, generative fathering, social support, and advocacy. These themes are consistent with an ecological systems/risk-resiliency framework in that: personal development is an individual level concept, generative fathering is a family level concept, and social support and advocacy are community level concepts. Also consistent with an ecological systems perspective, the way men's stories reflect these concepts seems to vary by the child's developmental status and changes over time in the men's personal situation (e.g., moving from homelessness to housed), the family's situation (death of a

partner/spouse), the kin and community networks, or other community level resources (policies).

Parenting Strengths or Rewards

Tell me about the strengths you bring to parenting/caring for your child with specials?

The first research questioned asked fathers/male givers to describe what it is like being the father/caregiver of a child with special needs. Fathers and male caregivers who participated in the focus group and discussions and interviews experienced individual, family, and community rewards or strengths when fathering their child with special needs. Some of these experiences included family routines; child development and socialization skills; positive family interactions; spending time; giving back to their children (generative fathering); serving as advocates; socializing the child through praise or direct teaching; and receipt of informal and formal social support. These rewarding experiences were also described at various levels within an ecological framework: at the individual level—seeing a child make progress in school or a developmental task such as tying his/her shoe; family level--spending time together at home or theme parks, and at the community level—serving as an advocate or participating in MCASG.

Parenting Challenges

Describe your challenges in parenting/caring for your child special needs?

Men who participated in the discussions and interviews experienced individual, family, and community level challenges that included feeling shocked to learn that their child has a special need and acknowledged their personal struggles with substance abuse, homelessness, and joblessness. Fathers wanted to provide better care for their child with

special needs by seeking public health information and knowledge about types/kinds of medicine and treatment for their child need with special needs. They also wanted improved relationships with the child's siblings. Fathers/ caregivers specifically talked about how challenging it was for them to interact with kin and community members who lacked knowledge of the special needs community, get information from health care providers, and deal with the lack of respect they received in health care settings.

Parenting Needs

Tell me the things that you need the most to assist you with parenting/caring for your child with special needs?

Fathers/male caregivers also reported on needs that (if addressed satisfactorily) would improve the quality of their own lives and the lives of children with special needs. Reported needs include: "wraparound services" (e.g., one stop shopping or case management for the child's and family's needs; "social marketing" of male caregivers' "support groups"; interagency collaboration such as through referrals and linkages to supportive networks and services; assistance with improving partner relationships; and cultural competency in services and programs to address racial/ethnic issues as well as the special needs community. Fathers/male caregivers thought that their community lacked developmental advances or technologies (e.g., schools equipped for children with special needs) that are appropriate for their child with special needs. Improved policies are needed to increase access and resources for children and families in educational and health care settings. Fathers also commented on the inadequate resources made available to their high risk, low-income community, East of the River in Anacostia, DC.

My Overall Comparison of Findings with Other Research

The research findings were consistent with the review of literature on fathering children with special needs. Previous studies have also identified many risk factors such as role strain and substance abuse and protective factors such as fathers' commitment and support groups factors likely to influence parent, child, and family functioning and outcomes in families with children who have special needs (King et al., 1999). This study's attention focused on factors related to fathering since there is limited focus on these variables in existing research (Darling & Gallagher, 2004). Participants shared both positive and negative aspects of caregiving for a child with special needs. Strengths, challenges, and needs of fathering children with special needs were selected as issues for exploration because of their potential for generating data for proactive interventions to promote resiliency in these families. I further discuss this study with respect to extant literature later in the Research Implications section.

Strengths and Limitations of this Study

Strengths

One strength of this study is that it was based on a qualitative approach that permitted fathers/male caregivers to share thoughts regarding their child's special needs. Most of the participants enjoyed the dialogue and felt vested in how their stories would be shared. They also appreciated the fact that they were more than "test takers" or "research subjects" that would be forgotten after the study was completed.

This study was also conducted within a specific cultural context by an African American male researcher. Murry et al. (2001) noted that even though the qualitative

approach can also be viewed as a culturally sensitive approach, few studies examining African Americans have used this approach. In addition, a small number of investigators have adopted the qualitative method with African American men. During my initial contact with the MCASG, I was informed that members "were tired of questionnaires." By using a qualitative approach I was able to listen and confirm themes through member checking during weekly MCASG meeting. Member checking ensured that I was on track by subjecting data to review by participants or other members of the target population (Padgett, 1998). As previously stated, I conducted two rounds of member checking to 1) review summaries of focus group and interview data and discuss preliminary findings with MCASG members, 2) repeat member checking processes with a second group of MCASG members during a weekly meeting, and 3) share preliminary data analysis with other group members who did not participate in the study and persons who work with African American fathers (e.g., agency staff).

Another strength that increased trustworthiness or validity in my study occurred through persistent observation. Persistent observation (Creswell, 2003) involved constant questioning. Persistent observation was also facilitated through the use of a journal that I maintained throughout my study. A final strength was the triangulation of themes across multiple data sources. MCASG information packages (e.g., group agendas, flyers from referral organizations) were used as secondary data sources to identify additional needs for study members. In addition to transcripts, notes from peer debriefings and member checking with MCASG confirmed themes and were used to explore interconnections between themes in the three major categories—rewards, challenges, and needs.

Limitations

There are several aspects of this project that limited the generalizability of the findings and the utility of the intervention for implementation with other populations of African American fathers or other male caregivers of children with special needs. Notwithstanding their multiple family roles, participants participated in the study in addition to the regular schedule of activities for their MCASG, which may result in competing demands on father's time.

Qualitative approaches used in this study have not been used extensively in the literature with fathers and have limited use with African American families. Attrition occurred due to fathers or male caregivers' availability to participate in scheduled focus groups or interview sessions. Agency members and support staff conducted recruitment of male participants. The primary goal of MCASG is to provide a forum for men to openly talk about challenges they experience while caring for a child with special needs. However, during the referral process, some participants were unsure if they had a child with special needs but wanted to participate in MCASG or benefit from the services (e.g., child care and transportation) that are provided for group members. Better recruitment strategies could have been used in order to ensure that only fathers, male caregivers, uncles, grandfather, or other male relatives participate in future studies. Focus group and interview times were based on fathers' arrival to group meetings. Some fathers also had competing priorities beyond the MCASG, since they are in families that are likely to have additional problems with family functioning, personal and family finances, child development, health care issues, and other demands. The MCASG staff placed reminder

calls to fathers the day before their scheduled focus group or interview. However, some fathers who committed to attend a focus group or interview did not participate.

HSC is the Medicaid service provider for Temporary Assistance for Needy Families (TANF) families in DC, but there were moderate problems in identifying a large pool of prospective participants. This pool was restricted in racial/ethnic diversity (largely African American followed by Latinos) and income range (poor families). Future research is needed that includes a larger sample in this community with wider racial-ethnic and socioeconomic diversity to further investigate the interrelationships among the risk and protective factors. For example, fathering issues could be examined among Latino families and working class, middle class, and upper class families. This study did not probe for fathers' or caregivers' experiences over time. Therefore, longitudinal studies are needed to that examine these experiences.

Only qualitative measures were used in this study. Although many of the issues that fathers discussed lend themselves to standard measurement (e.g., physical or mental health needs), most of these measures have been developed with mothers. Even though parents could report on their children's behaviors, the range of special needs among the children in the target population is not known, and some of their developmental needs might be difficult to untangle from behaviors that are often assessed in the field (e.g., child behavior problems). In addition, it would be difficult to know if a father's report of his child's behavior problems is the result of poor parenting, the nature of the child's special needs, the parents' own special needs, or parents' inaccurate perceptions of the child's behavior.

The Impact of the Research on Me: What I Learned

Results of this study can be used to develop culturally-sensitive interventions for fathers and caregivers of children with special needs. Specifically, fathers reported a need for comprehensive programs to help them become more effective partners, fathers, and advocates for their children. Current findings suggest fathers would benefit from programs that address personal mental health and social support, relationship issues with mothers/partners, and parenting children with and without special needs. Fathers in this study also reported needing to develop skills in dealing with health care providers and schools to address their children's unique needs. Programs and policies that address the strengths of African American families and rewards of parenting a child with special needs may be most effective in helping fathers to raise their children and draw on available community resources. Programs should also emphasize the reported strengths and rewards that fathers experience as a result of participating in support/kinship networks, taking on the responsibilities of social fathers, increasing their knowledge of child development, and experiencing pride in the special skills and achievements of a child with special needs.

Recommendations for enhancing rewards of the fathers/caregivers should reflect fathers' request for culturally and developmentally appropriate school curricula for children with special needs. Additional schools are necessary that are better equipped to meet the physical demands of children with special needs—e.g., therapeutic pools or wheelchair accessible playgrounds. Information technology and computer training for fathers (e.g., Medlineplus and PubMed) are necessary in order for fathers to provide

greater access to public health information so fathers can learn more about their health or their child's special needs.

Beyond these educational recommendations, examples of prominent themes for services and programs that fathers thought would "make their job easier" in caring for their child included health care screening, individualized mental health counseling or therapy, financial assistance, housing assistance, peer support groups, and job/vocational skill development. Although I did not report on my or fathers' specific recommendations to address their challenges, I include them here as guidance for developing culturally appropriate interventions. These recommendations were gleaned from my observations at weekly meetings, my journal notes, and additional review of the transcripts. They include:

- provide additional information regarding the rights, resources, and responsibilities for custodial and non-custodial fathers (e.g., understanding child custody and visitation rights);
- increase peer net working with other District agencies (e.g., Catholic Community Services, DC Parent Smart, Family and Medical Counseling Services, Inc.);
- develop model fatherhood curricula and parenting programs to be appropriate for fathers/caregivers of children with special needs; provide information on Rapid HIV testing and its impact in communities of color;
- understand problematic marital/partner relationships and difficulties in maintaining friendships with others who do not have a child with special needs);

- provide individual, family, and group counselors to discuss parenting conflicts (i.e., need to parent child with special needs and other children who have no special need);
- provide search assistance to lessen the strain of employment issues (i.e., finding work that will allow for participation in their child's life, including health-related appointments); and
- obtain adequate health care information (i.e., understanding insurance issues and negotiating health care for children with special needs).

I include additional recommendations for addressing fathers' needs based on the recurrent themes that resulted from data analyses in the "Implications for Practice" section of this study.

Implications

My research on strengths, challenges, and needs has implications for future research, policy and practice within the context of fathering children with special needs, particularly for African American fathers in urban communities. It was necessary to understand how conceptual and theoretical perspectives, Black fathers, community-based research, father involvement, cultural context, family interactions, and community programming might impact the environment of fathers/male caregivers of children with special needs. This study was designed and implemented from a strengths-based perspective. I encourage researchers, decision makers, educators, and program planners to build on such approaches to further examine African American fathers, their children, and families.

Research

Research on African American fathers/male caregivers should expand conceptualizations of father to capture the range of activities (e.g., doing errands, planning, providing, sharing activities, and teaching) that fathers do to influence their children's lives and include fathers of children with special needs (Palkovitz, 1997; Marsiglio, Amato, Randal, & Lamb, 2000). Studies should also recognize the diversity of life course, particular images of fatherhood in a broad sense of paternal involvement.

Studies on Black families have always used the White middle class as a referent. Black families will always be perceived negatively according to this yardstick, among other reasons because the majority of White middle-class families in this country, consists of married couples with children under age eighteen (Johnson & Staples, 2004). This research reports on an understudied group of African American fathers and expands research on fathering by focusing on this group as well as the fact that they are fathering a child with special needs. Much of the research on Black men suggests that they are absent, or when present "invisible" in their roles as fathers. There is a need to bring clarity on parenting strategies of children with special needs to the research of Black fathers in the African American community (Livingston & McAdoo, 2007). Such an assessment will assist in crafting policy and influencing human services practice that is more beneficial to Black families (Livingston & McAdoo, 2007).

In this research we found fathers who were very active in their children's lives. Many themes of generative fathering were prominent. This research expands research on fathers, African American fathers, and parenting a child with special needs. I next discuss the implications of this research expansion.

African American Fathers

The median age of Black men in the United States is 28.7 (U.S. Bureau of Census, 2000). Roughly 60% of Black men are between the ages of 18 and 64 with 9% of Black households maintained by single men. Given the high rate of unemployment at the time of their child's birth, children reared in such a context will face a considerable amount of challenges (McAdoo, 2007).

More studies are needed that describe contemporary Black fathers' parenting styles, attitudes, expectations, values, and beliefs about the roles they play in their families and the lives of their children. More culturally sensitive research is required to understand the kinds of socialization activities and interaction patterns that take place between Black fathers and their children in the home and community (McAdoo, 2007). Researchers understand that Black fathers come from all different social strata (e.g., lower-class, working-class, middle-class, and upper-class professionals) and that the role of traditional fathering in the Black community has changed to stepfathers, surrogate fathers, social fathers, and nonresidential fathers. In this research, I found several social fathers—relatives and non-relatives, who rose to do their best to ensure a quality life for a child with special needs. These were Black men, living in high-risk circumstances and parenting under challenging conditions. Yet, there were ecological factors that were protective for these fathers and supportive in their parenting roles.

Future research on fathers will have to not only understand ecological factors that affect fatherhood, but also the complex lives of Black men in American culture (McAdoo, 2007). Studies should focus on the socioeconomic factors such as low

minimum wage jobs that affect Black men across the SES spectrum from low to middle to upper income fathers of children with special needs.

Additional research is needed to understand how behavior and attitudes of the "double bind"—i.e., how the societal double standards of being a Black man and providing for your family affect caregiving roles of fathers who have children with special needs (Cazenave, 1979; McAdoo, 2007). Studies should examine fathers' resilience in providing the economic means for themselves and their family as well as care for their child's special need. Several fathers in this study had multiple children with special needs, and some had also been diagnosed with special needs. In interactions with health professionals, they were "invisible" even though they were there to support their child and/or spouse/partner. They went all out for their child even having to subject themselves to a community where there seems to be considerable stigma at all levels (from grandparents, siblings, child's peers, even in health care settings) and a lack of respect from some health professionals.

Research is also needed to understand how Black fathers of children with special needs are viewed by others in their community. For example, McAdoo and McAdoo (1994) suggest that the father's role in the family may be a function of "outside" or environmental factors that influence a father's access to economic resources and limit his capacity to fulfill the provider role. Fathers in this study expressed their need for job assistance and financial resources to increase their personal development, generative fathering, and advocacy efforts for their children. However, they did not let joblessness (or other risks) prevent them from being involved in their children's lives. This view

reinforces the need for additional studies on how work or employment is viewed as well as fathering across different social classes of African American fathers.

Father involvement

Studies should also examine the impact of father's involvement across the life span of their child with special needs, and how their involvement might impact fathers' responses to community level roles and responsibilities. For example, obtaining vocational and job training might assist fathers in helping their child with special needs in their transition adulthood (Gadsden & Smith, 1995).

Studies on the influence of stigma in shaping fathers' involvement are also needed. Yet, despite several reports of stigma from immediate family (the child's siblings), extended family (the fathers' parents or other relatives), and community members (the child's peers or parents' friends), the men in this study report that they weathered the negative reactions to get the services that their children needed or to simply provide children with a more normative lifestyle (e.g., going to a theme park). Research is needed to determine whether negative attitudes of relatives, siblings, and community members contribute to some fathers' lack of involvement in children's care, and to identify strategies that will help fathers cope with stigma and gain acceptance or support for the important role they are playing in their children's lives.

Multi-site and longitudinal studies of fathers who have children with special needs and other children are needed to examine issues related to siblings. These issues are complex and may not be sufficiently examined with small samples (Stoneman, 2005). Conceptual models of families often view children with disabilities as stressors for their parents and siblings. Research on siblings of children with disabilities are often

conducted from a deficit-based perspective, but should now focus of the strengths of these relationships. Qualitative studies should also be conducted in addition to longitudinal studies so that siblings of children with special needs might tell their own stories. In the present study, I was able to gather data from a father's perspective about the needs siblings might have, but siblings (if developmentally able) might tell a very different story. I understand very well the need to have the sibling's perspective. I am one of those siblings, who was affected by my family's journey with my brother who had special needs.

Community-based research and policies

Research should be conducted to reduce and eliminate health disparities related to access to care experienced by fathers of children with special needs. Health and policy makers should extend the limits of discussion on health inequality and consider what is inequitable in communities underserved or underinsured (Carter-Pokras & Baquet, 2002). Furthermore, research and policies should focus on what we know regarding how to avoid a given disparity--for example, these fathers who are parenting a child with special needs might be at greater risk for depression, substance abuse, hypertension and stroke associated with their role strain and lack of resource for effective coping. Additional studies and policies should also focus on what health determinants are amenable to individual, family, and community level interventions (Carter-Pokras & Baquet, 2002). This research demonstrates that community members such as these fathers are excellent reporters on issues that directly affect them. In addition, many of these fathers are well informed about educational and health policies affecting them and their families. Additional research is needed to better understand fathers who are not as connected (e.g.,

through the MCASG which is connected to a pediatric care facility), as well as to gather the perspectives of providers, spouses/partner, extended family members, and the community at large with respect to their understanding of special needs issues and the needs of these fathers and their children.

Community-campus participatory research

Research and practice in public health over the past several years has seen an increase in partnership approaches that emphasize individual and community participation (Israel, Shulz, & Becker, 1999). Community-campus participatory research will facilitate future research that is supported by combined efforts to address methodological, and broader social, political, economic, institutional and cultural issues of fathers with children who have special needs. There are noted implications for changes that can be made across multiple levels (e.g., individual training and institutional rewards), within and across organizations to include university, government agency, and community-based organizations (Israel et al. 1999). I conducted this study as part of a university-community research partnership between the HSCSN, Inc. and the Department of Family Studies at the University of Maryland, College Park. My theory-based approach and the agency's community-based program provided fertile ground for exploring the issues in this study. The agency's commitment to locate the MCASG in the low-income, high-risk community where these fathers live provided the opportunity for me to have a lived experience similar to those of the fathers, at least once a week. The group embraced me and this provided me, in my opinion, with richer data. Therefore, future research efforts should utilize a similar approach; even quantitative studies might

benefit from a mixed methods approach in which quantitative methods are combined with these or other qualitative methods.

Generative fathering

Research on father-child relationships in families with children who have special needs may expand our understanding of the connection to generative fathering or other theories of paternal involvement (Brotherson et al., 2005; Dollahite et al, 1997; Pleck 1997). Even my limited study provided new insights into generative fathering within a specific cultural context. Brotherson et al. included fathers who had at least one child with special needs as well as another child, but they reported on fathering the special needs child on a very limited basis. In my study, the fathering a child with special needs was the central focus. Although the sample was exclusively African American, this study has implications for studies of generative fathering in general. A key finding that I will continue to explore in future analyses of these data is father's concern with having to make adjustments in their developmental expectations for their child. In addition, some fathers were concerned with their child's transition to adulthood, and what would happen to their child upon the parents' illness or death. The impact of these issues on generative fathering (which presupposes that parenting is to prepare the next generation to be productive and carry on cultural connections) needs further exploration. The disproportionate experience of African American families with a child with special needs suggest that there might be some lessons to learn in how these fathers "rise to the occasion," "step up to the plate," "make sacrifices," and get everyone "on the same page" on behalf of a child with special needs. Finally, additional studies on generative fathering of children with special needs should focus on programs that identify best practices or activities (e.g., support groups) that work well with this population of fathers and provide insights into strengthening parent-child relationships (Brotherson et al., 2005).

Evidence-based programs

Future research should evaluate and address the measurement and effectiveness of programs to improve family functioning for male caregivers in African American and other ethnic minority families. Building the research base for culturally specific, evidence-based practices and programs will take a long time. In the meantime, formative evaluation can be used to culturally adapt existing evidence-based programs for use with African American fathers of children with special needs. In the present study, principles of effective community partnerships were used to mobilize researchers, hospital-based consumer/advocacy groups, and healthcare providers to address fathers' needs in this low income, Black community. In the future, I will continue to use these fathers and agency staff as partners in the research process. I will continue to cull the literature for examples of evidence-based research to further inform my efforts.

This research is but one confirmation of Murry et al.'s (2001) review finding that despite literature suggesting the absence of African American fathers' family involvement, many fathers in African American families are involved in their children's lives. The men in this study, like men elsewhere, have formed their own networks to fill gaps in services to fathers. My intent is to share these findings with these men so that they can continue to be actively involved in family life, strengthen their interactions with family and community, increase their advocacy efforts, and continue the hard work of developing their own parenting interventions for fathers (Palfrey, 2006).

Studies should also explore whether public policies address specific needs of African American fathers with children who are chronically ill (special needs) and the impact of this fathering on at-risk communities. Ironically, these fathers' involvement in

their children's lives might be serving as an important protective factor that buffers potential detrimental outcomes for which the fathers are at risk. Investigations on the role of African American male caregivers should examine other potential protective factors for families who often operate within the stressful environments to which these fathers allude (i.e., of economic strain, substance abuse, homelessness, being ex-offenders, and having little formal education).

Policy

This study has important implications for decision makers and policy makers addressing the needs of fathers/male caregivers of children with special needs. Policies and policy analyses are needed to understand the cultural context and political issues addressed by fathers of children with special needs have and how these fathers are able develop strong households and kinship networks. For example, research is needed to examine state and local level child custody policies that affect fathers of children with special needs. These policies should address issues when unwed or divorced mothers take fathers to court to collect child support, examining whether legal paternity takes on economic connotations that weaken the potential for sustained father involvement (Gadsden & Smith, 1995). The fathers of children with special needs in this study are very involved fathers, who despite the challenges associated with fathering in this situation, rise to the challenge of generative fathering. Current policies that force fathers to pay child support may interfere with the intrinsic motivation and rewards these fathers find in "stepping up to the plate" to care for and advocate for their children.

Finally, I recommend that HSCSN and MCASG continue to attend local legislative hearings and learn more about the District's effort to address gaps in services

identified in its amendment to the "Disability Rights Protection Act of 2006." This legislation was introduced and enacted to ensure that D.C. establish compliance and monitoring procedures to be implemented by all government agencies as described under the Americans with Disability Act (104 Stat. 327; 42 U.S.C § 12101 et seq.). I also suggest that local legislators support and/or attend the Male Caregivers Conference that is planned by the HSC Foundation and the University of Maryland, College Park, Department of family Studies for fall of 2007. The Conference is designed to examine unique rewards (strengths), challenges, and needs of male caregivers within a public health and family policy framework. This conference will also provide insights from professionals who work with male caregivers (e.g., educators, nurses, physicians, psychologists, and therapists) and establish research, programmatic, policy agendas that will identify evidence-based "best-practices" for caregivers.

Practice

Current findings from the study have implications for fathers/ male caregivers of children with special needs. The following recommendations for practice are made based on the findings reported for the three major research topics:

- develop family strengthening interventions and programs designed to empower fathers/male caregivers to become more actively involved with their child with special needs and other children;
- develop community and family leaders who can effectively advocate for the child with special needs;
- expand current referral systems that target fathers and male caregivers;

- increase access to recreational activities (e.g., painting, arts, crafts, and music) designed for children with special needs;
- increase peer-to-peer mentoring and support activities;
- increase social marketing of programs by ongoing participation in local talk shows, public service announcements, and enhanced program materials (e.g., an annual program brochure and fact sheet updates);
- increase community awareness by announcing program events during DC's Area Neighborhood Council (ANC) meeting;
- build community networks with faith-based leaders;
- identify affordable legal services to assist low-income fathers with legal aid to include housing law, family law, discrimination law, consumer protection, and outreach and development counsel; and
- enhance community capacity through better coordination and improved collaborations among agencies involved in supporting fathers, their children and families.

Conclusion

In closing, I suggest that we continue to review themes and sub-themes that are associated with challenges and needs of participants. Highlights from findings on coded themes can be reported in the form of a needs assessment. This needs assessment would highlight strengths, challenges, and rewards that African American fathers of children with special needs shared and can be used to shape culturally appropriate interventions and policies at the Federal, state, and local level. Although fathers feel that they are "invisible" in general in American society and specifically to health care providers, they

come together in the form of support groups to discuss parenting rewards, proactively develop strategies to address challenges and needs, and actively play a role in caring for their child with special needs. Additional research on the role of African American male caregivers is needed to examine other potential protective and risk factors for families living in sociocultural contexts such as these fathers.

My dissertation research permitted fathers/ male caregivers to share their stories and allowed researchers to hear strengths, challenges, and needs of parenting children with special needs. Future research might include focus groups or individual interviews about barriers and facilitators to their participation, other topics they would like to see included, suggestions for intervention design and implementation, and contextual factors that might influence their parenting of a child with special needs. Although I was unable to capture specific *strengths* (given that the men had difficulty with this concept), future research should explore ways to get at these strengths for the potential they hold in enhancing individuals' and communities' capacity to support fathers who care for children with special needs. These fathers function in a context in which there appears to be tremendous odds--e.g., I heard stories of struggles, fights, getting lost to the system, and difficult interactions with spouses, partners, friends, kin, and health professionals. Yet, I also heard these men say, "and still we rise!"

APPENDICES

Appendix A: Informed Consent Form

Informed Consent Form

Fathering African American Children with Special Needs:
Strengths, Challenges, and Needs

Hello,

I am a graduate student in the Department of Family Studies at the University of Maryland, College Park and conducting a study of African American fathers of children with special needs. Specifically, the purpose of this study is to learn more about the Strengths, challenges, and needs of African American fathers who are raising children with special needs.
If you would like to participate in this study, please read and sign the attached Informed Consent Form. If you would like assistance with the form, please let your group leader know. Please contact the individuals listed below, should you have additional questions or concerns regarding the study:

Mr. James C. Bridgers, Jr., M.S.
Doctoral Candidate
Department of Family Studies
1204 Marie Mount Hall
University of Maryland
Phone: 301-405-3672

or

Dr. Suzanne M. Randolph
Department of Family Studies
1204 Marie Mount Hall
University of Maryland
Phone: 301-405-4012

Initials _____ Date _____

CONSENT FORM

Project Title	Fathering African American Children with Special Needs: Strengths, Challenges, and Needs
Why is this research being done?	This is a research project being conducted by Mr. James C. Bridgers, Jr. and Dr. Suzanne M. Randolph at the University of Maryland, College Park. We are inviting you to participate in this research project because you are the biological father or primary caregiver of a child with special needs. The purpose of this research project is to learn more about the strengths, challenges, and needs of African American fathers who are raising children with special needs.
What will I be asked to do?	The procedure involves talking to the researcher about your experiences raising a child with special needs. The researcher seeks to interview fathers of children with special needs who not only understand what is going on, but who are also able to reflect on it and explain how strengths, challenges, and needs concerning their child affects them. Participants will be recruited from a male caregiver advocacy support group (MCASG) of African American children with special needs. You are being asked to participate in one of three focus groups (group discussions), which will take about 90 minutes of your time. You also might possibly be selected to assist us later by participating in an interview that will last about 60 minutes. The group and interview discussions will be held in a private room on site at the Health Services for Children with Special Needs (HSCSN) Pediatric Center in Washington, D.C. We will ask for your permission to tape the focus group and interview discussion. An experienced social worker will be provided by the HSCSN and available on-site to make any necessary referrals should any difficult emotions arise or you find that you may have other needs as a result of the focus group or interview discussion. You will receive $25 for your participation in the focus group discussion, and if asked to participate in the interview later, you will receive an additional $25 for your participation.

What about confidentiality?	We will do our best to keep your personal information confidential. To help protect your confidentiality, all information collected and reported in the study is confidential, and your name will not be identified in any study data or reports. Specifically, (1) your name will not be included on the interview note sheet and other collected data (i.e., audio tapes); (2) a numerical code or made-up name will be placed on the interview note sheet and other collected data; (3) you will be asked to identify yourself by first name only during the focus group or interview and to call others in the focus group only by their first names; and (4) only the researcher will have access to any identifying information. This research project also involves making audiotapes of you with your permission (see below). This audiotape will be used to assist the focus group leaders or interviewer in accurately capturing your responses. Only the members of the researchers' team will have access to them. The tapes will be maintained in a locked file cabinet at the University of Maryland, College Park in the Department of Family Studies, Room 1204 Marie Mount. We will make transcripts from the tapes and destroy the tapes and transcripts upon completion of the study. ___ I agree to be audiotaped during my participation in this study. ___ I do not agree to be audiotaped during my participation in this study. If we write a report or article about this research project, your identity will be protected to the maximum extent possible. Your information may be shared with representatives of the University of Maryland, College Park or governmental authorities if you or someone else is in danger or if we are required to do so by law.

Project Title	Fathering African American Children with Special Needs: Strengths, Challenges, and Needs
What are the risks of this research?	There are minimal risks associated with participating in this study. A resource person at the HSCSN Pediatric Center will be available to you should you have questions or concerns related to your parenting of a child with special needs.
What are the benefits of this research?	This research is not designed to help you personally, but the results from the study will help the researcher learn more about the strengths, challenges, and needs of African American fathers who are raising children with special needs. We hope that, in the future, other people might benefit from this study through an improved understanding of African American fathers who have children with special needs. You will receive a gift of $25 for participating in the study and will also receive a summary of the study findings and recommendations after the project is completed.
Do I have to be in this research? May I stop participating at any time?	Your participation in this research is completely voluntary. You may choose not to take part at all or withdraw from the study at any time. If you decide not to participate in this study or if you stop participating at any time, you will not be penalized or lose any benefits to which you otherwise qualify.
What if I have questions?	This research is being conducted by Mr. James C. Bridgers, Jr. and Dr. Suzanne M. Randolph, Department of Family Studies at the University of Maryland, College Park. If you have any questions about the research study itself, please contact Mr. James C. Bridgers, Jr. and Dr. Suzanne M. Randolph, Department of Family Studies at: 1204 Marie Mount Hall, University of Maryland, College Park, MD20742; 301-405-3672; jbridgers@mayatech.com; suzanner@umd.edu If you have questions about your rights as a research subject or wish to report a research-related injury, please contact: Institutional Review Board Office, University of Maryland, College Park, Maryland, 20742; (e-mail) irb@deans.umd.edu; (telephone) 301-405-0678 This research has been reviewed according to the University of Maryland, College Park IRB procedures for research involving human subjects.

Project Title	Fathering African American Children with Special Needs: Strengths, Challenges, and Needs	
Statement of Age of Subject and Consent ***[Please note: Parental consent always needed for minors.]***	Your signature indicates that: you are at least 18 years of age; the research has been explained to you; your questions have been fully answered; and you freely and voluntarily choose to participate in this research project.	
Signature and Date ***[Please add name, signature, and date lines to the final page of your consent form]***	**NAME OF SUBJECT**	
	SIGNATURE OF SUBJECT	
	DATE	

****Please note: When the consent form requires more than one page, please include a space for the subject to ini and date at the top right-hand corner of each page. The corner should appear as: Initials_____ Date_____ Also, each page must display a page range such as: Page 1 of 2, then Page 2 of 2. This additional information wo confirm that the subject agreed to the entire contents of the consent form. ****

Appendix B: Focus Group Facilitator Guide

FOCUS GROUP FACILITATOR GUIDE

GROUND RULES:

Before we begin our discussion, here are a few ground rules:

1. There are no silly answers.
2. Try to speak one at a time. Raise your hand and I will recognize you in turn. Sometimes there may not be time to get to all of you for a particular response, but I will do my best before moving on to a new discussion topic.
3. Everyone's opinion is to be respected. Try not to debate each other.
4. Feel free to speak up in any order. From time to time I may call on you or may have to interrupt you to move on to another discussion topic.
5. Please respect the privacy of the other members and do not share their input outside of this discussion.
6. Do not use your full name. Use only your first name or a nickname. Please write that name on your name tents so that others and I can refer to you by that name.
7. We have a resource person here for you should you have the need to talk to someone after the discussion or if you have questions that come up as a result of the discussion,

Now let's begin our discussion.

PREAMBLE:

Parents of children with special needs have different feelings about being able to raise a child with special needs. For some, things they may find they have particular strengths; other things they find challenging. I would like to know about your experiences in caring for your child. I would also like to know your suggestions for meeting the needs of fathers and caregivers like yourself. So after our discussion of your experiences and needs, we will spend some time discussing those suggestions.

CONTINUED

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DISCUSSION TOPICS

1. **OPENING**: First, describe what it's like being the father/caregiver of a child with special needs.

Probe: Tell me one of your proudest moments of being the father/caregiver for a child with special needs.

Probe: Tell me about a moment you are sorry happened.

2. **STRENGTHS**: Tell me about the strengths you bring to parenting/caring for your child with special needs?

a. Probe for specific examples: Tell me in what way you are particularly strong or good at parenting your child.

b. Probe: Tell me the source of your strengths/where do they come from?

3. **CHALLENGES**: Describe your challenges in parenting/caring for your child with special needs?

a. Probe for specific examples: Tell me about specific obstacles or barriers you face.

b. Is there anything that is particularly challenging?

c. Tell me what you do to address or to try to overcome these challenges.

CONTINUED

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4. **NEEDS**: Some fathers find that they need assistance in parenting or caring for their child with special needs.

Tell me the things that you need the most to assist you with parenting/caring for your child with special needs.

a. Probe for specific examples at home, school, in health care settings or the community: Tell me about particular services or resources that you need for:
1) Yourself

2) Your child

3) Your family

b. Tell me the extent to which you believe your needs or the needs of other male caregivers are being met.

1) Probe: How are these needs being met?

c. Tell me the suggestions you have for what could be done to meet/better meet your or other male caregivers' needs.

5. **CLOSING**: Is there anything we didn't discuss today that you want to say something about?

Thank you for your participation. Your responses will be very helpful and important in developing effective parenting interventions for parents such as yourself. Thank you, again, for sharing your experiences. END

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Appendix C: Interview Protocol and Guide

INTERVIEW PROTOCOL

Proposed Study: Fathering African American Children with Special Needs:

Strengths, Challenges, and Needs

Time of interview:_____ Date: _____ Interviewer: _____
Interviewee:_____ Location of interview:_____

Research for dissertation study conducted by: James C. Bridgers, Jr., Doctoral Candidate, Department of Family Studies, The University of Maryland, College Park.

Brief description of proposed study: Research on the social and economic history of African American men have aided in our understanding of family conditions. However, African American fathers have been a neglected population in general, with limited studies involving those fathers of children who have special needs or chronic illnesses. The goal of the proposed study is to learn more about the strengths, challenges, and needs of African American fathers or other male caregivers of children with special needs.

Description of interview guide: This interview guide will be used to facilitate the data collection process. The guide is organized around three themes--Strengths, Challenges, and Needs. The interview questions were designed to assist in gaining a better understanding of these themes. Your responses may also lead me to ask other questions that are not included in the interview guide.

Research Questions for the proposed study:

1) What are the strengths of parenting a special needs child?
2) What are the challenges of parenting a special needs child?

3) What do African American fathers need (i.e., types of resources, help) to assist with parenting a special needs child?

INTERVIEW GUIDE

TOPIC 1: PERSONAL AND FAMILY BACKGROUND

1. Please start by telling me a little bit about yourself, your child, and your family.

Probes:

a. Tell me about your birthplace? Tell me about your upbringing mother, father, or kin (probe regarding early care giving experience).

b. Tell me about how long you have lived in the United States/if you have a permanent U.S. residence? In the Washington, D.C. area?

c. Tell me about your work/job/career. Do you work? Are you retired? Are you looking for work? Are you in a technical school or other career development training?

d. If working: what do you do? Full or part time?

e. Did you finish high school or have a GED or post high education?

f. Are you married or partnered? Is your wife or partner the child's mother?

g. Do you live with your child? The child's mother? Tell me about your relationship with the child's mother.

h. Is there anything else you would like to tell me about yourself?

2. I understand that you care for a child who is between 2 and 12 years of age who is a client at the HSC Pediatric Center. Is that correct?

3. Are you the biological father of the child? Are you the primary caregiver of the child?

   Probe: If you are the caregiver:

   Are you grandfather, uncle, cousin, or "play" kin (e.g., godfather)?

4. Tell me about your relationship with your child who is a patient at HSCN.

   a. Is your child a boy or girl?

   b. How old is your child?

   c. Do you know why he or she is seen at the Pediatric Center (what illnesses or conditions does he/she have)? Has your child had this condition since birth?

   d. Do you have other children? Do they live with you? Or with the child who is seen at HSC?

   e. How many boys under age 18? How many girls under age 18?

   f. Are any of them children with special needs? If yes, what are their conditions?

TOPIC 2: REWARDS

Parents of special needs children have different feelings about various aspects of their child (some things they find rewarding, other things they find challenging)? I would like to know about your experience in caring for your child.

5. Tell me about the things that you find rewarding about being a parent?

    Probes: What makes you proud about raising your child?

    Please provide an example.

6. Is there anything else that is rewarding about raising your child?

TOPIC 3: CHALLENGES

7. Tell me what you find challenging.

    Probes: What do you find tough about raising your child? [Probe for challenges at home, school, and health care or community settings.]

    Please provide examples.

8. Is there anything else that is challenging about raising your child?

9. Tell me what you do to deal with these challenges?

TOPIC 3: STRENGTHS AND NEEDS

10. What strengths do you feel African American male caregivers bring to raising children with special needs?

    Probes: What about you personally?

    What about other male caregivers or other African American support groups?

What about mothers?

Or African American families in general—what are their strengths in raising these children? Tell me what is unique about African American families compared to other families (e.g., White, Hispanic, Asian American)?

11. Some fathers find that they need assistance in raising their special needs child. Tell me what kind of assistance you feel you need in raising your child.

12. What about other male caregivers?

13. Tell me how you feel about whether you or other male caregivers who receive assistance are getting their needs met.

14. What suggestions do you have for how these needs could be met/met better for you or other male caregivers raising a special needs child?

CLOSING

In closing there are three more things I'd like you to tell me about:

1. Tell me the one most rewarding aspect of raising your child with special needs.
2. Tell me the one most challenging aspect of raising your child with special needs.
3. In raising your child, what is your greatest need?

Is there anything else you would like to share before we end? Your responses have been very helpful and will be important in developing effective parenting interventions for parents such as yourself.

Thank you for sharing your experiences!

Follow up: Give phone number for follow up. Refer to mental health services or support groups if needed.

Appendix D: Field Notes Template

Field Notes			
Interviewer:	James C. Bridgers, Jr.		
Case Number:			
Date:		**Time:**	
Place:			
Participant:			
Descriptive Notes		**Reflective Notes**	

Field Notes
Self Assessment
Lessons Learned

Appendix E: Participant Information Form

Participant Information Form

To be completed just prior to the focus group discussion, after completion of the Informed Consent procedures

Before we begin the group discussion, we would like to know some background information about you and your child. This will help us to better understand the discussion of the members in the group.

DO NOT WRITE YOUR NAME ON THIS FORM. Please use the identification (ID) number that is provided by the facilitator. Place the ID number at the top right hand corner of this form. If you need assistance, let the facilitator know. The facilitator will collect the form from you.

1. What is your age? _____.

2. What is your marital status?
   - □ Single, never married
   - □ Married
   - □ Partnered, living with partner
   - □ Separated
   - □ Divorced
   - □ Widowed

3. How old is your child with special needs? _____(years)

4. What is/are the special need(s) of the child? _____.

   _____

5. Do you live in the same household as your child?
   - □ YES
   - □ NO

6. Are you a participant in the Male Caregiver Advocacy Support Group?
   - □ NO
   - □ YES: For how long? _____

Please return the form to the group facilitator.

THANK YOU.

Appendix F: Codebook

1. REWARDS
   - 1.1 Interaction
     - 1.1.2 Family routines
     - 1.1.3 Child development or parenting (teaching)
     - 1.1.4 Caregiving
   - 1.2 Social Support
     - 1.2.1 Family interaction/ structure
     - 1.2.2 Family satisfaction/ time
     - 1.2.3 Matriarchal influence
     - 1.2.4 Formal/ informal
   - 1.3 Generative Fathering (also see codes 2.4 and 3.6)
     - 1.3.1 Praise/prouds
     - 1.3.2 Spirituality
   - 1.4 Social Support (also see codes 2.4.2.2 and 3.8.1)
     - 1.4.1 Formal
     - 1.4.2 Informal
   - 1.5 Advocacy (also see codes 2.4 and 3.6)

2. CHALLENGES
   - 2.1 Personal (also see codes 1.1 and 3.10)
     - 2.1.1 Role strain
     - 2.1.2 Coping
     - 2.1.3 Emotional
     - 2.1.4 Disappointment
     - 2.1.5 Shame
     - 2.1.6 Frustration
     - 2.1.7 Anger
     - 2.1.8 Guilt
     - 2.1.9 Depression
     - 2.1.10 Parenting challenges
     - 2.1.11 Shock
     - 2.1.12 Patience
     - 2.1.13 Ambiguous expectations
     - 2.1.14 Hope/ optimism
     - 2.1.15 Pessimism
     - 2.1.16 Generative fathering (also see codes
   - 2.2 Child
     - 2.2.1 Child development challenges
   - 2.3 Family
     - 2.3.1 Stigma family interaction
     - 2.3.2 Substance abuse
     - 2.3.3 HIV

2.4 Community
2.4.1 Stigma community interaction
2.4.2 Knowledge
2.4.2.1 Lack of resources
2.4.2.2 Lack of social support (also see codes 1.4.1, 2, & 3 and 3.8.1)

2.4 Advocacy/efficacy (also codes 1.5 and 3.6)

3. NEEDS
3.1 Outreach
3.1.1 Recruitment of additional fathers or caregivers
3.2 Literature
3.3 Knowledge
3.3.1 Medical Information regarding prescription drug use and interaction
3.4 Resources
3.4.1 Computers
3.4.2 Job Assistance
3.4.3 Classroom education for professional staff (i.e., Staff who interaction with children who special needs)
3.4.4 Playground equipment for children
3.4.5 Therapeutic pools
3.4.6 Arts and Crafts for children with special needs
3.5 Social Marketing
3.5.1 MCASG fact sheets and brochures
3.6 Advocacy (also see codes 1.5, 2.4 and 2.1.16)
3.7 Spiritual inspiration
3.8 Service networking
3.8.1 Formal support groups (also see codes 1.4.1, 2, & 3 and 2.4.2.2)
3.9 Money
3.10 Professional counseling (also see codes 1.1 and 2.1)

Appendix G: Focus group and Interview Case Summary Table

Focus group and Interview Case Summary Table

Pseudonym	**Age of Participant**	**Child's Special Need**	**Focus Group**	**Face –to-Face Interview**	**Reflective Notes**
Mr. A	21	Youth member of group; blindness due to diabetes	X1		Negative Case; was not father or caregiver of child with special needs
Mr. B	23		X3		Negative Case; was not father or caregiver of child with special needs
Mr. C	23	Developmentally Delayed	X3		
Mr. D	25	Sickle Cell Anemia	X3		
Mr. F	26		X3		Negative Case; was not father or caregiver of child with special needs
Mr. G	36	Cerebral Palsy/Developmentally Delayed	X4		
Mr. H	40	HIV	X3		
Mr. I	41	ADD/ADHD/LD/ED	X1	I9	
Mr. J	42	Epilepsy	X3		
Mr. K	43	ADHD/ADD/ED	X2	I1	
Mr. L	43	ADHD/ED	X4		
Mr. M	44	ED/Behavioral Disability	X1		
Mr. N	45	ED/Anger Mgmt		I3	
Mr. O	45	Autism		I8	
Mr. P	45	None reported	X3		
Mr. Q	46	Developmentally Delay/ED	X3		
Mr. R	47	Mentally Retarded	X2	I7	
Mr. S	47	Developmentally	X2		

		Delayed group member and caregiver			
Mr. T	48	Down's Syndrome	X3		
Mr. U	49	Patience	X3		
Mr. V	50	Traumatic Brain Injury		I2	
Mr. W	50	Developmental/LD	X4		
Mr. X	53	Autism/ADHD	X1	I5	
Mr. Y	53	ADHD	X3		
Mr. Z	54	Downs Syndrome	X4		
Mr. AA	55	Ortho; Psoriases	X3		
Mr. BB	55	Developmentally Delayed/Autism	X2		
Mr. CC	57	Speech/Motor/Mental	X4		
Mr. DD	58	None reported	X1		
Mr. EE	68	Autism	X2	I4	
Mr. FF	71	Mental Retardation	X1		
Mr. GG	None reported	Developmentally Delayed		I6	

APPENDIX H

Sensitizing Concepts, Initial Themes, and Examples of Cross-Cutting Concepts

Rewards

In both focus groups and interviews fathers were posed the following questions to elicit positive expressions they had experienced related to fathering a child with special needs:

- What do you find rewarding?
- What makes you proud about raising your child?
- Please provide an example (of your "prouds").
- Is there anything else that is rewarding about raising your child?

Initial "Rewards" Themes

During open coding, transcripts were first read for fathers' responses to these items and coded as free codes. During subsequent open coding, fathers' responses to other questions in the protocols which reflected positive moments they had experienced in fathering their child with special needs were also tagged as "rewards." During axial coding, text units tagged as rewards were further tagged and coded into one of six categories: "interactions," "socialization," "family time," "family routines," "social support," and "generative fathering.

Emergent (Cross-cutting) Concepts for "Rewards"

In addition, each reward was also tagged as related to one or more ecological levels (individual, family, or community). The ecological levels were used to tag the themes as representative of one or more of the emergent themes that reflected the

crosscutting concepts. *Personal development* reflected themes at the individual level and included those that were father-focused and involved the father reflecting on his own developmental accomplishments or shortfalls, reflecting on his feelings when he observed his child's accomplishments or shortfalls (but was not necessarily involved in a shared activity), or on his pride in just being there or being able to serve in the role of father. *Generative fathering* reflected parent-child/family level themes and involved those in which fathers were involved in shared activities with their child with special needs which resulted in teachable moments for their child (e.g., developmental activities), connecting moments in which the father and the target child or his other children and immediate family were engaged in activities with him, expressions of responsibility for his child/children's well-being, pride in being able to give back or pass on skills and values to his child, and positive feelings about his relationships with the child's siblings and interactions with the child's mother that related to the child.

Two crosscutting concepts were used to organize text units that reflected community level themes: *social support* and *advocacy*. *Social support* themes were identified using essentially the same operational definitions as those tagged during open and axial coding; however, only those themes which reflected rewarding relationships at the community level (i.e., assisted or created informal support from kin and peers outside of the immediate family) and formal support from agencies and institutions) were retained under the *social support* cross-cutting concept. Themes that reflected support to/from the child's siblings or mother were tagged under the *generative fathering* crosscutting concept. Finally, for *advocacy*, themes were tagged that reflected father's involvement in activities to engage agencies to provide better services for fathers and/or

their children with special needs, efforts to change laws or policies, and expressions of ways fathers were involved in improving services or addressing the needs for the broader community of fathers and families as well as children with special needs. Palfrey (2006) defines advocacy as an act of "speaking out" or "speaking for" effective interventions and quality health care for parents and children who share the same risks, concerns, and life circumstances.

For *rewards*, themes for these cross-cutting concepts included, for example: 1) *personal development—e.g., "*social fathering" (i.e., just being there to serve in the father role in the absence of biological fathers for relatives or friends who have children with special needs), and "unconditional pride" (i.e., simply taking pride without involvement or facilitation in observing children's accomplishments no matter how small, such as, toileting and attempting to tie ones shoes; 2) *generative fathering*—e.g., applying knowledge about children's development to promote development in their child with special needs and having the ability to identify children's special skills (e.g., wheelchair basketball free throws which led to a Special Olympics championship); 3) *social support*—e.g., participation in created kinship networks, such as with peers in the Male Caregivers Advocacy and Support Group (MCASG); and 4*) advocacy*—e.g., doing all one can to get the best for their child with special needs. I present the data analyses with specific text units for "Rewards" later in this section following my discussion of the initial themes and examples of cross-cutting concepts for "Challenges" and "Needs."

Challenges

Fathers also reported a number of common *challenges*. These *challenges* were elicited in response to the following questions in the protocols:

- What do you find challenging?
- What do you find tough about raising your child? [probe for challenges at home, school, health care setting, community]
- Please provide examples.
- Is there anything else that is challenging about raising your child?
- What do you do to deal with these challenges?

Initial "Challenges" Themes

Initial review and coding revealed that fathers' challenges included the following themes: "relationship difficulties," "role strain," "generative fathering," "parenting conflicts," "lack of resources," "inadequate health care," and "environmental/structural challenges." My working definitions for coding these initial themes follow.

Emergent (Cross-cutting) Concepts for "Challenges"

As I did for "rewards" I also tagged each "challenge" theme as it related to one or more ecological levels (individual, family, or community). After using the constant comparison method to look for patterns in the data and re-reading the focus group and interview transcripts, the concepts that emerged from the organizing framework were applied. *Personal development* reflected themes at the individual level and included challenges that were father-focused such as a father reflecting on his own personal problems with respect to himself (substance abuse) or his troubling feelings (guilt, shame) about the birth of a child with special needs. *Generative fathering* reflected parent-child/family level themes and involved challenges in which fathers expressed lack of knowledge about parenting in general or for his child with special needs and negative feelings about his relationships with the child's siblings (e.g., parenting conflicts and

getting siblings to accept child with special needs) and interactions with the child's mother that related to the child (maternal influences, including interference with his interactions with the child).

Similarly, the two community-level, crosscutting concepts were also used to organize text units that reflected community level challenges. I used the same criteria to tag s*ocial support* challenges as I used for "rewards" and tagged those themes that reflected challenging (negative) relationships or experiences with sources of informal support (extended kin, peers) and formal support (agencies, institutions). For *advocacy*, themes were tagged that reflected father's lack of information about or difficulty getting involved in activities to demand better services for himself, his child, or the broader community of fathers and/or their children with special needs and efforts to change laws or policies; and expressions of poor assessment of available services utilized by and resources for the broader community of fathers, children with special needs, and their families.

Thus, for *challenges*, themes for these cross-cutting concepts included, for example: 1) *personal development*—dealing with the guilt of having fathered a child with special needs, "it runs in my family"; the need to obtain computer skills to get a (better) job; 2) *generative fathering*—the need for additional information on how to deal with the child's siblings and their view of the child; the need to parent that child differently; 3) *social support*—dealing with extended family who stigmatize the family for having a child with special needs; dealing with health care professionals who dismiss fathers or render them "invisible" when accompanying the child to health care visits; and

4) advocacy— fighting for the child's rights in a community where the fathers feels he his "losing another Black man to the 'system.'"

Needs

Finally, fathers reported on concrete needs that (if satisfied) would improve the quality of their own lives and the lives of children with special needs. As I mentioned earlier, I intended originally to ask fathers about both strengths and needs. However, in the pilot interviews fathers could not grasp the concept of "strengths" and thought other fathers might have the same difficulty; so I focused only on the "needs" questions in the protocol and used the "rewards" questions to reflect the strengths of these fathers. In asked the following questions about needs:

- Some fathers find that they need assistance in raising their special needs child. Do you need any assistance in raising your child?
- What about other male caregivers?
- Do you or other male caregivers receive any help in getting these needs met?
- What suggestions do you have for how these needs could be met/met better for you or other male caregivers raising a special needs child?

Initial "Needs" Themes

LaRossa (2005) indicated that there is a gap in the literature concerning personal (individual level) and cultural (community level) needs of fathers. It should be noted that I did not consider these levels of needs as mutually exclusive. Therefore, in my initial coding of "Needs" data, my tagging of text units for ecological levels was done simultaneous with coding for initial themes (rather than as a subsequent process as was

done for “Rewards” and “Challenges”). Five major thematic categories resulted during the coding process: “improved resources,” “wraparound services,” “social marketing,” “interagency collaboration,” “improving partner relationships,” and “improved interventions.”

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