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## **Redefining Responsibility: Welfare Reform, Low-Income African American Mothers, and Children with Disabilities**

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Redefining Responsibility:  
Welfare Reform, Low-Income African American Mothers, and Children with Disabilities

A thesis

Submitted to the Graduate Faculty of the  
University of New Orleans  
in partial fulfillment of the  
requirements for the degree of

Master of Arts  
in  
Sociology

by

Michelle Magee Balot

B.A. University of New Orleans, 2004

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## DEDICATION

This thesis is dedicated to the outstanding African American women who are raising children with disabilities despite financial strains and difficult circumstances. Thank you for trusting me with your stories and for providing me with a glimpse of your realities. Your resilience is marvelous and your strength is encouraging.

## ACKNOWLEDGEMENT

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## TABLE OF CONTENTS

List Of Figures .....	vii
List Of Tables .....	viii
Abstract .....	ix
Introduction .....	1
Background .....	6
Intersectionality Theory .....	6
Gender .....	10
Gender And Caregiving .....	11
Disability .....	13
Defining Disability .....	14
Critical Care .....	16
Caring for Children with Disabilities .....	17
Poverty And Disability .....	19
Race .....	21
Race, Childcare and Kinship Networks .....	21
Kin Networks and Children With Disabilities .....	22
Class .....	23
The Role of Welfare Reform .....	24
Welfare Reform, Caregiving, and Personal Responsibility .....	28
Organizing Poor Women's Lives .....	30
Research Design and Methodology .....	34
The Participants .....	36
Data Collection .....	38
Data Analysis .....	40
Findings .....	44
The Road To Welfare .....	44
The Measure of Good Mothering .....	49
Life At The Intersection .....	52
Lack of Caregiving Support from Men .....	53
Lack of Caregiving Support from Extended Kin .....	55
Lack of Employment Flexibility Despite Education .....	60
Post-Welfare Reform Survival Strategies .....	64
Housing Support from Relatives .....	65
Increased Education .....	65
Informal Work .....	66
Combining Employment with Public Supports .....	68
Discussion and Conclusion .....	70
Limitations .....	72
Significance of the Study .....	74
Implications for Research and Policy .....	74

Conclusions.....	76
References.....	78
Appendix A: IRB Approval Form .....	82
Appendix B: Recruitment Flyer.....	83
Appendix C: Screening Survey.....	84
Appendix D: Consent Form.....	87
Appendix E: Interview Guide .....	88
Appendix F: Resource List .....	89
Vita.....	95

## LIST OF FIGURES

Figure 1 .....	43
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## LIST OF TABLES

Table 1 .....	42
---------------	----

## ABSTRACT

Mothers of children with disabilities face a variety of problems compared to other mothers, but their experiences are not universal. This thesis provides a critical analysis of caregiving and disability by examining the experiences of a group of low-income African American mothers with children with disabilities. It explores the impacts of race, class, gender, and disability on mothers' experiences in the context of conflicting employment and caregiving demands for poor women. Drawing on in-depth qualitative interviews with ten low-income African American mothers of children with disabilities, I illustrate how the struggles of raising a child with a disability are amplified in the face of race and class inequalities. As a result, these women redefine the notion of personal responsibility and employ a series of survival strategies.

### Keywords:

caregiving, disability, gender, race, class, intersectionality, welfare reform

## INTRODUCTION

It is the phrase no mother wants to hear: your child has a disability. Little impacts a woman's view of motherhood as much as those dreadful words. Before birth many soon-to-be mothers delight in the expectation of their impending happy and healthy bundle of joy, but for some women that expectation quickly vanishes with the news of a physical, mental, or developmental impairment. Her life will be forever changed.

I started this project as a mission to find answers to a basic question. How do low-income women experience caring for a child with a disability? I had my own lived experiences of being African American, female, and poor, but for me disability was an unexpected experience. Throughout most of my life I had never noticed anyone with a disability, and even those near to me were not disabled, they were just people. For example, my uncle was unable to walk due to a double amputation, but to me he was just my uncle. He was not a person with a disability because I did not recognize him as having a limitation. Once my own daughter was diagnosed with autism my relationship to disability surfaced for the first time and I began to wonder: Had I been too young to notice? Too naïve to comprehend? Too shallow to care? Clearly, I did not think about disability until it was staring me in the face. As is the case of many able-bodied individuals who go about our daily tasks of living, I just never thought about it before.

Now that my relationship to disability had changed, I could no longer ignore it. Once I got over the initial shock that my daughter was different, I realized that I had also been changed. I became a mother of a child with a disability. More than that, now I was a poor Black woman with the child with the disability. Mothering my child with a disability was much more difficult

than I ever imagined. My mother always said that motherhood is one of the hardest jobs in the world. Now, that seemed like a profound understatement. To me this was foreign territory and I was an outsider.

After my daughter's diagnosis I found myself in the awkward position of having to explain her behaviors to curious and annoyed strangers – that she is not a spectacle; she is not behaving badly; she is not strange; she has a disability, and no, I am not a bad mother, although I silently questioned that fact at times. Besides all of that, there was much work to be done, information to uncover, appointments to make, questions to answer. For some it could have been an easier transition, facilitated by the advantage of class. A more privileged woman could have opted to hire someone to relieve her of some of the strains associated with the constant and intensive caregiving responsibilities. She could spend her time advocating for the rights of persons with disabilities. For some women, like me, it is not so simple. Because I am less privileged, relief is not readily available and I must navigate these uncertain seas alone. Motherhood is a much harder course for women who are impacted by simultaneous race, class, gender, and disability oppressions. For these women relief is less available, and they must manage with little support within a system that emphasizes employment over caregiving responsibilities. The very structure of their lives must change.

I started this project with a clear profile. I needed to locate fellow margin dwellers, low-income African American women raising children with disabilities, preferably with welfare experience. I figured that if I was having this much stress and difficulty, with my husband's steady – if low – income to keep us barely afloat, it must be profoundly more difficult for women with fewer financial resources. The mission was simple: talk to these women and learn about their situations. My task was to locate them and discover their hidden understandings: how they

balance work and family responsibilities and how their decisions are impacted by a post-welfare reform state. The following thesis is a culmination of my efforts to understand the situations of women who are faced with multiple vulnerabilities and the knowledge they have gained from their situations.

### *Why Disability and Welfare Reform?*

Since its inception, the 1996 Personal Responsibility and Work Opportunity Reconciliation Act (PRWORA), commonly known as welfare reform, continues to be the topic of debates, with policy makers, advocacy groups, and researchers from various disciplines continually interested in examining its effects on poor women. PRWORA changed Aid to Families with Dependent Children (AFDC), an entitlement program, to Temporary Assistance to Needy Families (TANF). Policy makers declare the success of welfare reform by focusing strictly on the numerical reduction in the welfare rolls, neglecting to recognize the impacts of the policy on the lived experiences of poor women. Most states support the caregiving of poor women for very young children. Forty-five states grant some women temporary exemptions from work requirements to care for their infants. However, this is usually defined as less than twelve months of age (Seccombe 2007:122 – 123). Nonetheless, in most states parental care for older preschool children is not supported, and the main emphasis is on moving women into paid work rather than valuing family caregiving (Seccombe 2007). Welfare reform generally does not take into consideration the necessary carework done by women who care for children with disabilities.

Childhood disability is associated with a variety of negative impacts for mothers. However, disability analyses alone only partially explain how childhood disability impacts

family life. Race and class are important variables that impact women's caregiving experience. Poor women with children with disabilities are disenfranchised by welfare reform policies. Work requirements and sanctions force poor mothers to choose between caring for their dependent children and participating in the low-wage labor force, even when they provide critical care to their children. In effect, their motherhood roles are pitted against their roles as workers.

This thesis begins with the recognition of the interaction between race, class, gender, and disability, and how these forces affect women's social and economic conditions as well as their micro-level experiences. This project explores four main research questions. In a post-welfare reform context, how do gendered worker and caregiver ideologies affect low-income African American mothers of children with disabilities? How is the current welfare program incompatible with the needs of these women, and are there any advantages? How do they make their work related decisions? Finally, how do they balance work and family? An examination of these experiences is crucial in order to understand how women negotiate economic limitations with employment and family responsibilities in a post-welfare reform era. This study considers how their experiences and their decisions are shaped by welfare reform even when they do not receive a welfare check (i.e. low-wage working women).

This thesis seeks to add to the understandings of the situations of women who are faced with multiple vulnerabilities, and to highlight the knowledge that they have gained from their experiences. This study intends to provide insights into the lives of women who are confronted by issues of race, poverty, and disability. An analysis of these issues points to tensions between the ideals of welfare reform and the actual lived experiences of its participants. It is important to

elicit these experiences in order to provide an understanding of how women balance economic limitations with employment and family responsibilities.

## BACKGROUND

In this thesis I offer an examination of some of the lived experiences of low-income African American women with children with disabilities as they navigate the tensions between caring for their children and working outside of the home. These women's experiences indicate how intersectional social inequalities shape the lives of women. More so, they illustrate the importance of raising disability to a category of analysis when discussing women and family issues. In order to analyze these experiences, I begin with intersectionality theory as a guiding framework for this study. I then move to the broader issues of gender, disability, race, and class.

### *Intersectionality Theory*

Early feminists of color revealed the difficulties of a unitary framework in evaluating the lives of women, emphasizing the inaccuracy of a universal female experience (Truth 1851; Cooper 1892). This issue was further theorized with the development of intersectionality theory, when Kimberlé Crenshaw (1989) coined the phrase in her analysis of the complexity of Black women's experiences with violence. Intersectionality theory explains that social inequality is not simply the result of hierarchical power relations, but rather the interaction and intersection of various identities and power relations occurring at the same time. Multiple forms of oppression interconnect with each other to create various positions of power and privilege. Crenshaw (1989) argues that both feminism and antiracism, when taken alone, erase the experiences of Black women because "both are predicated on a discrete set of experiences that often [do] not accurately reflect the interaction of race and gender" (p. 24). Black women's identities are not



simply the result of either their blackness or their femaleness, because their raced and gendered selves do not operate independently of each other.

Because race and gender are inseparable, Black women do not experience their race to the exclusion of their gender any more than they experience their gender separately from their race. Similarly, Black women's experiences are not simply the result of a race or gender discrimination. Race and gender simultaneously impact their identities, producing experiences that are distinct from those of Black men and White women. The result is a specific set of inequalities that cannot be explained by a race-only or gender-only analysis. Crenshaw (1989) explains:

The apparent contradiction is but another manifestation of the conceptual limitation of the single-issue analysis that intersectionality challenges. The point is that Black women can experience discrimination in any number of ways and that the contradiction arises from our assumption that their claims of exclusion must be unidirectional. Consider an analogy to traffic in an intersection, coming and going in all four directions. Discrimination, like traffic in an intersection, may flow in one direction and it may flow in another. If an accident happens in an intersection, it can be caused by cars travelling from any number of directions and, sometimes, from all of them. Similarly, if a Black woman is harmed because she is in the intersection, her injury could result from sex discrimination or race discrimination (p. 28).

Crenshaw continues that while Black women's situations may be similar to those of both Black men and White women, "often they experience double discrimination – the combined effects of practices which discriminate on the basis of race, and on the basis of sex. And sometimes they experience discrimination as Black women – not the sum of race and sex discrimination, but as Black women" (Crenshaw 1989:28). Collins (1998) explains the complexity of Black women's experiences noting that intersectionality is better suited to explain their situations than race-, gender-, or class-only approaches.

Whereas race-only or gender-only perspectives classify African-American women as a subgroup of either African Americans or women, intersections of race, class, and gender among others, create more fluid and malleable boundaries around the category of African

American women...Intersectionality theory thus highlights how African American women and other social groups are positioned within unjust power relations, but it does so in a way that introduces added complexity to formerly race-, class- or gender-only approaches to social phenomena (Collins 1998:205).

One-dimensional approaches disregard differences in social location, whereas an intersectional approach recognizes how differences in identity and experience are shaped by the intersection of various social dimensions, such as race, gender, and class. Intersectionality theory exposes the problems that occur when those intersections are not acknowledged. One such consequence has been the historical exclusion of African American women from social and political agendas, rendering them “theoretically invisible” (King 1988).

While intersectionality has become an increasingly important aspect of feminist research, its application does not go far enough to uncover the experiences of invisibilized women. In theory, intersectionality may be used to explain the impacts of an infinite combination of social categories. However, in practice, it is most popularly applied to the intersections of race, class and gender, or “triple jeopardy.” In her discussion of multiple jeopardy, King (1998) acknowledges the limitations of both double and triple jeopardy frameworks.

The triple jeopardy of racism, sexism, and classism is now widely accepted and used as the conceptualization of Black women’s status. However, while advancing our understanding beyond the erasure of Black women within the confines of the race-sex analogy, it does not yet fully convey the dynamics of multiple forms of oppression (King 1998:46 – 47).

As Crenshaw (1989) stated, Black women’s oppression can come from many directions. The focus on these three main forms of oppression, therefore, erases the experiences of some women.

One particularly neglected social category in the application of intersectionality theory is disability. The omission of disability ignores the privilege afforded to able-bodied individuals, deeming it an irrelevant social category. Social researchers rarely focus on the knowledge and experiences of women impacted by disability partly because of the invisibility of disability as a

social category. Able-bodied individuals often take for granted the functioning of the body with which people with disabilities struggle. Their privilege is manufactured out of a system that considers them “normal,” whereas people with disabilities are considered “deviant” or “abnormal.” Furthermore, most people are unaware of their able-bodied privilege.

When intersectionality theorists ignore the role of disability on experience, able-bodiedness remains as a taken-for-granted “marker of power” (Collins 1998: 204) that many people possess. Garland-Thompson (2002) explains how the inclusion of disability has the potential to illuminate feminist thought. In her discussion of the need to integrate disability with feminist theory Garland-Thompson (2002) contends, “The most sophisticated and nuanced analysis of disability in my view, comes from scholars conversant with feminist theory. And the most compelling and complex analysis of gender intersectionality take into consideration what I call the ability/disability system- along with race, ethnicity, sexuality and class” (p. 2). The exclusion of disability erases the experiences of some of the most marginalized women, those with disabilities and those who provide care for people with disabilities. Crenshaw (1989) points out that it is problematic to “treat race and gender as mutually exclusive categories of experience and analysis” (Crenshaw 1989: 23). I argue that it is equally problematic to exclude disability as a category of analysis when examining race, class, and gender discrimination. Furthermore, issues of caregiving and disability cannot be fully understood outside of racial and economic contexts.

While disability research tends to focus on the person experiencing a disability in his or her own body, this thesis centers the experiences of raising children with disabilities. I recognize that caring for a child with a disability does not create the same experience as living with a disability; however the experience of raising a child with a disability is a distinct social position

that frequently shares many of the hardships associated with disability, such as financial difficulties, stress, and unequal opportunities (Dowling and Dolan 2001). For women whose lives are located at the intersections of race, class, and gender inequalities, disability seems to exacerbate their already marginalized experiences. It is not the addition of these inequalities that shape their lives, but the interaction.

It is here, at the intersection of race, class, gender, and disability, where I begin this investigation by focusing on the caring work done by low-income African American women with children with disabilities. These women's lives reveal aspects of social life that are obscured by a single-factor analysis. They face simultaneous racism, classism, sexism, and ableism, resulting in hardships that are exponentially more complex, more profound, more difficult, and more invisible than other women's. Their experiences, once exposed, can provide insights to the real life successes and pitfalls of social policy and how it affects the lives of women.

### *Gender*

An examination of women's caregiving experiences must begin with the gendered nature of caregiving. In this section I discuss women's relegation to childcare and housework. Although women have entered the workforce in greater numbers, they still perform the majority of carework compared to men. I begin this discussion with the ideology of separate spheres. This is followed by a discussion of how low-income women and women of color continue to work outside of the home, while maintaining their gendered caregiving responsibilities.

*Gender and Caregiving.* Women's caregiving responsibilities make it inaccurate to discuss caregiving without a gendered focus. This is because throughout modern times most reproductive labor has been performed by women. Women's relegation to the home is rooted in the 19<sup>th</sup> century ideology of separate spheres which divided employment and caregiving across gendered lines (Walter 1966).

This ideology of separate spheres encouraged men to work away from home and women to confine productive activities to the household. Reinforcing these beliefs were stereotypes of men as strong, aggressive and competitive and of women as frail, virtuous and nurturing – images that depicted men as naturally suited to the highly competitive nineteenth century workplace and women as too delicate for the world of commerce (Padavic and Reskin 2002:22).

In middle-class heterosexual families, women were expected to take care of the home, the private sphere, while their husbands worked outside of the home in the public sphere. This sexual division of labor romanticized women's domestic work, deeming women naturally suited for the care of the children. "For a woman to be truly feminine and womanly she had to devote herself to home and family. Thus the ideal, glorified role for women, focused entirely on the more limited and less socially valued domestic role" (Newman and Grauerholz 2002: 283). Although the tasks that women performed often included reproductive tasks such as cooking, cleaning, childcare, and home maintenance, they also performed physical tasks that resembled the same work for which men received pay. Women's reproductive labor also includes the invisible work of making appointments, entertaining guests, maintaining relationships, and caring for the sick, disabled, and elderly. However, the work that women provided in the home was unremunerated and typically devalued (Cancian and Olicker 2000). Even now, the childcare and housework that women perform at home are considered non-work and less prestigious by many, as it is "often trivialized, ignored, and unsupported" (Cancian and Olicker 2000: 9).

At the turn of the twentieth century, the work that men did for pay was considered central to their family's survival, while the work that woman performed in the home was considered supplementary (Walter 1966). The husband's job was to provide economically for the family and the woman's domestic labor was designated to support the paid labor, providing a sanctuary for her husband to return to after the grueling labor of the workforce. "Respectable married women had two responsibilities: creating a haven to which her husband could retreat from the world of work and demonstrating through their own non-employment their husband's ability to support their families" (Padvic and Reskin 2002:23). She was expected to be responsible for the mundane tasks of caring for her family while her higher status man did the important job of working outside of the home to earn a wage. Based on this ideal, his higher status afforded him the constant care and loyal support from his loving wife whose labor was supplemental to his as "[t]he unpaid work that most women did in the home was accorded little social value" (Newman and Grauerholz 2002: 284).

The scenario for working-class women and women of color was very different than upper and middle-class women. Throughout history these women have always participated in the workforce at higher rates than their more affluent counterparts. Paid work was often a necessity for them, either because there was no husband present or because the wages of White working class men and men of color were too low to sustain their families. Their economic situation "required that they contribute to their family's livelihood" (Marger 2002:321). African American women have labored since slavery. Subsequent race discrimination in employment made it impossible for many of them to survive on low male wages after emancipation. Padvic and Reskin (2002) explain, "Black women have always been employed in great numbers, both because employers sought workers for low-wage, low-status jobs and because discrimination

against Black men heightened Black women's need to work for pay" (p. 27). Despite the persistent need for them to work outside of the home, they nonetheless bore most of the gendered responsibilities for caring for the family. Thus, low-income women and women of color were responsible for the demands of household labor, childcare, and low-wage employment.

Women's relegation to the household responsibilities contributed to their continual marginalized positions, even as more middle-class women began working outside of the home. As they entered the workforce their domestic responsibilities did not shrink. They still perform most of the caring work at home. Instead of them being confined to household labor they are participating in full-time employment and then returning home to their "second shift" (Hochschild 1989). These women work outside of the home for part of the day and then return to their homes where they perform the vital work of meal preparation, cleaning, childcare, and nurturance. In general, the shift towards women's increased labor participation was not met with a gendered shift away from their caregiving responsibilities. Despite increased participation by men in household labor and childcare, employed women still perform the majority of housework and family management, and they continue to provide primary care for children (Sayer, Cohen, and Casper 2005).

### *Disability*

Women whose children have disabilities perform carework that is more demanding than that provided for children without disabilities. Therefore, any discussion of caregiving is incomplete if it neglects the impact of childhood disability on mothers' experiences. The following section addresses some of the issues related to caregiving and disability. I discuss how disability is defined and how the nature of carework is different for women with children with

disabilities. This is followed by a discussion of how the child's disability impacts mothers' experiences and how that can translate into social inequalities for the mother.

*Defining Disability.* The most recent disability data from the United States Census reveals that “one in every 26 American families reported raising a child with a disability” (U.S. Census Bureau 2000:16). This is an estimated 2.8 million families with experience caring for a child with a disability. There is some variability in how disability is recognized and therefore there is no universal definition of disability. Although impairment and disability are often used interchangeably, they are different. The World Health Organization identifies impairment as “any loss or abnormality of psychological, physiological, or anatomical structure or function” (Barnes, Mercer, and Shakespeare 1999:23). Braddock and Parish (2001) explain that “disability exists as it is situated within the larger social context, while impairment is a biological condition” (p. 11). One of the most popular disability models is the medical model which describes disability as the result of a physical or mental impairment that limits specific functions or activities of an individual. Stedman's Medical Dictionary defines disability in the following way:

Any restriction or lack of ability to perform an activity in a manner or within the range considered normal for a human being. The term disability reflects the consequences of impairment in terms of functional performance and activity by the individual; disabilities thus represent disturbances at the level of the person (Stedman's Online Medical Dictionary).

The medical model focuses on how a bodily impairment creates a “functional incapacity” (Barnes, Mercer, and Shakespeare 1999:21) that prevents a person from performing “normal” activities. Thus, the solution is to introduce medical, psychological, or educational interventions that will enable the disabled person to function in society. While the medical model of disability



declares that disability is the consequence of bodily impairment, the social model of disability, which is currently the most prominent opposition to the medical model, declares that disability is a social construction.

The social model shifts the designation of disability from a personal medical impairment that requires the individual to be “fixed” or rehabilitated, to the lack of social support that socially excludes people with impairments. This view argues that people are not disabled by physical, cognitive or mental limitations, but by society’s failure to recognize and accommodate their differences, thus creating social barriers that prevent them from participating fully in society. According to this model, disability is the result of discrimination and social exclusion rather than bodily impairments.

This model presents an individual who is disabled, not because he or she is unable to walk, but because society does not accommodate his or her inability to walk. For example, being unable to walk does not in itself, prevent an individual from going shopping, but public transport that is inaccessible to wheelchair users does. The individual is being disabled, not by the impairment, but by the failure of society to take account of and organize around difference (Dowling and Dolan 2001:23).

Dowling and Dolan (2001) explain that based on the social model people are disabled, not by their medical impairments, but by structures and social organization that fail to recognize and accommodate their differences. This model does not deny the existence or the impact of bodily impairments, but identifies society’s role in shaping the disability experience.

Dowling and Dolan (2001) draw on the social model of disability to move beyond individual experiences of disability to experiences at the family level. They argue that “social organization disables not just the family member who has an impairment, but the whole family unit, specifically when that family member is a child” (Dowling and Dolan: 2001:24). This view is supported by a growing number of researchers who examine how childhood disability impacts

families (Breslau, Salkever, and Staruch 1982; Marks 1998; Litt 2004). Some of these difficulties stem from the type of caregiving required to raise these children.

*Critical Care.* The structure of carework changes when there is a child with a disability in the family. The additional caregiving time that mothers spend with their special needs children is unlike that of mothers of children without disabilities. Children with special health needs require care that is qualitatively different than that given to typically developing children. They tend to have increased emotional needs, developmental difficulties and/or behavior problems. The childcare provided by parents of children with disabilities is often critical to their health, development, and survival. This type of care often includes health management, daily care, emotional support and physical assistance across the life course. In many cases “the care of disabled children is more demanding” than that of children without special needs, and “the demands are not restricted to the early childhood period, but often continues into adulthood” (Lewis, Kagan, and Heaton 2000:1031). This is characterized as critical care which “often requires specialized knowledge, extensive elaboration with health professionals, and the acquisition of skills by parents usually associated with professional health care work” (Leiter et al. 2004:382).

Mothers with children with disabilities often assume the role of caregiver more intensely than the usual feeding and bathing requirements of mothers with typically developing children. These parents often provide home based therapies and perform medical tasks for their children especially when the children’s activities are severely restricted by physical, cognitive, or mental impairments. The more extensive the disability, the more dependent the child is on the mother for daily caregiving. The constant supervision required to take care of these children has impacts

on the health of these women as they experience fatigue and poor health as they have to immerse themselves for periods well beyond infancy in the care of these children. As a result of the critical care required of mothers of children with disabilities, these women and their families often face a range of inequalities that others do not (Dowling and Dolan 2001). Researchers have identified several problems complicating the lives of these families that other families do not have to deal with such as increased costs (Lukemeyer, Meyers, and Smeeding 2000), restricted employment opportunities (Shearn and Todd 2000), and reduced quality of life (Park, Turnbull, and Turnbull III 2002). This has led researchers to conclude that families with children with disabilities are different from other families (Dowling and Dolan 2001). In addition to the social inequalities faced by these families, they are more likely to be poor compared to other families. Dowling and Dolan (2001) explain that these families are more likely to “experience the double difficulty of lower incomes and greater expenses” (p. 32). These families have lower incomes to cover family and household expenses and greater expenses related to the care of their children (Lukemeyer, Meyers, and Smeeding 2000).

*Caring for Children with Disabilities.* The women in the current study would not be considered disabled by either the medical or social model of disability because they do not suffer from their own impairments. However, they are disenfranchised, nonetheless, by their association to disability due to the critical care that they provide to their children. Ryan and Runswick-Cole (2008) contend that mothers of children with disabilities may experience a form of disablism, “as they experience directly and by proxy many of the discriminatory practices and attitudes their disabled children face” (p. 202). Their relationship to disability is as relevant as if they were disabled themselves.

Childhood disability has been found to significantly impact mothers by way of increased stress, decreased employment opportunities, and increased caregiving requirements. Dowling and Dolan (2001) claim that it is not the care burden – caring for a child with a disability – that causes a reduction in the quality of family life, but “structures, systems, and attitudes of society towards the family” (p. 22). Their research which was based on thirty-eight in-depth interviews with parents – mostly mothers – and caregivers of children with disabilities ages twelve months to over eighteen years of age exhibits how disability inequality is not limited to the child with a disability but can greatly impact the family as well.

The effects of childhood disability are contingent on the socioeconomic location of the family. More privileged families face fewer difficulties in integrating the care of a child with a disability into work and social life due to increased private and professional supports. “These families can purchase the labor of others to ease their children into schools, to make the transition from school to home, and to help with the everyday tasks of cooking, cleaning, and childcare. They have access to a range of therapeutic options and generally face little suspicion about their parenting” (Litt 2004:625). There exists a huge gap between the advantages afforded to upper and middle-class women raising children with disabilities and the struggles of poor women charged with the same responsibilities. Litt (2004) explains that the combination of low-paying jobs and poor women’s dependency on public resources means that they “have few resources about how to organize carework” (p. 626). They do not have the flexibility of options and caregiving relief that other families have. I do not mean to imply that childhood disability does not impact the experiences of other women with children with disabilities. I do, however, suggest that the availability of social support, increased economic security, and greater childcare

options buffer upper and middle-class women from some of the negative impacts of disability on the family.

*Poverty and Disability.* The effects of raising children with disabilities on poor families is a growing concern as indicated by the emergent body of research conducted on the subject that attempts to unveil the previously hidden impacts of childhood disability on family life in low-income households. Researchers studying the intersection of poverty and disability have noted its impacts on several issues such as childcare options (Boothe-LaForce and Kelly 2004), mother's employment (Breslau et al 1982; Shearn and Todd 2000), caregiving requirements (Litt 2004; Leiter et al 2004, Park et al 2004), and quality of family life (Dowling and Dolan 2001).

According to the U. S. Census Bureau, families with children with disabilities reported lower median incomes than all families raising children and children with disabilities and “were more likely to live in poverty than other children” (U.S. Census Bureau 2000:18). In 1999 the Bureau found that 12.6% of families raising children without disabilities lived in poverty while 21.8% of families raising children with disabilities lived in poverty. Among both types of families, families with a female householder (no husband present), experienced a higher proportion of poverty, with 42.7% of single mothers raising children with disabilities being poor compared to 31.5% of single mothers raising children without a disability. According to Census data, Black families with children with disabilities reported the highest poverty levels (37.7%) compared to any other race raising children with disabilities. Among White families raising children with disabilities, 14.4% lived in poverty. Based on these statistics we can see how race, poverty, and disability intersect, how they “are not completely separate sources of disadvantage

that parallel each other. Race and disability are overlapping identities that are both related to systemic inequality” (Pokemper and Roberts 2001: 6).

The coincidence of poverty and disability has become an increasingly important topic among scholars in various fields such as law, sociology, social work, and child development as indicated by the increase of research on disability and family life. Childhood disability has been shown to reduce the financial resources of working families and to decrease the already limited resources available to poor families. Within this growing discourse is an increased concern for the experiences of poor women raising children with disabilities. Despite new research initiatives the voices of this vulnerable population remain largely unheard. Rosman and Knitzer (2001) explain that “we still know very little about the population of families who are both on welfare and living in or near poverty and also have children with disabilities” (p. 25).

While there has been an increase in the literature that examines the impacts of poverty on caring for children with disabilities, existing research tends to universalize the caregivers’ experiences, focusing on the care burden and changes in labor force participation. Discussions such as the consequences of caring, the caregiving experience, and meanings of motherhood for mothers with children with disabilities (Landsman 2009) tend to neglect the impact of racial and socioeconomic inequalities on the lives of women. Researchers neglect to account for differences in race and class that present low-income women of color with unique caregiving experiences and employment limitations, not to mention the “patterns of poverty and exclusion” (Pokemper and Roberts 2001:7) and unequal access to quality medical care that contribute to “higher incidence of illness and/or disability” (Pokemper and Roberts 2001:3) among African Americans.

## *Race*

Race is an important dimension of social life as it relates to caregiving. This section examines race by exploring the importance of kinship networks for African American women. These women have relied on the support of kinship networks since slavery, and poor Black women continue to rely on them for survival. Childcare support is especially crucial for low-income African American women whose children have disabilities because of the lack of affordable and qualified facilities to care for these children.

*Race, Childcare and Kinship Networks.* Kinship ties have been important to people of African descent since the beginning of slavery. African families were ruthlessly separated during the slave trade, dividing mothers from their children and husbands and wives from each other. While some slaves were blood relatives, unrelated slaves worked and lived in close proximity, creating family-like networks in which they developed and maintained strong relationships with each other, and participated in rituals. Although many slaves maintained nuclear family relationships as well, strong extended kin networks were intensely valuable to Africans in America. Roberts (1997) explains:

Most significant, slaves created a broad notion of family that incorporated extended kin and non-kin relationships. Although the only recollection Frederick Douglas had of his mother was “a few hasty visits made in the night,” he played with his cousins and grew close to his grandmother Betsey until he was hired out at age nine. Because families could be torn asunder at the slave master’s whim, slave communities created networks of mutual obligation that reached beyond the nuclear family related by blood and marriage...Children were expected to address all Black adults as “Uncle” and “Aunt,” a practice Gutman suggests “socialized [children] into the enlarged slave community and also invested in non-kin slave relationships with symbolic meanings and functions (p. 54).

Kin networks included extended family members such as aunts, uncles, grandparents, and unrelated slaves, as networks often reached across household boundaries to include neighbors and friends.

Networks of shared care for African Americans have continued to be important, especially for very poor families. Roberts (1997) explains, “The slaves’ communal bonds left a legacy that continues to shape the meaning of family in the Black community today. This flexible family structure has proven to be an adaptive strategy for surviving racial injustice” (p. 54). Stack (1974) defines these kin relationships as “extensive networks of kin and friends supporting, reinforcing each other – devising schemes for self-help, strategies for survival in a community of severe economic deprivation” (p. 28). She documents the resourcefulness of survival strategies of poor African Americans, describing the “collective help of kinsmen” (Stack 1974:24) that consisted of exchanging goods and services, sharing resources, and providing care for each other’s children. Poor Blacks depend on these communities for survival as they provide material and emotional support, including childcare assistance. Extended kin provide care for each other’s children by supervising them, feeding them, teaching them, and disciplining them. This support relieves poor mothers of the need to provide constant care for their children, freeing them to work and to participate in other activities.

*Kin Networks and Children with Disabilities.* Brewster and Padvic’s (2002) research shows that African American women’s reliance on kin-networks for childcare has declined over the past 30 years coupled with an increase in dependency on childcare centers. However, according to the researchers, the trend is more pronounced for upper- and middle-class Black families, as working-class and poor families still rely heavily on kin networks for material



support and childcare. While the lack of available and affordable childcare is an important issue for many families, this issue is magnified for families whose children have special needs.

Childcare is a major issue as it relates to maternal employment, especially in the case of low-income single mothers' need to participate in the labor force. When there is a child with a disability in the home, the need for dependable childcare is especially crucial. A lack of affordable and qualified childcare limits mothers' availability for work, therefore limiting the financial resources for families with children with disabilities. Boothe-LaForce and Kelly (2004) found that preschool age children with disabilities participated in formal childcare in lower percentages than typically developing children. These researchers state that although all early childhood programs are required to be accessible to all children, many of them do not have the training and resources necessary to meet the needs of children with disabilities. Boothe-LaForce and Kelly (2004) argue that adding the additional costs of childcare to other related expenses, such as transportation, medication, and special services "may be problematic for families, particularly for those who are low income and children with special needs are overrepresented in poverty samples" (p. 14).

### *Class*

In this section I examine class through the lens of welfare reform and its impact on women's employment and caregiving choices. I examine the role of welfare reform by comparing it to welfare before 1996, and by noting the problems of both policies. A focus on welfare elucidates the economic context of women's carework and how poor women balance work and family.

*The Role of Welfare Reform.* More than ten years have passed since President Clinton changed the structure of American welfare policy by enacting the 1996 Personal Responsibility and Work Opportunity Reconciliation Act (PRWORA), known as welfare reform. The reform altered the lives of poor women across America. PRWORA transferred the nation's responsibility for its poor residents to the state level and ended welfare benefit entitlements to the poor. However, although PRWORA is seen as the most restrictive welfare policy to date, it is not alone in its punitive effects on poor women.

Previous welfare policy, in the form of Aid to Families with Dependent Children (AFDC) was intended to protect the caregiving roles of women, and deter them from entering the workforce.

Welfare programs for poor families – from state and local mother's pensions to federal A(F)DC – were originally based on the widely held material belief that children received the best care from full-time mothers. Materialist reformers, mainly White upper-class and middle-class women hoped that these programs would ensure that poor mothers could stay at home with their children, and portrayed aid as compensation for the work of raising good citizens (Reese:2005:22).

While the program's original design was intended to safeguard women's roles as caregivers, "so that they [poor single mothers] might engage in the full time care of their children" (Mink 1998b:1), welfare payments have always been meager and, therefore, have never sufficiently supported poor families (Piven and Cloward 1971). "From the outset, these programs were grossly inadequate to meet the needs of female headed families" (Roberts 2004a:11).

Consequently, poor mothers often combined welfare payments with paid work – either legal or illegal – in order to make ends meet (Kemp, Jenkins, and Biehl 1996). Combining public assistance with paid work was a survival strategy even before the 1996 welfare reform, because poor mothers often found it "almost impossible to survive within the benefit levels of welfare. Poverty is still very much a condition of their lives" (Kemp, Jenkins, and Biehl 1996:78).

To make matters worse, poor mothers were subject to the constant scrutiny of welfare caseworkers, having to disclose intimate details of their lives, in order to continue receiving assistance. “This probing forces recipients to assume a submissive stance lest offended caseworkers throw them off the rolls. With the power to cut a client’s lifeline, bureaucrats often berate and degrade the mothers who pack the welfare office, adding to the humiliation of begging for public assistance” (Roberts 1997: 226). Women who received welfare navigated the devaluing constraints of the welfare system, while providing care and support to their dependent children.

Despite its problems, welfare was a necessary resource for poor single women who did not have other forms of financial support. In general, most women on welfare moved into the workforce within two years of receiving aid. However, when employment work was not available, such as in the case of a job loss or illness, they had the option of returning to welfare as a temporary “safety net” until their situations improved. This is the distinguishing feature of welfare reform.

While the welfare system has gone through a series of reforms over the past 40 years to decrease welfare dependency – each implementing stricter regulations such as increasing work requirements for women receiving aid, and proclaiming marriage and hard work as the tickets out of poverty – the 1996 welfare reform was the turning point in welfare history. PRWORA legally forces poor mothers to choose between caring for their children and working outside of the home (Mink 1998a), by declaring the workforce to be the proper place for poor women. The removal of welfare entitlements meant the elimination of the temporary “safety net” that had been available to poor women. As a result of even stricter regulations and firmer policies, poor women can no longer receive public aid indefinitely, but are limited to five years or less

depending on how stringent the state policies are in which recipients live. Edin and Lien (1996) explain “ [m]others who fail to sustain their families with their wages, after a lifetime limit of five years, have no government safety net to fall back on” (p. 253). Now, poor women no longer have the option to return to welfare if they needed to, regardless of the need.

One outcome of this policy shift has been a dramatic drop in the welfare rolls, which has been interpreted as a success of the program. In its 2003 proposal suggesting the reauthorization of PRWORA, the Bush Administration declared that “given the great success achieved by the 1996 reforms, the basic structure of TANF and childcare programs should remain intact” (“Working Toward independence” 2002: 13). The report echoes other claims that the 1996 reform was successful, noting that since its implementation there has been a decline in the number of people receiving welfare. The report states that “[t]he result has been an historic decline in the welfare rolls, substantial increase in employment by low-income mothers, unprecedented increases in earnings by low-income female heading families, and a sustained decline in child poverty, particularly among African-American children” (“Working Toward Independence” 2002:3).

While the number on welfare has declined, this statement ignores the impacts of the reform on the poor and working poor. For example, a large percentage of people who left welfare for work found very low-paying jobs and a large percentage of them remain in poverty (Hays 2003; Lindhorst, Mancoske, and Kemp 2000). As a result, those who oppose the reform are concerned about its long-term impacts on the situations of poor women. The White House report and others like it do not mention that this “historic decline” in the welfare rolls is associated with increased economic hardship and vulnerability of former welfare recipients (Hays 2003).

At the core of welfare reform, beneath the political rhetoric proclaiming America's desire to promote citizen self-sufficiency by ending poor people's reliance on public assistance, there is a clear racial context. After Black women fought for access to welfare during the Civil Rights Movement, the face of welfare changed from the worthy White virtuous mother to the poor undeserving women of color (Neubeck and Cazenave 2001). These women were not seen as worthy stay-at-home mothers who should be supported by the state to raise good citizens, rather they were characterized as "welfare queens."

Although we should not underestimate this class dimension of programs that regulate welfare mothers it is crucial to see that race equally determines the programs features and popularity. Because class distinctions are racialized, race and class are inextricably linked in the development of welfare policy. When Americans debate welfare reform, most have single Black mothers in mind (Roberts 1997:110).

Welfare's original design supported the carework of White women, whereas the current reformed policy targeted the caregiving of Black women, resulting in the increased regulation of all welfare recipients. What was once designed as a safety net for middle-class White women to protect their caregiving responsibilities now emphasizes employment over caregiving. It is important to note here that although Blacks are seen as the face of welfare reform, they are not the majority. However, they do make up a large proportion of racial/ethnic groups receiving welfare and are, therefore, disproportionately impacted by welfare reform. According to the Administration for Children and Families, in 1997, 35% of TANF recipients were Black, 36% were White, 21% were Hispanic, 4% were Asian. In 2003, 38% were African American, 31% were White, 24% were Hispanic, and 2% were Asian (Administration for Children and Families). Despite these statistics, many continue to see poor Blacks as paradigmatic welfare recipients. Now it was the mother's individual responsibility to provide economically in order for her family to survive.

*Welfare Reform, Caregiving and Personal Responsibility.* One of the socially damaging aspects of the reform is the construction of a double-standard for mothering, which supports racialized expectations of women. While middle-class White women are judged negatively for not being home to take care of their children, poor women are told to get jobs in order to be worthy role models and good mothers. Poor women have long been the focus of many heated debates that scrutinize their mothering and question their morality. The good mother is one who is financially independent and who takes personal responsibility for caring for her children by participating in the paid workforce. Sharon Hays (2003) contends that

[A]rguments that demonize welfare mothers, laying the blame for widespread social ills at their doorstep, completely ignore the broader and historical basis of poverty, single parenting, and welfare use. All welfare mothers, like all individuals, are embedded in, and socialized by, social institutions; all are shaped and constrained by the structures of our economic, cultural, and political systems. When we make use of the “personal responsibility” framework and find them guilty, we are simply allowing the proverbial trees to obscure our view of the larger forest (p.126-127).

Welfare reform’s message is ideologically inconsistent as it forges a relationship between independence and personal responsibility by identifying low-wage employment as the measure of good and proper mothering. This reasoning ignores the invisible paid work done by low-income mothers and the level of dedication such women have to their children. More so, it deems their participation in the low-skilled, low paid labor force as testament to their commitment to their children. Their mothering is viewed as insufficient, their decisions are invalidated, and their experiences are made invisible.

Welfare reform declares that if poor women truly care for their children they will be responsible and find a job, any job, rather than rely on the state to provide for them. It is their individual responsibility to make sure that their material needs are met. This relegation to the workplace robs them of the right to choose between caregiving and working outside of the home,

and sets their roles as mothers against their labor market participation, by emphasizing employment over caregiving responsibilities.

Welfare reform's philosophy – that paid employment is the test for good parenting and should take precedence over nurturing children – accords no economic recognition for the work of raising children and generates policies that foreclose recipients' decision to care for their children at home. It is part of a broader culture that stigmatizes the household labor of poor, single, and minority women in particular (Roberts 2004b).

Poor women's mothering roles are judged not by their capacity to care, but by economic qualifications and racist assumptions. The logic is that these women lack the moral standards required to be good mothers because they do not have the economic resources required to be stay-at-home mothers. They need to go to work to prove that they are good mothers and worthy citizens. Those who do not are considered socially irresponsible delinquents who are the cause of a host of social problems.

The view of the welfare mother continues to be that of the undeserving poor. Fueled by racist attitudes toward Black women's reproduction (Roberts 1997) and supported by White middle-class feminist views of independence through paid employment (Mink 1998a), welfare reform strips poor women of the choice between caring for their children and working. Yet the injustice of the reform is hardly questioned in political venues. "Ending welfare as we know it" is viewed by many as the long-awaited policy that America has needed to transform poor women into responsible mothers, and to remove them from the public consciousness. TANF's construction of personal responsibility situates low-income women as individually liable for their suffering and separates their experiences from the social context. This focus blames poor people for being poor by ignoring the structural causes of poverty "such as the shortage of living-wage jobs and racial discrimination" (Reese 2005:27).

The women in this study, even those who work outside of the home, do not live up to the welfare reform's ideals of personal responsibility for several reasons. For example, the structure of low-wage work such as low-remuneration, inflexible hours, and low-prestige are incompatible with their caregiving needs. Secondly, the ideology of personal responsibility inherent in welfare reform is inconsistent with their understandings of good mothering. As a result, they refine the notion of personal responsibility so that it is compatible with their lived experiences.

*Organizing Poor Women's Lives.* Welfare reform's legalized emphasis on low-wage work devalues the carework provided by low-income women. In addition, the conditions of low-wage work are incompatible with women's caregiving needs, shaping poor women's caregiving decisions. When women internalize the value of paid work over caregiving, they unknowingly encourage the very social organization that marginalizes them. Jill Weight (2006) argues that "carework – the labor of being responsible for and caring for dependents – is organized by forces originating outside of women's lives as they work in the low-wage labor market in the post-welfare restructuring context" (p. 333). She examines how low wages combined with family needs and conditions at low wage jobs affect women's caregiving experiences. She identifies three discourses that shape low wage-mother's caregiving and focuses on how mothers align with these discourses, using them both to understand and compromise their situations.

The first is a mothering discourse which Weight explains is often echoed on an institutional level, reflected by society's hailing of the idealized Standard North American Family (Smith 1993), the image of the two-parent nuclear family. Second, the discourse of work enforcement is characterized by mandated entry into the workforce for welfare mothers. Finally, a discourse of neoliberalism seeks to "separate the private realm of the family from the public



realm of the market and the state” (Weight: 2006:348), so that the conditions faced by these women are reflections of family life and not the state or the labor market. Weight explains that for low-wage mothers, the more influential mothering discourse draws attention away from the conditions of low-wage work to their personal shortcomings. As a result they think that they are solely responsible for their caregiving practices as if they live in a vacuum unaffected by structural forces.

As mothers try to balance low-wage work after welfare reform they face low wages and a lack of resources combined with stressful economic conditions, such as working long hours and being unable to pay for living expenses. Following Weight’s mothering discourse these women blame themselves for the lack of time and unavailability to their children. The same is true if they are unable to provide financially for their children and their families needs.

[I]n using the framework of the mothering discourse, a subtle shift occurs in which mothers, to varying degrees, express their difficulties in terms of how they are failing to live up to ideal mothering rather than how their arduous material conditions prevent them from caring for their children in ways they deem appropriate (Weight 2007:343).

The mothering discourse places sole responsibility for a woman living up to the unattainable ideals of the Standard North American Family on the mothers and none on the social structure in which she lives. The discourse of work enforcement places the importance of carework by work ethic and personal responsibility in mothers to be self-reliant, a theme strongly supported by the 1996 Personal Responsibility and Work Opportunity Reconciliation Act.

Alternatively, low-income women who care for children with disabilities do not have the option *not* to spend time with their children. Their time and care is crucial to the survival of these very dependent children well into the life course. Welfare policy does not take into account the critical caregiving responsibilities carried by this group of women. According to Rosman and Knitzer (2001), welfare reform does allow states to exempt a percentage of its

welfare recipients from work requirements, but there is no indication how many are used for mothers with children with disabilities. Booth-Laforce and Kelly (2004) explain that the issue of childcare is complicated because of the unavailability of qualified professionals to care for them and the high cost of specialized care. As a result, the direct costs of caring for a child with a disability are magnified for poor families. In the face of low or no incomes or meager welfare payments, the additional expenses required to care for a child with a disability can be extremely burdensome.

Poor mothers with children with disabilities are likely to be in very difficult situations as they try to balance welfare regulations, the conditions and demands of low-wage work, and the care they must provide to their children. Mink (1998b) argues that “for some mothers responsibility for children simply cannot be reconciled with wage earning” (p. 116). As poor women with children with disabilities negotiate the dual roles of caregiver and provider after welfare reform, they may experience acute incompatibilities between caregiving and employment. Mink (1998b) explains:

The difficulties faced by poor single mothers with disabled or chronically ill children may not be typical, but they are instructive. Hardship creates stark and often unresolved conflicts between outside work and care-giving. For single mothers who are poor – as for single or married mothers who are better off – wage earning is a privilege, affording for those who can hire surrogate care-givers and costly for those who cannot (p. 117).

When mothers cannot find work because of childcare limitations they are likely to be sanctioned or lose their welfare benefits. Those who do not receive welfare face losing their jobs, or trouble finding good paying jobs that will accommodate their needs to provide primary care to their children. The caregiving required to care for a child with a disability conflicts with notions of personal responsibility through the paid labor force as prescribed by welfare reform.

Taken together, this literature suggests the importance of critically examining the lives of low-income women with children with disabilities. Low-income African American women with children with disabilities have experiences that have not been previously explored. The ability to balance work and family in a post-welfare restructuring context is an important issue for many poor women. For this particular group of women, race, class, gender, and disability intersect in ways that further complicate the work-family balance they must achieve. The goal of this study is to bring the experiences of these women to the forefront and to discover how they manage the conflicting demands of work, welfare, and critical caregiving. In the next section I describe the methods used in this project in order to accomplish this goal.

## RESEARCH DESIGN AND METHODOLOGY

This section presents the methods I used to answer the research questions posed in this thesis. The purpose of this study is to examine the lived experiences of low-income mothers raising children with disabilities, and how their experiences have been shaped by the 1996 Personal Responsibility and Work Opportunity Reconciliation Act. My goal is to gain a “thick description” (Geertz 1973) of the circumstances surrounding these women’s caregiving and employment decisions. I use an intersectional framework to examine how the interaction of race, class, gender, and disability shows up in their lived experiences. To explore these experiences, I conducted a series of in-depth qualitative interviews with ten low-income Black women with children with disabilities. This research was approved by the University of New Orleans IRB Committee and deemed compliant with both University and federal guidelines (See Appendix A).

In order to participate in this study, the women had to meet two criteria. First, participants had to be either a biological or adoptive mother of a child with a disability. Second, they had to have received in the past, or currently receive at least one form of public support: Temporary Assistance to Needy Families (TANF), food stamps, Medicaid, Supplemental Security Assistance (SSI), or housing assistance. All of these programs are means-tested, meaning that eligibility requirements are based on a person’s income, which must be below a certain level. The following are definitions of these programs.

- *Temporary Assistance to Needy Families (TANF)*: A federal program offered through the Louisiana Department of Social Services, Office of Family Support, which provides cash assistance to poor families with children. Assistance is limited to five years over a

lifetime, and recipients must work within two years of receiving aid. The Louisiana Program is called Family Independence Temporary Assistance Program (FITAP). The government delivers FITAP benefits electronically onto a Louisiana Purchase Card, a card that is used in the same manner as a debit card.

- *Food Stamps*: A federal program offered through the Louisiana Department of Social Services, which provides low-income families with monthly benefits to buy food. In Louisiana, the government delivers food stamp benefits electronically onto a Louisiana Purchase Card. Qualified food purchases do not require sales tax.
- *Medicaid*: A federal program offered through the Louisiana Department of Health and Hospitals, which provides medical coverage to the poor. The program enables individuals to visit the doctor and hospital with no out-of-pocket expense. Families who receive FITAP or SSI are automatically eligible for Medicaid.
- *Supplemental Security Income (SSI)*: A program offered through the U.S. Social Security Administration, which provides cash assistance to “disabled adults and children with limited income and resources” (Social Security Administration). The program also offers monthly cash benefits to low-income people over age 65. Benefits are delivered by mail or electronically deposited into their bank accounts.
- *Housing Assistance*: A program offered through the U.S. Office of Housing and Urban Development, which provides public housing and rental assistance in the form of housing vouchers to poor families.

Women who fell into the following categories were not eligible for participation in this study: minors, women with cognitive or psychological impairments, prisoners, the elderly (age 65 and older), and women who were pregnant. Race was not a determining factor for inclusion

for this study; however all of the participants in this study were African American. The reasons I only found Black women to participate in the study may include: 1) the facility where I posted flyers has a predominately Black clientele; and 2) the population of poor Black women with children with disabilities in New Orleans is much higher than the population of poor non-Blacks, rendering Black women easier to access.

I used a variety of strategies to recruit participants for this study. First, I posted flyers at a local organization that provided special services to children with disabilities (see Appendix B). Second, respondents were recruited by word-of-mouth through three informants who had access to women with children with disabilities. Third, I asked each participant to refer another potential participant. However, none of the references agreed to participate in the study. Once a respondent replied to the invitation for participation, I conducted a screening survey (see Appendix C) to determine if they met the qualifications for inclusion. These techniques yielded a sample size of ten women with children with varying disabilities.

### *The Participants*

The participants in this study all identified themselves as African American or Black. They were all residents of the Greater New Orleans area prior to Hurricane Katrina which struck in 2005. Nine of the women returned to the Greater New Orleans area after Katrina and one relocated to another part of Louisiana near New Orleans. The location of this study is relevant in that Louisiana has a very high poverty rate, and is reported to have one of the highest poverty rates of families with members with disabilities. Louisiana has the third highest poverty rate (20.0 %) among families with a member with a disability preceded by Mississippi and the

District of Columbia (20.7% each) and Puerto Rico (49.1%) (United States Census Bureau 2000).

Table 1 presents the demographic characteristics of the women, including the nature of their children's disabilities and the programs in which the mothers participated. In order to preserve anonymity the names of all participants have been changed. The participants' ages ranged from 25 to 54 years old and their children's ages ranged from four to thirty-two years old. Among the women there were a total of thirteen children with disabilities whose diagnoses included autism, mental retardation, Attention Deficit Hyperactivity Disorder (ADHD), dyslexia, learning disability, depression, Oppositional Defiant Disorder (ODD), epilepsy, asthma, speech delay, vision impairment, and shaken baby syndrome. Most of the children had multiple impairments, so this list does not represent the complexity of disabilities that these mothers faced. There were nine children without disabilities in the households who are not considered in this analysis, including three adult children, two teenagers, and four school-age children. Two of the women were married, six were never married, one was divorced and one was widowed. Of the never-married women, two of them resided with their children's fathers, three lived with their own mothers, and two lived alone. The divorced mother also lived with her mother.

All of the women were either currently employed or formerly employed and actively seeking employment. Six of the women participated in Temporary Assistance to Needy Families (TANF) prior to the interviews, while four of them never received TANF. Of the former welfare recipients, none of the women were receiving welfare at the time of the study. Although none of the women currently received welfare, they all were currently receiving some form of public support such as Food Stamps, Medicaid, Supplemental Security Income (SSI), or housing assistance.

### *Data Collection*

This research uses in-depth qualitative interviews conducted between January 2008 and February 2009 to explore the experiences of raising children with disabilities in a post-welfare restructuring context. Seidman (2006) defines an interview as “a basic mode of inquiry” which is rooted in “an interest in understanding the lived experiences of other people and the meaning they make of that experience” (p. 8 – 9). Qualitative researchers use this strategy to learn about individual and group behaviors because it ultimately allows researchers to discover “subjective understandings,” the meanings, perspectives, and motivations behind those behaviors. Seidman (2006) further explains that

Interviewing provides access to the context of people’s behavior and thereby provides a way for researchers to understand the meaning of that behavior. A basic assumption in in-depth interviewing research is that the meaning people make of their experience affects the way they carry out that experience...To observe a teacher, student, principal, or counselor provides access to their behavior. Interviewing allows us to put behavior in context and provides access to understanding their action (p. 10).

Babbie (2004) explains that a “qualitative interview is essentially a conversation in which the interviewer establishes a general direction for the conversation and pursues specific topics raised by the respondents” (p. 300). At each interview I had a list of prepared questions that I used to guide the conversation topics. However, I based each subsequent question on the participants’ previous response. Follow-up questions were used to probe deeper into the participants’ meanings and to gain a fuller understanding of what was said. The nature of these interviews was one in which the participant did the majority of the talking. Although my experiences as a mother of a child with a disability were important in establishing trust and rapport with the women, ultimately their experiences, not mine, were the focus of the conversations.

At the beginning of each interview I gave each respondent an introduction to the project. I explained to them that their participation was completely voluntary and that they did not have



to answer any question that they did not want to answer. Once I was convinced that they willingly gave their consent, each respondent signed a consent form (see Appendix D), and received a list of both crisis resources and disability resources for future reference (see Appendix F). These were guided face-to-face interviews at the respondents' chosen location. In two instances, the participants were not able to meet in person, so I conducted initial telephone interviews with them. At later dates, I met the participants for face-to-face interviews.

The interview questions were divided into two parts (see Appendix E). The first part focused on the women describing themselves and their situations, which included descriptions of their children's disabilities and their living situations. The second part focused on their caregiving experiences, their relationship to welfare, and balancing work and family. Each interview lasted one to two hours each, following a loose format that allowed the participants to describe their experiences with motherhood, welfare, employment, and childcare. They were intended to gain a sense of the women's circumstances and their perceptions of their situations. For example, I sought to understand how they viewed their roles as mothers and how they thought their roles were affected by their children's disabilities. I wanted to gain a sense of the how their financial situations impacted their caregiving and decision making processes. I also examined how the women viewed their caregiving and employment options.

I interviewed seven of the women twice, which allowed me to transcribe and review the content of the first set of interview questions before moving on. In three cases, due to participants' schedules, both sets of questions were covered in a single conversation, eliminating the need for a second meeting. Seidman (2006) suggests a three-interview format because "it encourages interviewing participants over the course of 1 to 3 weeks to account for idiosyncratic days and to check for the internal consistency in what they say" (p. 24). Although the current

research design relies on two interviews, rather than three, the design allowed me to increase the validity of the participants' statements through multiple interviews.

### *Data Analysis*

I recorded each interview and personally transcribed each tape verbatim. After I transcribed the interviews, I began the analytic process by reading through each transcript and open coding the text. According to Babbie (2004), coding is “[t]he key process in the analysis of qualitative research data” (p. 376). Charmaz (2006) defines coding as “attaching labels to segments of data that depict what each segment is about. Coding distills data, sorts them, and gives us a handle for making comparisons with other segments of data” (p. 3). During open coding, researchers assign labels to segments of text, “coding the data for its major categories of information” (Creswell 2007:64). I coded each line of text in the first transcript by underlining the appropriate text and writing the code in the margin of the paper. I began this process without any preconceived codes, because I wanted the codes to be derived strictly from the text.

Seidman (2007) explains that in analyzing interview transcripts, “researchers must come to the transcripts with an open attitude seeking what emerges as important and of interest from the text...The interviewer must come to the transcript prepared to let the interview breathe and speak for itself” (p. 117).

After coding several of the interviews, I compared the coded transcripts to each other, looking for similarities and differences between them. During this process of rereading and analyzing, I looked for recurring themes, strategies, and perceptions of the participants. After coding, I returned to the documents and, using a word processing program, sorted and grouped similar codes together in categories. Figure 1 presents a sample of grouped codes and relevant

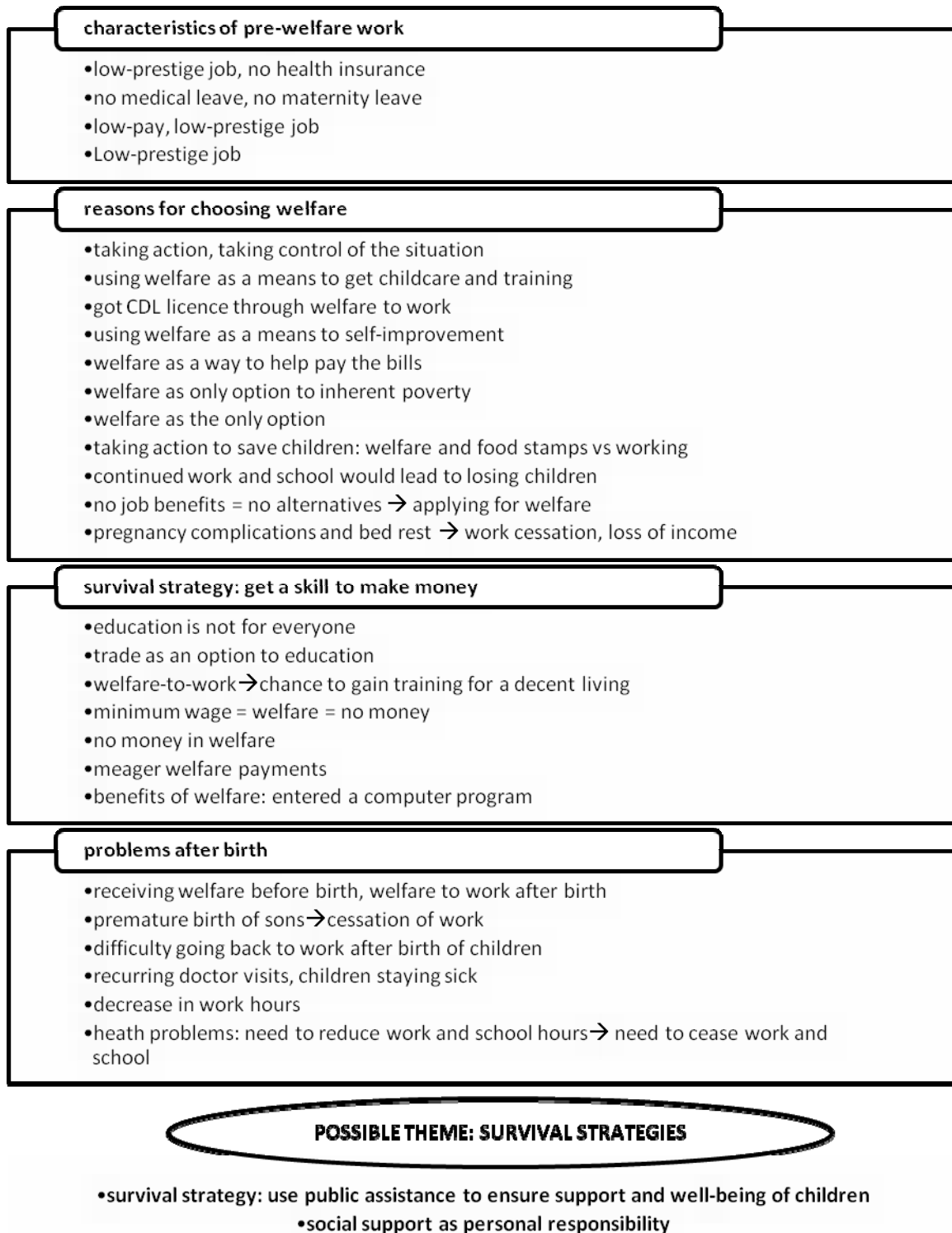
categories. Throughout the coding process I wrote memos that described my interpretations of the meanings of the initial codes. While many of the memos related to the codes and themes, some of them were self-reflective, noting my personal reactions to participants' statements, describing categories that seemed interesting or that struck my attention, and making notes about statements that I did not understand.

This data analysis provided me with a description of the women's situations and an understanding of how welfare reform and disability shapes their caregiving and employment experiences. The following section presents the results of my analysis, including the circumstances leading up to some of the women choosing welfare, the role of gendered worker and caregiver ideologies, and their post-welfare reform survival strategies.

Table1: Participant Characteristics

Participant	Age	Race	Marital Status	Child's Age	Child's Disability	Welfare (Past)	Food Stamps	SSI	Medicaid	EITC	Housing
Leslie	34	B	M	8	Autism		•	•	•	•	
Donna	54	B	W	34	Autism/ Mental Retardation	•		•	•		
Stephanie	40	B	S	6	Autism		•	•	•	•	
				8	ADHD/Dyslexia						
Allison	34	B	S	4	Autism		•	applied	•	•	
Latisha	25	B	S	16	Learning Disability/Depression	•	•		•	•	•
Myra	26	B	M	5	ADHD				•	•	
Shannon	27	B	S	5	ADHD/ODD	•	•	•	•		
Lori	36	B	D	7	Autism	•	•	•	•	•	
Eileen	35	B	S	11	Epilepsy/Asthma/ Speech Delay	•	•	•	•		
				11	Asthma/Speech Delay						
				9	Epilepsy						
Tamika	33	B	S	7	Shaken Baby Syndrome/Visually Impaired/Speech Delay/Epilepsy	•	•	•	•	•	•

Figure 1: Sample Codes and Categories



## FINDINGS

This section presents the results of my qualitative analysis in relation to issues of welfare, women's work and caregiving choices, and balancing work and family. To reiterate, this project explores four main research questions. In a post-welfare reform context, how do gendered worker and caregiver ideologies affect low-income African American mothers of children with disabilities? How is the current welfare program incompatible with the needs of these women, and are there any advantages? How do they make their work related decisions? Finally, how do they balance work and family? First, I describe the factors that lead the former welfare-reliant mothers to choose welfare in the first place. Next, I discuss how they view their mothering roles in a post-welfare reform context. Then, I examine some of their caregiving and employment experiences. Finally, I discuss the strategies that the mothers employ in order to balance work and family responsibilities after welfare reform.

### *The Road to Welfare*

Of the ten women I spoke to, six had received welfare in the past. The following section describes the reasons why the former welfare recipients turned to welfare. Five of the six former welfare recipients applied for welfare due to medical problems related to their pregnancies resulting in the loss of income. The sixth applied for welfare following her divorce, which left her without financial support. The interviews did not reveal stories of women trying to "milk the system," but rather instances of women in desperate situations searching for real solutions. Each of the women I spoke to regarded receiving welfare as itself a form of personal responsibility.

Prior to becoming pregnant in the 1970s, twenty-year-old Donna worked in a hospital cafeteria. She became pregnant by her long-time boyfriend whom she thought she would eventually marry. When she told him that she was pregnant he became emotionally abusive towards her, began to act physically violent toward her and her family members, and denied the paternity of the child. After getting a protective order for her own safety, she began showing signs of depression. She explains:

I had to get a grip on my life. So I just stayed depressed all the time because I'm here. Okay, I'm pregnant. I had just only had sex that one time and I got pregnant and he wanted to say it wasn't his. So it mentally had messed me up and then I had went through a lot of like depression things, and then in doing so they said that I had a kidney infection.

In addition to the depression, Donna became extremely ill with a kidney infection and a high fever. The stress of her situation deepened her depression, so much so that she began to feel that she did not want to have the baby. Confused and searching for help, she turned to her friends for advice, who suggested she apply for welfare. She followed their advice and applied for welfare, later regretting her decision.

I just thought it was the in thing. Everybody was doing it. They told me to go get some welfare cause you pregnant...so that's where I went, listening to other people...It was rough being pregnant, cause after I had gotten pregnant I didn't want it...I didn't want no baby. You know, but it was there and I had to do right by it so...But it really wasn't an easy thing because like I said I had gotten sick with the pregnancy so. [Welfare] wasn't something that I really wanted and it's not something I would ever really want for my children.

While Donna's initial decision to apply for welfare was at the suggestion of her friends and as a response to medical problems, the absence of the child's father meant that she would have to care for the child alone. Her sickness during pregnancy made it impossible for her to continue working, so applying for welfare was her only option. She thought that although though she did not want to have the baby, it was her duty to do what she had to do to take care of

it. She had to be responsible, deal with the situation and “do right by” her child. This sense of personal responsibility was echoed throughout the interviews I had with other former welfare recipients.

Prior to applying for TANF, Tamika worked two low-income jobs in order to make ends meet, one as a truck driver with a commercial license, and the other as a personal care attendant for adults with disabilities. During her pregnancy her doctor informed her that she would no longer be able to work due to an incompetent cervix, a condition in which the cervix widens, increasing the risk of miscarriage or premature delivery.

So, I was on bed rest so that just wiped me out, couldn't make no money, couldn't do nothing. So, the doctor...that's how I really got on welfare because once they send you the letter saying that you can't work you can't do nothing. Then being in the driving field I had to wind up resigning from the job and with the other job you had to be on your feet or whatever and we didn't get any insurance with this job or nothing like that. So that was like you didn't have no insurance. You didn't have no medical leave. You didn't have no maternity leave. So I had applied for [welfare].

Tamika's situation paralleled other former welfare recipients I spoke to who had complications during pregnancy. She decided to apply for TANF because of health problems related to her pregnancy that prevented her from working. Realizing that her choices were limited, she needed some way to care for her family. She saw welfare not only as an immediate safety net, but as acting responsibly to provide for the wellbeing of herself and her future child.

Eileen, a mother of three children, including twins, whose disabilities include epilepsy, speech delay, and asthma, had a similar experience to Tamika and Donna. She was working full-time as a nursing assistant and going to school part-time when she got the news that she had to stop working during her pregnancy.

I went to my last doctor's appointment. The doctor sat me down and he said, “Well, you gone have to slow down with work. You gone have to slow down with school. You gone have to drop some hours, drop some classes.” The next time I went to the doctor the doctor told me, “I'm sorry. You gone have to stop working, stop going to school.” I was



like, “Why?” Either you gone lose the kids or they gone die...I had to stop working and stop going to school. I was on complete bed rest...Or else if I would have continued to work, continued to go to school at the hours I was going I could have lost them. So I had to choose between me going to school, me working and my kids. I was told that I couldn’t have kids so you know I was gone fight for my kids. So, I went and applied for welfare and food stamps. I qualified but I had to, cause I didn’t have no money coming in.

Now if I’d a had some money coming in I probably wouldn’t have applied for welfare and food stamps. But you have to do what you have to do to get some income coming in because you have kids. You need food. You need pampers. So whatever program that was out there for children I applied. They got the WIC which was very helpful because they had to get the powdered milk and the powdered milk was like twelve dollars a can. That’s a lot. So I didn’t have no choice. I did what I had to do.

When these women were unable to work, welfare was a way to replace their lost incomes. They were not confronted by the choice between welfare and work, but by the choice between survival and eminent deprivation. It is the same desperate situation that leads many poor women to turn to the welfare office. Without public support most of them would have faced impoverished conditions during their pregnancies and medical risks.

Sharon Hays (2003) discusses this dilemma and concurs that some poor women apply for welfare out of their perceptions of personal responsibility. Hays found that some low-income women view welfare as a logical alternative to low-income work because often the conditions of low-wage work are incompatible with their responsibilities to their children. Hays’ study reveals the ideological inconsistencies inherent in welfare reform and how those contradictions manifest in the lives of the working poor who are judged by middle-class standards. For the women I spoke to the problems surface when the conditions of low-wage work, such as little-to-no benefits, inflexible schedules, and low-pay are no longer compatible with their family needs and caregiving responsibilities. In relation to my second research question, welfare has the advantage of allowing these women to deal with their pregnancy-related illnesses without the fear of impoverishment or greater medical risk. When they cannot work, they face the choice

between impending destitution and possible sustainability; welfare appears to be the only solution.

With no alternatives to provide for their families the women who turned to TANF considered it a short-term-safety net. Realizing that the assistance is temporary, they also considered the program to be a means to boost their future earning potential. Although welfare provided meager monthly payments, the job training and childcare programs would allow them to learn a skill or a trade that would make them more marketable for future employment. Tamika explains:

So with that they had the welfare-to work and I said like well if I get into this program they'll pay for Cyrus to go to daycare and I'll get a trade. So that's two things out of one program. It ain't no money. What's a hundred and something dollars? But if I can get a trade off of this. You see what I'm saying? I can make it better for myself and my child.

The women I interviewed identified various ways in which they challenged the idealized notions of personal responsibility as prescribed by welfare reform. They explained ways in which they *were* socially responsible in their situations, despite their financial constraints. This definition of personal responsibility differs from the current political definition, which is based strictly on raced and classed notions of proper women's roles. Welfare reform defines personal responsibility for poor mothers as working rather than providing care for their children. It stipulates that in order to be good mothers poor women must not rely on the government for assistance. This notion ignores the fact that neither welfare nor low-wage work provides poor women with financial security in the first place. Neither option leads to economic self-sufficiency for many poor women.

### *The Measure of Good Mothering*

Although all of the women in my study did not receive welfare in the past, they all lived on very low incomes, warranting the need for some type of public assistance. In addition, they all have children with disabilities who required care that differed from most women's typical caregiving responsibilities. The presence of childhood disability intensifies the type and amount of care these mothers need to provide to their children. They not only need to provide economically for their families, but they must also provide intensive caregiving support. As a result, their perceptions of personal responsibility extend to their mothering roles. The women I interviewed have definitions of personal responsibility and good mothering that go beyond the basic idea of getting a job. To them, the idea of a good mother is a complex concept that includes providing for the needs of their families, offering constant care, educating their children, and providing value and protection to their children in the face of an unjust society. All of this must be done regardless of financial constraints.

This view of personal responsibility defines the good mother as one who puts the needs of her children first, doing whatever is necessary to care for her family, and ensuring a successful and hopeful future for the child. To these women, the measure of a mother is not based on their financial situations. It is rooted in the value that she places on her children and her commitment to mothering them. A good mother is one who nurtures and cares for her child despite financial restrictions. These ideas are a direct contrast to the welfare supported definition, which focuses on economic self-sufficiency.

Shannon, whose five year old son suffers from ADHD, explains that "Some things are more important than money." She, too, had a difficult pregnancy resulting in the need to stop working as a hotel maid. However, she decided not to go back to work immediately because she

wanted to be home during the day with her children. When given the opportunity to take a managerial position at the store where she worked before Katrina, she declined.

If I want to I could be practically running [the store] already you know, but it's just that my kids come first. I like making money. Don't get me wrong. I love to make money cause I love to shop and I love to shop for my kids, but at the same time the needs of other things is more important than the shopping and money...So my kids need attention, more time, more me, you know. No matter how you look at it, it has to be more me somewhere.

Shannon's views reflected the common notion for these women that providing care to their children was more important than their economic security. Shannon also notes that "If I don't put my kids first, who will?" This statement is significant because it captures the women's realization of the low value that society places on Black children, especially poor Black children. Stephanie's explanation of this statement is this: "If we don't show them that they are worth something, they will go through life believing what the world says about them. We have to show them what they are. They are depending on us." These statements reflect another dimension of redefined personal responsibility in which it is Black mothers' ultimate duty to make sure that their children are valued and protected in a society that often seems to consider them social ills.

Education is an essential value to all of these women. They place a lot of emphasis on their children getting an education, despite their disabilities. Shannon explains: "If you don't have your education, you basically don't have anything. In some places you can't even go in for a job unless you have a high school diploma and I don't want him to be left behind just because he can't keep still at school." Stephanie is a forty year old mother of three. Her youngest was diagnosed with autism and her oldest son has dyslexia and ADHD. In order to be home during the day, she works the graveyard shift as a records clerk in a hospital. She also goes to community college on the weekends. When I asked her why school was so important to her she said:

I make sure they see me studying. I make sure that I go sit at the table while [my oldest son] is at the table doing his homework and I'll be like, "Ooh. I got so much homework to do and I got a test tomorrow." And I'll come home and I'll say, "Guess what I got on my test?" "I got a B" or "I got an A." Just to let him see that it can be done...I just I don't want him to get discouraged cause like his reading is low. I want him to know that he can do it regardless. You may have dyslexia but don't let dyslexia have you.

Eileen explains that despite her children's disabilities she encourages them to do well in school and to have a positive attitude in order to be successful. She does not want them to think that they are limited by their disabilities or their current financial situation.

Don't say, "Oh well I have this type of illness. Ain't nobody gone hire me. I can't do this. I can't do that." Don't do that. Think positive and tell yourself, "I can do this. Ain't nothing wrong with me." Don't put it in your mind, "Oh, I'm sick. I can't do that." But [say] "Yes, I can do whatever I want to do to become whatever I want to become." You know just because my momma sacrificed what she had to do for us as a parent don't think well oh I got to follow my momma's footsteps. I did what I needed to do to make sure y'all was safe and happy.

Amid their desires for education and encouragement, there was an underlying racial context that fueled their caregiving practices. They recognize that the problems of poverty and racism could lead their children, mostly sons, to crime. They also knew that their current decisions not only affected their present situations, but more importantly they impacted their children's futures. The problems of race, poverty, and crime were real issues that some of them may have to face one day. Shannon explains this as her motivation for being so involved with her son's education.

Even though ADHD is really not a life threatening thing, but also if you don't treat it early it could lead up to jail, you know him stealing and breaking the law...he don't have to do that and I don't want him to do that. So you know I have to look for the future and think about tomorrow at the same time as what's gonna happen the next day and the next day and they next day. You know so I have to sit down and make my decision on what's going to be the best for him, not what's best for me.

Middle and upper-class White women do not tend to worry about their disabled sons turning to crime. Tamika's son was shaken at a home-based daycare center. He now suffers from shaken

baby syndrome, epilepsy, speech delay, and visual impairment. She notes that while her child's disability is distressing, there is one positive, if poignant, aspect. His mental and physical limitations mean that she may not have to face the race and crime problem.

You know what? By my child being a Black male, and I tell people this all the time, I'm so glad I can dictate what he gone do. I don't have to worry about when he 16 or 17 somebody calling me saying, "I done got stopped by the police." "Ma, I'm in jail." "Ma, I just had a fight." "Ma, somebody done robbed me." Or somebody calling me saying, "Ms. Wilson, your son done been in a bad car accident" or "Mrs. Wilson your son was shot." Just and people be like, huh? Just in this society, our Black males have less of a chance to make it to the age of twenty one than your daughter have it to make it to the age of thirty. It's just...that's the best part about me having my son. He still gone be my baby. He ain't gone talk back to me. I don't know. Maybe I'm wrong for that but that's how I feel.

Tamika's worries about Black men and crime are rooted in a social reality for Black males.

Although her child has a number of incapacitating impairments, she finds solace in knowing that her son is less likely to face racial profiling, stereotyping, or criminal activity because of his race, class, and gender. Her son's inability to walk and talk will likely prevent him from being targeted as a criminal. Recognizing that others might view these thoughts as selfish, she argues that all of these things lead to shortened life expectancy for young Black males. Therefore, she would rather have her child, with all his severe disabilities, than have to face those risks.

### *Life at the Intersection*

The women I spoke to had many experiences that, in general, paralleled those of other mothers with children with disabilities, such as increased caregiving requirements, increased stress and fatigue, and feelings of social isolation. However, there were some distinct differences due to their situatedness at the intersection of racial and economic subordination. Three major experiences impacted these women's lives: the lack of caregiving support, having to provide round the clock caregiving, and the lack of employment flexibility.

*Lack of Caregiving Support from Men.* Donna's husband, who recently died of health problems, played a major role in the caregiving of their adult son. Prior to his death, he stopped working due to his own diabetes-related illnesses. This allowed him to be home during the day to watch after their son while Donna went to work to support the family. As her husband's health deteriorated, her husband could no longer care for him, and Donna faced the decision to put her son in a group home in order to continue working.

He [son] stayed depressed and he kept flipping me out because he used to being with him [husband] in the daytime and seeing him in the daytime. He would be here with him all day when I was at work because he mostly cared for him. And that was one of the reasons they took him from under us because my husband could no longer care for him. But that was the reason he had to go. I had to work.

As her husband's illness progressed, Donna realized that she was unable to work full time and care for her son. As a result, she decided that it was best for the group home staff to "take" her son. This way, her son could receive proper care, and Donna could continue to work while she coped with her husband's illness. Donna's son went back and forth from the group home to the psychiatric ward at the local hospital, where he remained until the day of her husband's funeral.

It was the week of my husband's death that they had put him back in [the hospital] in the psych ward and they said that something had happened. They didn't know what really happened, but, the day my husband died, the day they buried my husband they had made me come and they told me I had to take him back with us. The people who came to get him from the group home said he cut up so bad that they wouldn't take him back with them. So they asked me and my son to come back to the hospital and they told me that I had to take him back with me. Although they said they know that my husband had just died and I was already going through, they told me that I needed to take him back home with me.

Donna eventually found out that her son had been sexually abused by one of the caretakers at the group home. She decided not to send him out to a group home again and receives help from local respite services so that she can work.

For the other women I interviewed, caregiving support from their spouses and children's fathers was not evident. For them, the fathers were either present and not contributing to care, or absent from the family altogether. The women who lived with partners reported performing the majority of the carework for their children. Allison, for example, does not have the caregiving support of her children's father. Although they live together, he contributes very little to the care of their four year old son, Michael, who was diagnosed with autism. She reasons that his lack of caregiving support is due to his late-night work schedule.

His dad works three to eleven and when Michael is at school all day, he don't see his dad. When he's at home he still don't see his dad. When his dad gets home Michael is sleeping. So he only sees mom. So I'm the only one that he. I do everything for him. I bring him to school. I pick him up from school you know I bring him to his therapy appointments. You know everything is just me, me me. And like I said I'm not complaining because you know when I found out that my son have autism his dad and I both agreed that was something that have to be done. He have to go to his appointments you know there's no ifs, ands or buts about it. That is not something that we can put off and say we'll I'll go next week or next time.

Stephanie explained how her children's father left soon after her son was diagnosed with autism. Now, she struggles to take care of them and work full time. "Right now it is challenging because I find myself, like I told you, going to work early trying to do things, trying to, and it's – plus I'm trying to make them not feel like their daddy don't love them." Since she does not have caregiving support from the children's father, she relies heavily on the support of her mother to care for the children so she can work at night. "It's me, my kids and my mother lives with me. My mother helps me. She watches them while I go to school and when I go to work. And like she'll go places with me to help me." Without the caregiving support from her mother, Stephanie would likely experience greater difficulties in balancing caregiving and work responsibilities.



It was unclear whether the lack of caregiving support from men was due to the children's disabilities, or to other factors. Nevertheless, the lack of caregiving support from the children's fathers meant that these women did not have another person to assist with the daily tasks of critical care, dealing with hospitals and therapy appointment, and tending to their educational needs. For many African American women, networks of extended kin are important in establishing a community of caregiving support for children. However, for these women, the loss of caregiving support from fathers was coupled with a loss of caregiving support from kin.

*Lack of Caregiving Support from Extended Kin.* Previous research has confirmed the importance of extended care networks for women in low-income African American families for economic survival (Carol 1978; Litt 2008). However the extensive childcare sharing networks that have been the cornerstone of the survival of low-income African American communities are less evident in the lives of the women I spoke to. These women not only found themselves with fewer resources, greater expenses, intense caregiving requirements, and a lack of caregiving support from their husbands and children's fathers, but the kin-networks that low-income African American women have historically relied on are unavailable to them as well.

Although some of the mothers characterize their families as close knit, when it came to the actual work of caring for the children, which would provide a respite as well as increased availability for employment opportunities, these mothers still had the sole responsibility of providing care. There was no collective care to relieve them of the care burden. Some of the women explained that extended kin were not willing to help out because of the severity of the child's disability. There are several costs associated with the loss of caregiving networks for these women. For instance, because there was no one to relieve them of their critical caregiving

responsibilities, these women provided non-stop care for their children. Providing constant care meant that they rarely get a break from caregiving responsibilities. For the mothers who were not employed this meant that they were providing care twenty-four hours a day. For the working mothers, once they returned home from their paid jobs they were confined to their homes. Their private lives were defined by caregiving, domestic tasks, and transporting their children to and from therapy and medical appointments. In other words, they worked at caregiving constantly. All of this restricted the time that they were available for employment opportunities and restricted them from having time to themselves for rejuvenation or leisure. Tamika explains her experience of not having a network of care to rely on.

I had an aunt who said, “Oh, no. I can’t watch him cause I’m scared.” I’m like, “You scared?” What the hell you scared of?” “Oh no. Cause he might fall out. He might do this. He might do that.” I’m like he don’t do nothing more than a normal child would do. But my aunts don’t keep him. My mom barely keeps him...I feel like sometimes I need somebody to say, “I got it.” “I got it.”...And so it’s like it makes you feel like you in this by yourself. That’s just to sum it up. You in this yourself. And a lot of people ask me, “Why you don’t have no more children?” I say cause I’m already doing it by myself. I don’t need to have any more children.

Tamika’s feelings of social isolation are representative of most of the women I spoke to. They believe that the childcare support of extended kin is imperative to their ability to provide quality care for their children. Without a network of support these women lack the resources that they need to mother effectively. They needed time away from their children in order to recuperate from the constant stress associated with critical care. Those women who felt that they had the support of family and friends did not report the same intense feelings of isolation. However, they still believed that no one else understood their situations. It appeared that the more severe the child’s disability, the less likely the willingness of family members to assist in childcare. When the child’s disability was seen as severe, family members were not willing to help the mother with her caregiving responsibilities, as was the case with Tamika, Donna, and Rosemary.

Seven of the women reported a lack of caregiving support from fathers and extended kin, which meant that they singularly bore the requirements of intensive caregiving responsibilities. Ironically, although these mothers discussed a perceived loss of network support, all of them participated in caregiving networks *as caregivers*, by taking care of other family members' children and sick relatives. However, they were rarely the recipients of care. These mothers lose the caregiving support that could potentially alleviate some of the stress that they feel from the care burden, and acquire increased care responsibilities. This contributes to their sense of social isolation.

Donna, whose son is now thirty-two years old, works full-time as a patient care assistant to the elderly and people with disabilities. She has provided care for a number of sick relatives including her aunt, mother, brother and grandchildren. She explains,

I took care of my aunt. I took care of just about everybody in my family that has been sick. I took care of them... Well, my auntie took sick first and we was living with my auntie at the time, my momma sister, and when she took sick I just started taking care of her. Me and my sister took care of her cause she was more like a momma because she raised us cause my momma worked and my auntie raised us. Sometimes my momma would work two jobs to take care of us. And so it was always my auntie that raised us and when she got sick, but then we really didn't want anybody else to take care of her but us because that was like our momma. And in caring for her after she took sick and she died then it just was a normal thing.

Then my uncle took sick. So when my uncle took sick I just felt that I should have been the one to take care of him cause I just took care of my auntie and I know what I'm doing, and my sister knew what she was doing cause we had done took care of our auntie.

Although she has provided care to many of her family members, including taking care of her grandchildren once a week, she does not receive the same level of caregiving support from other women in her family. For example, on one occasion she saved up the money to take a vacation so that she could get a break from the continuous care that she provides for her son. A lack of child support from relatives meant that she could not go.

Like I said it begins to be a hindrance and that's only because sometimes I'm not able to actually get a sitter for my son. And I feel that sometimes I just want to go if I could just go and stay a week somewhere, two weeks somewhere you know and it doesn't happen for me all the time. I paid for a cruise and wound up I couldn't go to the cruise. So, then I couldn't get my monies back because I didn't have anybody to take care of my son. And it was hurting because it's something I really was looking forward to...I paid for the trip and December the first I couldn't go. So. Everybody had things to do. And I couldn't get mad. I couldn't get mad and then the thing that really aggravated me was that my sister who was going on the same cruise and the day of, she decided not to go and I asked her if she could keep him and she said she didn't take no vacation to watch no baby. So then that really hurt me, you know cause I felt like well you not going and I mean you was gone be home. You could have kept him but that's the way it went down so. I just didn't go. Money was wasted...Sometimes it gets very challenging because sometimes it gets me to the point where it's been –what it's been about two years now? And mentally I have not been able to just really get away, just me wanting to be-- just get away with myself. Just get away, having time for me because it's hard to find people to watch my child.

Eileen, whose three children suffer from multiple disabilities including epilepsy, asthma and speech delay explains the toll that constant caregiving can have on poor mothers.

It's hard and it gets depressing at times because you are constantly on the go to where you know your child needs this and stuff like that. You get depressed and it's like soon as you think you gonna get a break something else happens. So it's hard. It's stressful and it's depressing, but you know as a parent you have to do what you have to do to take care of your child...It's stressful. It's depressing. Sometimes you want to give up and it's hard. Sometimes it seems like you don't have nobody to talk to. You feel like you by yourself, and you just want to curl up and just be like, "I'm done." I don't feel like doing it anymore. But deep inside you know that you can't give up because you have kids to take care of. It's stressful. It's very stressful.

The strength that would have come from a community of carers now has to come from a single individual. The women talked about feeling lonely and isolated, but the overwhelming issue was that they had to be strong for their children all the time. It is an exhausting task that often meant that they suffered personally by neglecting their own needs for that of their children. They rarely got a break from the duties of constant caregiving. One result of this lack of essential support was increased stress, fatigue, and depression for the mothers. Tamika explains,

Yeah. You sad. You have crying. I have days where I might just cry and cry. I mean I still do it. I still might. He can be, like I made one of the rooms into a play room for him

and some days he can be in the room and I might have just a straight up crying spell. Just bust out crying and I don't know where it's coming from. I don't know if it's a release cause you have to be so strong everyday or what or if it's just the depression that's coming up on me and you know up and I'm just letting it out. I don't know what it is.

But I mean I think I'm growing and I think he's teaching me more of you know being patient and understanding so I think that's where I'm getting it from. That's how I'm able to deal with society as a whole because I have to know that regardless at the end of the day it's gone always be me and him. You know nobody else is gonna come in here and just say you know I'm gonna give you a break or whatever so at the end of the day I can't worry about what they think or what they say or whatever. I just got to be me and I have to be more happy you know. I can't let the depression or whatever get me down.

Tamika's sentiments resonate with most of the women. They spoke of their situation as feeling like it was only them and their children versus society. This "us" versus "them" mentality meant that their children were at the center of their lives. Unfortunately, it also meant that they continued to provide critical caregiving without support.

The need for caregiving support was not limited to the need for relief from intensive caregiving responsibilities. It meant that the mothers had to provide continuous care for their children without a break which also led to a reduction in employment options. Familial childcare is often important to low-income African American's women's availability for employment which translates into their earning capacity and ultimately their economic survival.

Caregiving support also relates to opportunities for educational attainment and social mobility. The women who were able to go to school were the ones who had the help of their mothers, but their plights were not much easier. Stephanie, who works at night and goes to school during the day, describes how hectic this balancing act can be.

Stephanie: My days are like I get off when I get off I get home at about 6:40, 6:45. My mom has already [Son] dressed I just need to brush his teeth. I get my oldest son to go bring him to the bus stop which is right across the street from our house, like right in the front of our house so I'm standing in the door watching him. My mother takes my oldest son to school cause he goes to school in Jefferson Parish and um then after that I go to sleep. And then I sleep for like two hours until my daughter wakes up and then that's it

for me. And I may get another hour sleep in the evening time and um then after that I'm on my way to work.

Michelle: So you might get about three hours of sleep every day?

Stephanie: Between three and five, cause once I get up I have to make sure I have all of my stuff ready and make sure I have something for them to eat you know whether it's cooked or go buy it and have it there for them. So yeah I sleep about three, four hours and like every day. It's the same like every day and every day, except on Saturdays. I go to school on Saturdays.

As Stephanie tried to balance caregiving, work, and school she neglected her own need for rest.

Aside from work and school Stephanie "very rarely" gets a break from her children. In order to get a much needed respite, she hides out in the bathroom. "Like when I told you I was in the bathroom, that's my time to myself...that's my vacation, the bathroom, taking a bath or I'll sit in there and read hiding out."

*Lack of Employment Flexibility Despite Education.* A couple of the women I interviewed were college graduates. By the time I met Leslie she was married to her second husband and had just started a new job with a local organization providing advocacy and services for people with disabilities. She was very proud of her accomplishments; especially as she had recently experienced great difficulty in finding a job with her degree. Since the birth of her son, Leslie worked in a daycare center in order to pay the bills.

At that time, I was just in the job that I was just really not happy in. I was working in a daycare center and he was going to the daycare center that I was working at and so I had [a degree] and I was just desperately just trying to get something in my field...I just wasn't happy cause I didn't go to school to be, you know I didn't get a bachelor's degree to work at a daycare center.

Leslie had held several low-paying jobs including a hotel clerk and a waitress while she was in college. After graduation, she married her first husband, but was dissatisfied with what she saw as his complacency as a grocery store manager. This on top of her inability to find a job in her field added to her frustrations while working in the daycare. Her two year old son was beginning

to show signs “that something was wrong,” exhibiting behaviors that she could not understand, such as yelling and throwing tantrums. The doctor eventually diagnosed this behavior to be autism.

You know and then we didn’t have a car so I would be traveling [on the bus line] with a two year old. And at the time you always hear stories about the terrible twos but at the time coupled with what I didn’t know at the time was autism. It was not pleasurable. It was not the most...you know cause he would get on the bus and it was a long ride so naturally he’s restless so my goodness. It was not the most pleasurable experience taking the long bus with a child who would just not cooperate... I had no clue as to what to do. And at that time in my life financially although we wasn’t struggling financially I was just not happy. You know and then I had this child who was like I had no clue and normally at home I never had a problem with him being home. It’s just once we got out into the public, going to Wal-Mart was murderous. Going to Toys-R-Us was murderous. Cause he would scream and tantrum and throw fits and I had no clue as to why this child would throw these tantrums like that. No clue.

Leslie’s dissatisfaction with her financial situation was three-fold. She was unable to achieve her desired level of self-sufficiency through education. Her plan of social mobility was interrupted with the discovery of her son’s autism, which required her to provide increased amounts of care, as opposed to working full-time. In addition, she felt that her husband’s “lack of drive” prevented him from finding more lucrative work to make up for the minimal income she contributed. The chances of her getting a better paying job was slim considering the amount of care she needed to provide to her son.

As her son got older his autism appeared to be less severe and his doctor characterized him as “highly functioning.” Now that he is in school, Leslie can focus on her own passions, poetry, music, and travelling. She appears to have struck a balance between caring for her son, maintaining her own personal interests, and her job. She takes pride in her new job, which pays substantially more than the daycare job. She explains that she enjoys her work teaching seminars as a disability rights advocate because she has her own child with a disability: “I wouldn’t have been as understanding if I wasn’t affected by it.”

Despite her earlier difficulties, she disapproves of women being “consumed” by their children’s disabilities. She explains, “I am a parent of a child with a disability. It’s just part of my life, not my life. A lot of people, they get consumed, not me. [laugh] It’s not my life. It’s part of my life.” Leslie’s newfound financial security meant that she had the resources and time to enjoy avenues of personal fulfillment as opposed to “being consumed” by critical caregiving. Her son’s disability does not overwhelm her and she is able to separate herself from her child’s disability because of the privilege she obtained with two incomes (hers and her current husband’s), her education, and her son’s “moderate” diagnosis.

Neither Leslie’s current identity nor her future plans were contingent on her son’s disability. Some of the other women I spoke to, especially those with fewer resources and those who were single mothers, were not able to separate themselves from their children’s disabilities so easily. For example, Tamika and Stephanie, both single working mothers, felt that their current and future choices were limited by their children’s disabilities. Tamika talked about how she was unable to do anything besides work and take care of her son. “I got to a certain point where I was like I’m just the caregiver. I’m a be taking care of him for the rest of our lives.” Stephanie, who also possessed a less-than optimistic view believed that her son’s autism limited both her current situation and her future plans.

Stephanie: Like I don’t think I’ll be able to, like I always planned when my kids get older I’ll want to move. I don’t think that I’ll just be able to move.

Michelle: Okay. Like out of state or something?

Stephanie: Yeah I don’t think I could do that. If he were like I don’t want to say normal cause normal is not a definite.

Michelle: Like typical?

Stephanie: Right and like an average child I could and I can say, “Y’all call me.” But I couldn’t move out of state and leave [him] behind...I would always worry about all of



them but with him especially with his disabilities. So if I move I'll probably wind up taking him with me. Which, yeah, it would be limited.

Michelle: You never thought about that before? Before me asking you that question?

Stephanie: No, no.

Michelle: Cause I see you thinking about it.

Stephanie: Yeah cause I was like well see when I move y'all can have this house long as y'all share it or whatever and I'm gone. But now I'm thinking about it. No, I ain't going nowhere.

Allison's experiences with work and education paralleled Leslie's. Allison never received welfare. She graduated from college with plans of working in psychology, her field of choice. When her son was diagnosed with autism her plans changed because his limitations restricted her availability for work. When the contract ended on her administrative assistant job, she had difficulty finding a job that would accommodate her schedule. She currently survives by living rent-free in her deceased parents' home and relying on her fiancée's income. Although she was a college graduate, she was having a hard time finding a job, and since her son was still very young she had less scheduling flexibility. Although she saw her son's autism as mild, she thought her caregiving work prevented her from finding a job.

See, now that's the problem that I have because the last two jobs that I had they did work with my schedule and they did allow me to work with my schedule so that I can pick up my son from school and to bring him to his therapy appointments. So the interviews are...it always depend on the hours and whether or not it will be full-time or part-time and whether or not they'll work with my schedule. If they'll work with my schedule and they'll allow me to leave to pick up my son then of course it's a good thing, but you know sometimes I'll be going on I interviews and they'll be like, "No. I need you to work from nine to five," and I just can't do it...I put it out there at the very beginning. The first thing they say you know is, "Tell me a little bit about yourself." I explain to them that I have a son that has a disability and that he has therapy appointments and you know I have to bring him to do therapy.... I let them know I have to leave at a certain time and if they can't accommodate my hours then you know I just have to look for employment elsewhere. And if they say the hours are this or whatever I already know what's going to happen from there.

Lack of caregiving support from support from her child's father and from extended kin, and the inflexibility of prospective employers prevent women like Allison from finding gainful employment. She had to choose between being available to her child and the structure of the prospective job, where inflexible schedules are incompatible with her family needs.

### *Post-Welfare Reform Survival Strategies*

For these women, welfare was a responsible short-term decision. Post-welfare reform, its limited availability meant that they needed to come up with some other plan for long-term survival. For those who did not receive welfare, the conditions of low-wage work were incompatible with their caregiving needs. The lack of affordable and reliable childcare alternatives and the loss of caregiving support from extended kin meant that these women were solely responsible for the care of their children. This lessened their chances of being available to work the rigid schedules that many employers demand. Regardless of the level of caregiving support, these women had to find a way to balance work and family. Most of the women I interviewed were either employed or seeking employment. Those who worked talked about never getting a break from some sort of work activity. Those who did not work talked about the problems of being confined to constant critical caregiving and the difficulties they faced finding employment that would accommodate their children's needs and pay a sufficient wage.

In the absence of sufficient wages, the women pieced together various survival strategies in order to meet their financial obligations, to be available to their children, and to ensure future security. Many of their children were school age, which for other mothers would free up time during the day for mothers of children with disabilities to participate in the labor force. However, this was not necessarily the case. Having their children in school presented some with

yet another challenge: the need to be available during school hours in case of a behavioral problem or a medical emergency. The only exception to employment limitations was Eileen, who was recently diagnosed with epilepsy and told that she could no longer work. This news added to her frustrations of previously being unavailable for work because of her children's disabilities. Instead of working she relies on her and her children's monthly SSI payments of \$637 each. The next sections present the common survival strategies among the women for balancing critical caregiving with the employment constraints after welfare reform. These were receiving housing support from relatives, increasing their educations, and combining employment with public supports. Although only one woman talked about participating in informal work, this strategy is included in this discussion.

*Housing Support from Relatives.* Although family members did not provide childcare support, they played an important role by assisting with housing. Allison, Shannon, Eileen, Myra, Lori, and Leslie all depended on their relatives for housing support. Either they lived with their mothers or they lived in a family house that was paid for. Donna provided housing to other relatives following Katrina, Stephanie housed her mother, and Latisha and Tamika received Section 8. Housing support from relatives was very important because their wages were not sufficient to pay for all of their living expenses and additional expenses related to their children's disabilities. Although family members were not willing or available to provide caregiving support, their provision of housing support freed up money for other expenses.

*Increased Education.* As mentioned before, to the women in this study, responsible mothering meant looking beyond their current financial situations. These women were not only

concerned with providing for the immediate needs of their children. They wanted to ensure their future economic survival as well. The use of welfare was a temporary fix for some mothers, but the availability of job training programs meant that they could work towards a future goal. However, welfare's job training and education programs were not seen as the ultimate solution for many of these women. In fact, seven of the ten women I interviewed were enrolled in a degree seeking program. Shannon left welfare voluntarily because the job training program was not as valuable to her as a degree-seeking program at the community college. When her worker told her that in order to keep her TANF benefits she would have to quit school and go to work or attend job training, she refused.

Shannon: Um actually they was gonna cut me off...I was still in school at the time and this is what he told me to do. I had to get a part-time job or I had to do Job One thirty something hours a week and I wasn't gonna be able to go to school and I told him he could just cut it off because I can schedule Job One and still go to school but it was like no I had to stop going to school. I was like I can't do that. That's just ridiculous.

Michelle: So they wanted you to do Job One and you wanted to go to school at the same time?

Shannon: Yeah. But they wanted me to stop going to [college] and just do Job One.

Michelle: Why?

Shannon: I didn't understand that either, but that's what he told me and I'm like no. I'm not gone do it. I'm not gone do it. I said that's just ridiculous because I only go to school what two days a week... I just didn't understand what he was talking about. I was like, "You know what? This ain't even enough money for me to argue with you over." I said, "Just go ahead and cut it off or whatever."

Michelle: So why was school more important?

Shannon: Cause I can get more money and a better job... Cause ain't no way in the world I'm gone stop going to school. In that case I will find a way to work and go to school.

*Informal Work.* Only one mother discussed earning money outside of formal employment. I expected to find more of the women working in the informal labor market, but

this was not the case. I speculate that other women would have performed informal work, but their already demanding schedules may make this another likely burden for mothers of children with disabilities. It is also possible that some of them did work on the side but were wary of disclosing that information. Whatever the case, most of them did not talk about making any money outside of or in addition to formal employment. However, one mother did talk about earning money outside of formal employment.

Lori's six year old son was misdiagnosed as mentally retarded by a pediatric neurologist when he was three. After many visits with doctors and therapists her son was re-diagnosed with mild to moderate autism. She experienced a sudden loss of income support after her divorce, ended up on welfare, and moved in with her mother. Her son attends a special education program at school, which frees up time for Lori during the day, but Lori, who considers herself a very "dedicated mom," has chosen to remain at home. She does hair in her living room in order to make money. Being home during the day means that she is readily available to attend school meetings, therapy sessions, and doctor appointments. This also allows her to go to school to pursue a nursing degree.

She recognizes the regular income that full-time employment would provide, but she appreciates the flexibility that working for herself offered. This way she does not have to be limited to a specific work schedule. Instead, she can choose her own hours, work as much as she wants, and fulfill the role of stay-at-home motherhood. It is important to note that in order for Lori to do all of this, she relies on the financial and housing support of her mother who works full-time.

*Combining Employment with Public Supports.* The conditions of low-wage work combined with intense caregiving responsibilities created an atmosphere filled with stress and fatigue for all the women I spoke to. The lack of caregiving support meant that they did not have vital caregiving assistance that would have potentially allowed them to supplement their incomes with additional employment. Realizing that low-wage work was insufficient in providing for the needs of their families, some of them believed that the remedy was to increase their educations. For others the severity of their child's disability made the prospect of social mobility through education difficult, if not impossible. Intense caregiving responsibilities, financial constraints and a loss of social support exacerbate work-family dilemmas that these women experience. As a result they were overwhelmed and socially isolated with no relief in sight. One tactic was to combine low-wage work with other public supports.

Working full-time and never receiving welfare did not make the women immune to the problems of poverty after welfare reform. Low wages, low benefits, and inflexible work schedules made it difficult for these women to survive on low-wage employment alone. Like the former welfare recipients, the women who never received welfare were unable to achieve the ideal of self-sufficiency through low-wage work. As a result, they depended heavily on food stamps, SSI, and Medicaid in order take care of their obligations. The need to boost their incomes with public support is a strategy of every woman I spoke to, even those who had never received a welfare check. Despite their economic situations these women held firm the idea of self-reliance, although their actual lived experience falls short of the independence they were trying to achieve. Their own lives did not reflect independence through employment because their low-wage jobs did not offer them enough pay and flexibility to take care of their families' needs. In response, they supplemented their incomes with public supports such as food stamps

to feed their children, Medicaid to provide medical care, and Supplemental Security Income to help pay the bills and buy supplies for their children. Some of them received public housing assistance, while others relied on the support from their own mothers.

## DISCUSSION AND CONCLUSION

This thesis documents the struggles of ten low-income African American women as they negotiate the demands of caring for children with disabilities with the need to provide financially for their families. In a post-welfare reform era, the intersections of race, class, gender, and disability place these women at extreme disadvantages compared to other women. Their situations are characterized by amplified hardships, social invisibility, and the development of micro-level strategies to combat structural level problems.

These women had intersectional experiences that were evident in their intensified gendered caregiving responsibilities, racialized worries about crime and abuse, and by the devaluation of their critical mothering roles. This distinguishes them from other women. These mothers not only bear the burden of providing constant care and financial support to their children with disabilities, as do other mothers with special needs children, but they do so in a context of welfare reform that virtually guarantees their failure. The interaction of race, class, gender, and disability on their lives amplifies their hardships, resulting for most women in the experiences of inadequacy and invisibility, regardless of their level of education, marital status, welfare receipt, or perceived level of family support.

The requirement to choose between achieving financial independence and providing proper critical care to special needs children is an issue that other women do not have to confront. However, such specific intersectional experiences, while unique to this group, represent larger conflicts for low-income women. The need to successfully balance work and family is not an either/or condition. The problem is not simply that these women have to choose between employment and caregiving, but that their commitment to mothering is rendered



inadequate, although their caregiving is vital to the survival of their children. Their stories reveal how poor women's lives are governed by a hierarchical social structure and policies that obscures the real causes of social problems.

Welfare reform blames poor people for being poor. It mandates participation in the workforce for poor women, even when their lives are incompatible with that restriction. While childhood disability shapes these women's motherhood experiences, their choices are influenced by structural inequalities that limit their options. For example, although their relatives may provide material support in the form of housing, these women singularly bear the responsibilities for continuous caregiving to children with disabilities. This is an undertaking that upper and middle-class mothers with better resources and education do not have to manage. Some of them lost the networks of care that have been a source of strength for low-income Blacks throughout history. As a result, they do not have access to the pooling of resources or the sharing of childcare responsibilities that would provide better flexibility in employment. In response to these issues, they develop micro-level strategies to compensate for the loss of caregiving and income supports.

The responses of these women to their circumstances – increasing their educations, receiving housing help from relatives, and combining income with public supports – are all micro-level strategies that will have no impact on the structural level causes to their problems. While they recognize agency and personal responsibility for their decisions, they do not identify the limitations of their choices or how their lives are socially organized (Weight 2006). Their survival strategies will in no way offset the lack of caregiving recognition, employer inflexibility, or the existence of racialized public policies. On the other hand, their strength and

resolve in the face of economic constraints is testament to the resilience that is necessary for their survival and the well-being of their children.

Although they redefine the notion of personal responsibility to include welfare receipt as a responsible decision, rather than a social transgression, they continue to regard their problems as personal rather than political. In reality, their lives are a constant struggle to navigate a social structure that devalues their children and marginalizes their mothering roles. The invisibility of their situations signifies society's continual disregard for the situations of African American women, caregivers, poor people, and people with disabilities. Their lives reflect a social climate that produces inequalities based on race, class, gender and ability.

### *Limitations*

As with any qualitative research, this study has its limitations. First, this research is not representative of all situations and experience of low-income women with children with disabilities. This study is situated within the context of New Orleans, Louisiana, a region severely impacted by the 2005 hurricanes Katrina and Rita. One limitation is that the selection of participants was restricted to those women who were able to return to the Greater New Orleans area after the storms. Therefore, it does not include residents who were displaced and have since relocated to other parts of the United States. One consequence of this limitation is that while some of the participants in this study had access to housing support from family members who returned to the region, this does not necessarily reflect the availability of shared resources for former residents who were not able to or who chose not to return. It may be that the women who did not return are surviving without government or kin support, or that they

remain reliant on the welfare system. They may be doing better in other states that have greater resources for poor families.

A second limitation of this study is that it focuses on the experiences of mothers as providers of care. This restriction excludes other primary caregivers, such as grandparents, fathers, and extended kin who may provide critical care for children with disabilities. Although mothers are more likely to provide primary care for children with disabilities, the experiences of other caregivers should not be minimized. It is important to recognize the variability in family composition in order to get a realistic representation of the impact of poverty and disability on the caregiving experience.

Third, while the location of the study restricts the ability to generalize my findings to poor African American women with children with disabilities outside of Louisiana, the sampling design provides a similar limitation. Because this study focuses on African American women, it cannot offer claims to the experiences of poor non-Black women with children with disabilities. These women may share similar experiences, but it is probable that they have distinct experiences requiring the development of different survival strategies. It is important for future research to examine the impact of racial and ethnic differences on the disability experience of poor mothers. Furthermore, this research does not illustrate the entire range of negotiations poor women with disabled children develop on behalf of their children over time and across different circumstances. Instead, it presents a snapshot of some of the experiences of these women, which can offer other researchers a glimpse into a previously hidden aspect of social life.

### *Significance of the Study*

Despite its limitations, this study is significant for a number of reasons. It contributes to the growing realm of research that examines the impacts of welfare reform on the lives of poor mothers raising children with disabilities. This study can provide insights into how low-income mothers balance welfare regulations with caring work in the presence of a disabled child. This information can potentially help researchers distinguish between the assumptions and expectations of social policy and the social and cultural biases inherent in its implementation. Understanding relationships between welfare reform, disability, and work ideologies can reveal discrepancies between the claims of welfare reform's success and the lived experience of poor women. Understanding the underlying logic of welfare reform and then contrasting it to actual realities and acute experiences of poor women can possibly help policy makers assess its guidelines to improve the program. Finally, this study can be a starting point in examining how social policy impacts women who are multiply disenfranchised.

### *Implications for Policy and Research*

The women I interviewed discussed a variety of difficulties that cannot be explained in a strict race-only, class-only, or gender-only context. For example, their reasons for choosing welfare, due to pregnancy related illnesses, is borne out of specific raced and classed inequalities. This identifies the need for supportive workplace policies and quality health care programs for poor families. The loss of caregiving networks is an issue that is influenced by race, class, gender, and disability. This issue points to the need for available and qualified caregiving support for low-income women with children with disabilities. Similarly, their inability to work-full time and provide continuous care for their children identifies the

inconsistencies of gendered worker and caregiver ideologies, warranting the importance of revising incompatible welfare and workplace policies.

The depression and fatigue experienced by many of these women are symptoms of a much larger problem. Policy makers must restructure work-family policies so that low-income women who provide continuous care for their children with disabilities may continue to do so without fear of losing their jobs or their welfare benefits. Further, I suggest a greater recognition of the value of the carework done in the home through modification of family and workplace policies so that they do not exclude women who are multiply disenfranchised.

Mothers of children with disabilities face a variety of problems that other mothers do not, but the caregiving experience is not universal. Low-income African American women with children with disabilities experience hardships that are similar to those faced by other women, but which also may be more profound. Their experiences, while often made invisible within the growing discourse of caregiving and disability research, provide us with important insights into the impacts of intersectionality. An analysis of caregiving is inaccurate if it neglects the influences of race, class, gender, and disability. In order to get a more thorough understanding of the impacts of caring for children with disabilities it is important to examine the effects of social inequality on the motherhood experience.

In this thesis, I have illustrated how the struggles of raising a child with a disability are amplified in the face of race and class inequalities. In doing so, I hope to broaden current understandings of caregiving issues and to demonstrate the importance of a more thorough intersectional analysis. While race, class and gender are essential to the application of intersectionality theory, I suggest that researchers not neglect the value of disability as an analytic category.

Ableness is often a taken for granted characteristic as previous caregiving research has neglected to fully examine its impacts on family life. Its omission effectively excludes the experiences of a vulnerable segment of the population. It is essential, therefore, for further research to include a disability analysis in order to obtain a more accurate representation of women's lives. This would allow policy makers and researchers to better evaluate the success and failures of our policies so that we do not cause greater hardship to American families.

Finally, in doing this research, I have inadvertently grouped together different types of impairments under the umbrella term "disability." Researchers should be cautious of this tendency, because the family's disability experience may vary based on the severity of the child's impairment. It is worthwhile for future research to examine how the severity of childhood disability impacts some of the issues found in this study, such as mother's employment options and their perceived level of social support from kin networks.

### *Conclusions*

The women I interviewed redefined personal responsibility to transcend economic independence. Personal responsibility includes providing for the basic needs of the family despite financial constraints, giving ongoing caregiving support regardless of the difficulties involved, and providing value and support to their children. Social policy, such as the 1996 welfare reform regulation, that supports idealized notions of personal responsibility at all costs, disregards the realities of women's experiences and stigmatizes the important care work done by poor women of color, and those who care for children with disabilities. The lives of women should inform social policy, not the inverse. Social policy that continues to disregard the

realities of women's lived experiences will undoubtedly persist in causing undue harm to women as they do the necessary work of balancing work and family in a post-welfare reform era.

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## APPENDIX A: IRB APPROVAL LETTER

### **02sep07 approval letter**

Laura Scaramella

**Sent:** Tuesday, November 27, 2007 1:00 PM

**To:** Rachel E Luft; Michelle Shantell Balot

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*University Committee for the Protection  
of Human Subjects in Research*

**University of New Orleans**

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*Campus Correspondence*

Rachel Luft, PI  
Michelle Balot, Co-I  
LA 373

11/27/07

RE: Triple jeopardy: The impact of welfare reform and gendered work ideologies on mothers of children with disabilities

IRB#: 02sep07

The IRB has deemed that the research and procedures are compliant with the University of New Orleans and federal guidelines

Please remember that approval is only valid for one year from the approval date. Any changes to the procedures or protocols must be reviewed and approved by the IRB prior to implementation.

If an adverse, unforeseen event occurs (e.g., physical, social, or emotional harm), you are required to inform the IRB as soon as possible after the event.

Best of luck with your project!  
Sincerely,

Laura Scaramella, Ph.D.  
Chair, University Committee for the Protection of Human Subjects in Research

## APPENDIX B: RECRUITMENT FLYER



UNIVERSITY of  
NEW ORLEANS

### Research Participants Needed

I am a mother of a child with a disability looking for other women to talk to. I am conducting a research study to learn about the lives of women raising children with disabilities.

Qualifications include:

- Woman age 18-65
- Mother of a child with a disability
- Have received or currently receiving welfare benefits (TANF, Food Stamp, SSI, Medicaid, or Housing Assistance)

Study participation involves:

- 2-3 personal interviews
- You will be compensated for your time
- Families also receive list of community resources

For more information and to enroll in this study, please contact:  
Michelle Balot at (504) XXX-XXXX

Principal Investigator:  
Rachel E. Luft, PhD



Mothers of Children with Disabilities Project Michelle Balot (504) XXX-XXXX	Mothers of Children with Disabilities Project Michelle Balot (504) XXX-XXXX	Mothers of Children with Disabilities Project Michelle Balot (504) XXX-XXXX	Mothers of Children with Disabilities Project Michelle Balot (504) XXX-XXXX	Mothers of Children with Disabilities Project Michelle Balot (504) XXX-XXXX	Mothers of Children with Disabilities Project Michelle Balot (504) XXX-XXXX	Mothers of Children with Disabilities Project Michelle Balot (504) XXX-XXXX	Mothers of Children with Disabilities Project Michelle Balot (504) XXX-XXXX	Mothers of Children with Disabilities Project Michelle Balot (504) XXX-XXXX	Mothers of Children with Disabilities Project Michelle Balot (504) XXX-XXXX
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## APPENDIX C: SCREENING SURVEY

### Mothers of Children with Disabilities Project Eligibility Screener

#### Screening Script

Thank you for talking to me about our research study. My name is Michelle Balot; I am a graduate student at the University Of New Orleans Department Of Sociology. I am also a mother of a child with a disability.

The purpose of my research study is to learn about the experiences of women with welfare experience that are raising children with disabilities.

As part of the study, I will be asking women to complete a series of interviews about their experience with welfare and their experiences taking care of their children.

But before we begin the study, we need to determine if you are part of the group we are studying. So, what I need to do now is to ask you a series of questions about yourself. These questions will take approximately five minutes. You do not have to answer those questions if you don't want to. You also may choose to stop participating in this conversation at any time; if you want to stop, please tell me.

It's important that you give honest answers. All your answers will be kept confidential.

The purpose of this screening interview is only to see if you meet the criteria for participating in this research study. Remember, your participation is voluntary; you do not have to complete these questions.

*Do I have your permission to ask you these questions?*

{If NO}: Thank you very much for calling.

{If YES}: Ask screening questions on next page.

Screening Questionnaire

- 1) How old are you? \_\_\_\_\_  
*[If younger than 18 or older than 65 then, Not Eligible → go to ineligible script on next page.]*
- 2) Are you a mother of a child with a disability? \_\_\_\_\_  
*[If NO then, Not Eligible → go to ineligible script on next page.]*
- 3) Has your child been diagnosed by a med. professional? \_\_\_\_\_  
*[If YES or NO then, go to next question.]*
- 4) Do you currently receive or have you received in the past any of the following forms of welfare:  
    i. A welfare check? \_\_\_\_\_  
    ii. Food Stamps? \_\_\_\_\_  
    iii. A Housing Voucher? \_\_\_\_\_  
    iv. Medicaid? \_\_\_\_\_  
    v. SSI? \_\_\_\_\_  
*[If NO to all then, Not Eligible → go to ineligible script on next page.]*
- 5) Are you currently pregnant? \_\_\_\_\_  
*[If YES then, Not Eligible → go to ineligible script on next page.]*
- 6) Have you been diagnosed with any of the following? (no)  
    a. A physical disability? \_\_\_\_\_  
    b. A learning disability? \_\_\_\_\_  
    c. A psychological impairment? \_\_\_\_\_  
*[If YES to ANY then, Not Eligible → go to ineligible script on next page.]*
- 7) Do you have any medical problems that would make it difficult to complete an in-depth face to face interview? \_\_\_\_\_  
*[If YES then, Not Eligible → go to ineligible script on next page.]*
- 8) Do you have any physical limitations? \_\_\_\_\_  
*[If YES then, Not Eligible → go to ineligible script on next page.]*

INELIGIBLE SCRIPT

Based on the information you gave me, you are not eligible for this study.  
Would you be interested in receiving a list of community resources that may be helpful to you?

{If NO}: *Thank you so much for your time.*

{If YES}: *Get name and mailing address and mail them a list of resources.*

Name: \_\_\_\_\_

Phone #: \_\_\_\_\_

Mailing Address: \_\_\_\_\_

ELIGIBLE SCRIPT

Based on the information you gave me, it looks like you are eligible for this study.

You will be reimbursed for your time at a rate of \$15 per interview.

*Are you interested in participating in this study?*

{If NO}: *Thank you so much for your time.*

{If YES}: *May I take down your contact information and we can ~~you~~ to set up a scheduled time to meet in person?*

Name: \_\_\_\_\_

Phone #: \_\_\_\_\_

Mailing Address: \_\_\_\_\_

Best time to call \_\_\_\_\_

3



## APPENDIX D: CONSENT FORM



THE UNIVERSITY of  
NEW ORLEANS

DEPARTMENT OF SOCIOLOGY

### ADULT CONSENT FORM

#### Mothers of Children with Disabilities Project

Dear Participant:

I am a graduate student under the direction of Professor Rachel Luft in the Department of Sociology at the University of New Orleans. I am conducting a research study to investigate the experiences of women raising children with disabilities. I am studying the ways in which single mothers with limited incomes who are raising children with disabilities develop strategies and understandings about living with a child with a disability.

Sociology, as a discipline, is interested in studying the social context of individuals within groups, and larger societal and cultural institutions. We have found through our research that individuals have knowledge about their living situations that is not known. My purpose in the interview is to discover the knowledge that you might have about caring for a child with a disability. I am interested in the effects of work, welfare, disability and Hurricane Katrina on your daily life.

I am requesting your participation, which will involve three personal interviews lasting approximately one and a half hours. Interviews will be conducted approximately three days to one week apart so as to be completed within one to three weeks. Your participation in this study is voluntary. If you choose not to participate or to withdraw from the study at any time, there will be no penalty. The results of this research study may be published, but your name will not be used.

My purpose in the interviews is to discover the knowledge that you might have about mothering a child with disabilities in your financial situation. I am a graduate student, not a therapist. My questions are designed for information, not to probe for feelings or to cause you emotional distress. However, due to the sensitive nature of some of the interview questions you may experience discomfort or distress as a result of the interview process. If this happens, you may choose not to answer any question you do not wish to answer. If you get tired during the course of the interview you may take a break.

You will be reimbursed for your time at a rate of \$15 per interview. If you terminate your interview early you will still receive payment. The possible benefit of your participation is to advance the knowledge of the lives of women caring for children with disabilities and/or the lives of women with welfare experience.

At the end of this study you may be asked to participate in a focus group with other mothers in similar circumstances. The reason for this focus group is to clarify themes that came out in several interviews. Participating in the focus group is not required. You have the option not to participate in the focus group.

365 Liberal Arts Building Lakefront Campus 2000 Lakeshore Drive New Orleans, Louisiana 70148 504.280.6301 fax 504.280.6302

A Member of the Louisiana State University System Committed to Equal Opportunity

## APPENDIX E: INTERVIEW GUIDE

### MOTHERS OF CHILDREN WITH DISABILITIES INTERVIEW SCHEDULE

#### PART 1

1. Tell me about yourself and your situation.
2. Tell me about your childhood.
3. Describe how you came to where you are in your life today.
4. Tell me about your children. Describe your child's disability.
5. What is it like being the mother of a child with a disability?
  - a. Describe a typical day. What is it like for you?
  - b. Describe the things you do to take care of your child that he's or she cannot do for himself/herself
6. How would you describe your role as a mother?
7. Have your views and expectations changed since having a child with a disability?
8. Describe the challenges you face caring for or raising your child.
9. What is the most challenging aspect?
10. What are the highlights?
11. Tell about your support systems?

#### PART 2

1. How has hurricane Katrina impacted your life?
2. Can you talk to me about your financial situation?
  - a. How does having a child with a disability affect your financial situation?
  - b. How does your current financial situation affect your ability to care for your children?
3. What is your experience with welfare?
  - a. What made you apply for welfare?
  - b. Have you ever thought about applying for welfare? Why or why not?
4. If you could be on welfare would you? Why or why not?
5. What have you learned from being in your situation?
6. Looking over your life, what has done the most good for your children? For you?
7. What lessons do you want your children to learn from your experiences?
8. Pretend that you will serve as a mentor for a mother with a child with a disability who also is in the same financial situation. What one piece of advice would you give to her?
9. Can you recommend to me another mother who would be good to talk to?

## APPENDIX F: RESOURCE LIST

*This is a partial list of crisis intervention resources and disability related services. Additional information and links to other service providers can be obtained by visiting the organizations' websites or by contacting them by phone. Please call the organization you are interested in for the most updated information.*

### Crisis Resources

#### **Catholic Charities Archdiocese of New Orleans**

Phone: (504) 523-3755

Fax: (504) 523-2789

Website: [www.ccano.org](http://www.ccano.org)

\*this website provides links and information for other emergency services such as emergency food and shelter

#### **Children's Bureau of New Orleans**

Phone: (504) 525-2366

Website: [www.childrens-bureau.com](http://www.childrens-bureau.com)

Provide community-based mental health services to children ages 0-17 and their families who have been impacted by Hurricane Katrina and/or other pre- or post-Katrina traumatic event. Clients will be seen in their homes, shelters, churches, trailer communities, and/or other locations per client's request, if necessary.

#### **Common Ground Health Clinic**

Phone: (504) 361-9800

Website: [www.cghe.org](http://www.cghe.org)

"The Common Ground Health Clinic is a non-profit organization that provides free quality health care for the greater New Orleans community, and develops and provides programs to address community health care needs through collaborative partnerships. The clinic provides a range of health services including regular medical check ups, prescriptions and some medications, mental health services and alternative healing treatments. For residents unable to travel, the clinic offers home visits and a mobile clinic."

#### **COPE LINE**

Phone: (504) 269-COPE (2673)

Toll Free: (800) 749-COPE (2673)

24 hour telephone crisis intervention service. Calls relate to emotional distress, abuse, violence and everyday stress. Counselors trained in suicide intervention and prevention.

#### **Crescent House**

Business line: (504) 866- 7481 (For counseling appointments)

Crisis line: (504) 866- 9554 (24 hour line)

Provide shelter and transitional housing services to battered women and their children. The programs offer housing and meals, as well as individual and group counseling, information, referrals, advocacy, and community education.

**Metro Battered Women's Shelter**

24 hour crisis line: (504) 837-5400

Website: [www.metrobatteredwomen.com](http://www.metrobatteredwomen.com)

"Services are provided to survivors of domestic violence, stalking, and sexual assault. Metro provides services throughout the greater New Orleans area." Services include: crisis line, counseling, shelter, legal information, advocacy and referrals. Anonymous and free.

**New Orleans Mission**

Phone: (504) 523-2116

Website: [www.neworleansmission.org](http://www.neworleansmission.org)

Offering free transitional housing for up to 18 months, free meals and clothing, free laundry services, a free health clinic, a limited rehabilitation program for men, free education and employment services, and free relocation assistance including transportation, case management, free groceries and furniture, and free employment counseling and support.

**United Way for the Greater New Orleans Area**

Phone: (504) 822-5540

Fax: (504) 821-4378

Website: [www.unitedwaynola.org](http://www.unitedwaynola.org)

\*This website also provides links to other resources

Disability Advocacy and Services

**Arc of Greater New Orleans**

Phone: (504) 897-0132

Website: [www.arcgno.org](http://www.arcgno.org)

Early Intervention: Provide early intervention services to children birth to 3 years with developmental delays / disabilities to include speech, occupational, and physical therapy as well as parent education.

Employment Services: Assist in placing/re-placing individuals with developmental disabilities into employment as well as supporting individuals who are currently employed to maintain employment.

Family Service Coordination: Links families with children birth to three (3) years with developmental delays/disabilities to resources and to coordinate needed services to enhance their abilities.

Project H.E.L.P - Respite and Supported Living: Provide respite services to families supporting a child or adult who has disabilities at home. Also assist families attempting to re-locate to habitable areas in order to re-establish their residences, including some direct assistance for household items.

Individual Options: Provides meaningful and age-appropriate social, recreational, health and leisure activities for adults with cognitive disabilities, also opportunities to volunteer and work within the community.

Uptown Learning Center- Childcare: Provide childcare services to children six weeks to five years of age with and without developmental delays/disabilities.

### **Families Helping Families of Greater New Orleans**

Phone: (504) 888-9111

Toll Free: 1-800-766-7736

Website: [www.fhfgno.org](http://www.fhfgno.org)

"Our mission is to enable and empower Louisiana families of individuals with disabilities through an effective coordinated network of Resources, Support, and Services. Our vision is to ensure all individuals with disabilities have the opportunity to attend school, live, work and recreate in their community with typical peers." from FHFSELA Website

We offer these three services:

- ☐ Information and Referral
- ☐ Education and Training
- ☐ Parent to Parent Support

### Disability-Specific Organizations

\*This information was obtained from the Families Helping Families of Greater New Orleans website [www.fhfgno.org](http://www.fhfgno.org)).

### **Attention Deficit Disorder**

To identify an ADD group in your state or locality, contact either:

Children and Adults with Attention-Deficit/Hyperactivity Disorder (CHADD)

8181 Professional Place, Suite 150

Landover, MD 20785

(301) 306-7070

(800) 233-4050 (Voice mail to request information packet)

Web: [www.chadd.org](http://www.chadd.org)

Attention Deficit Disorder Association (ADDA)

P.O. Box 543

Pottstown, PA 19464-0543

(484) 945-2101

Web: [www.add.org](http://www.add.org)

### **Autism**

Division of Educational Improvement and Assistance

Louisiana Department of Education

P.O. Box 94064

Baton Rouge, LA 70804-9064

(225) 342-3513

Web: [www.louisianaschools.net/lde/index.html](http://www.louisianaschools.net/lde/index.html)

Louisiana State Autism Chapter

5430 S. Woodchase Court  
Baton Rouge, LA 70808  
(800) 955-3760  
E-mail: [pjmanco@cox.net](mailto:pjmanco@cox.net)  
Web: [www.lastateautism.org](http://www.lastateautism.org)

### **Blind/Visual Impairments**

Jaelyn Packer, Ph.D., Director of Information Center  
American Foundation for the Blind  
11 Penn Plaza, Suite 300  
New York, NY 10001  
(212) 502-7600; (800) 232-5463  
E-mail: [afbinfo@afb.net](mailto:afbinfo@afb.net)  
Web: [www.afb.org](http://www.afb.org)

### **Cerebral Palsy/Developmental Disabilities**

Janet Ketcham, Executive Director  
UCP/Baton Rouge--McMains Children's Development Center  
1805 College Drive  
Baton Rouge, LA 70808  
(225) 923-3420  
E-mail: [jketcham@mcmainscdc.org](mailto:jketcham@mcmainscdc.org)  
Web: [www.mcmainscdc.org](http://www.mcmainscdc.org)

Jo Bugg, Executive Director  
United Cerebral Palsy of Greater New Orleans  
2200 Veterans Memorial Boulevard, Suite 103  
Kenner, LA 70062  
(504) 461-4266  
E-mail: [info@ucpgno.org](mailto:info@ucpgno.org)  
Web: [www.ucpgno.org](http://www.ucpgno.org)

### **Down Syndrome**

Karen Scallan, President  
Down Syndrome Association of Greater New Orleans  
P.O. Box 748  
Destrehan, LA 70047  
(504) 251-8953  
E-mail: [kscallan@dsagno.org](mailto:kscallan@dsagno.org)  
Web: [www.dsagno.org](http://www.dsagno.org)

### **Epilepsy**

Dorothy Martino, LCSW, Executive Director  
Epilepsy Foundation of Louisiana  
3701 Canal Street, Suite H  
New Orleans, LA 70119

(504) 486-6326; (800) 960-0587  
E-mail: [epileps@bellsouth.net](mailto:epileps@bellsouth.net)  
Web: [www.epilepsylouisiana.org](http://www.epilepsylouisiana.org)

### **Intellectual and Developmental Disabilities**

Laura Brackin, Executive Director  
The Arc of Louisiana  
8336 Kelwood Drive  
Baton Rouge, LA 70806  
(225) 303-0463  
E-mail: [lbrackin@thearcla.org](mailto:lbrackin@thearcla.org)  
Web: [www.thearcla.org](http://www.thearcla.org)

### **Learning Disabilities**

Kristina Braud, Educ. Program Consultant 2 - Mild/Moderate  
Bonnie Boulton, Ph.D., Education Program Consultant 3 - Mild/Moderate  
Division of Educational Improvement and Assistance  
Louisiana Department of Education  
P.O. Box 94064  
Baton Rouge, LA 70804-9064  
(225) 342-0576  
E-mail: [kristina.braud@la.gov](mailto:kristina.braud@la.gov)  
E-mail: [bonnie.boulton@la.gov](mailto:bonnie.boulton@la.gov)  
Web: [www.louisianaschools.net/lde/index.html](http://www.louisianaschools.net/lde/index.html)

Barbara Duchardt, Associate Professor of Special Education  
Northwestern State University  
Teacher Education Center, Room 104J  
Natchitoches, LA 71497  
(318) 357-5154  
E-mail: [duchardt@nsula.edu](mailto:duchardt@nsula.edu)

### **Mental Health**

Yakima Black, Executive Director  
Mental Health America of Louisiana  
660 N. Foster Drive, Suite C-201  
Baton Rouge, LA 70806  
(225) 201-1930  
E-mail: [yblack@mhal.org](mailto:yblack@mhal.org)  
Web: [www.mhal.org](http://www.mhal.org)

Jennifer Jantz, Executive Director  
NAMI Louisiana  
P.O. Box 40517  
Baton Rouge, LA 70835  
(225) 926-8770; (866) 851-6264



E-mail: [namilouisiana@bellsouth.net](mailto:namilouisiana@bellsouth.net)  
Web: [www.namilouisiana.org](http://www.namilouisiana.org)

Verlyn "Vee" Boyd, Executive Director  
Louisiana Federation of Families for Children's Mental Health  
5627 Superior Drive, Suite A-2  
Baton Rouge, LA 70816-6085  
(225) 293-3508; (800) 224-4010  
E-mail: [yboyd@laffcmh.org](mailto:yboyd@laffcmh.org)  
Web: [www.laffcmh.org](http://www.laffcmh.org)

### **Special Health Care Needs**

Phyllis Landry, Executive Director  
Family Voices Louisiana  
1539 Jackson Avenue, Suite 200  
New Orleans, LA 70130  
(504) 299-9175  
E-mail: [familyla@bellsouth.net](mailto:familyla@bellsouth.net)  
Web: [www.familyvoices.org](http://www.familyvoices.org)

### **Speech and Hearing**

Bland O'Connor, Director  
Louisiana Speech-Language-Hearing Association  
8550 United Plaza Boulevard, Suite 1001  
Baton Rouge, LA 70809  
(225) 922-4512  
E-mail: [lsha@pnepa.com](mailto:lsha@pnepa.com)  
Web: [www.lsha.org](http://www.lsha.org)

### **Spina Bifida**

Spina Bifida Association of Greater New Orleans  
P.O. Box 1346  
Kenner, LA 70063  
(504) 737-5181  
E-mail: [sbagnos@sbagnos.org](mailto:sbagnos@sbagnos.org)  
Web: [www.sbagnos.org](http://www.sbagnos.org)



## VITA

Michelle Magee Balot was born in New Orleans, Louisiana and graduated from Benjamin Franklin High School in New Orleans. She received her B.A. in 2004 from the University of New Orleans. Her research interests include gender, social stratification, and work and family policy.