Georgia State University
Digital Archive @ GSU

Counseling and Psychological Services Dissertations

Department of Counseling and Psychological Services

2-12-2008

An Exploration of the Stressors, Coping Resources, and Resiliency of Rural Mothers of Children with Special Needs

Claudia D. Brasfield
brasfields@gmail.com

Follow this and additional works at: http://digitalarchive.gsu.edu/cps_diss

Recommended Citation
Brasfield, Claudia D., "An Exploration of the Stressors, Coping Resources, and Resiliency of Rural Mothers of Children with Special Needs" (2008). *Counseling and Psychological Services Dissertations*. Paper 17.

This Dissertation is brought to you for free and open access by the Department of Counseling and Psychological Services at Digital Archive @ GSU. It has been accepted for inclusion in Counseling and Psychological Services Dissertations by an authorized administrator of Digital Archive @ GSU. For more information, please contact digitalarchive@gsu.edu.

ACCEPTANCE

This dissertation, AN EXPLORATION OF THE STRESSORS, COPING RESOURCES, AND RESILIENCY OF RURAL MOTHERS OF CHILDREN WITH SPECIAL NEEDS, by CLAUDIA DURST BRASFIELD, was prepared under the direction of the candidate's Dissertation Advisory Committee. It was accepted by the committee members in partial fulfillment of the requirements for the degree Doctor of Philosophy in the College of Education, Georgia State University.

The Dissertation Advisory Committee and the student's Department Chair, as representatives of the faculty, certify that this dissertation has met all of the standards of excellence and scholarship as determined by the faculty. The Dean of the College of Education concurs.

_____
JoAnna F. White, Ed.D.
Committee Chair

_____
Greg J. Brack, Ph.D.
Committee Member

_____
Roger O. Weed, Ph.D.
Committee Member

_____
Michele B. Hill, Ph.D.
Committee Member

_____
Date

_____
JoAnna F. White, Ed.D.
Chair, Department of Counseling
and Psychological Services

_____
Ronald P. Colarusso, Ed.D.
Dean, College of Education

AUTHOR'S STATEMENT

By presenting this dissertation as a partial fulfillment of the requirements for the advanced degree from Georgia State University, I agree that the library of Georgia State University shall make it available for inspection and circulation in accordance with its regulations governing materials of this type. I agree that permission to quote, to copy from, or to publish this dissertation may be granted by the professor under whose direction it was written, by the College of Education's director of graduate studies and research, or by me. Such quoting, copying, or publishing must be solely for scholarly purposes and will not involve potential financial gain. It is understood that any copying from or publication of this dissertation which involves potential financial gain will not be allowed without my written permission.

_____

Claudia Durst Brasfield

NOTICE TO BORROWERS

All dissertation deposited in the Georgia State University library must be used in accordance with the stipulation prescribed by the author in the preceding statement. The author of this dissertation is:

Claudia Durst Brasfield
1310 Milstead Trace
Marietta, GA 30066

The director of this dissertation is:

Dr. JoAnna White
Department of Counseling and Psychological Services
College of Education
Georgia State University
Atlanta, GA 30303-3083

VITA

CLAUDIA DURST BRASFIELD

ADDRESS:

1310 Milstead Trace
Marietta, GA 30066

EDUCATION:

Ph.D	2008	Georgia State University Counseling Psychology
M.S.	1999	Georgia State University Rehabilitation Counseling
B.A.	1994	Emory University Psychology and Anthropology

PROFESSIONAL EXPERIENCE:

2007-2008	Pre-Doctoral Intern Emory University Counseling Center Atlanta, GA
2006-2007	Instructor Georgia State University Department of Counseling and Psychological Services Atlanta, GA
2001-2002	Vocational Specialist Shepherd Center Atlanta, GA
1999-2001	Program Coordinator Emory Center for Rehabilitation Medicine Atlanta, GA

CERTIFICATIONS:

2006-2007 Certified Mediator
2006-2007 National Certified Counselor
1999-2007 Certified Rehabilitation Counselor

PUBLICATION:

Brasfield, C. D., Blasko, L. S., & Hill, M. B. (2004). Stress management. In N. E. Commander, M. Valeri-Gold, & N. R. Masfield (Eds.), *Learning to succeed, 2nd Edition.* Dubusque, Iowa: Kendall/Hunt Publishing Company.

PROFESSIONAL PRESENTATIONS:

Brasfield, C. D., Blasko, L. S., & Hill, M. B. (February, 2005). Comprehensive clinical assistance for students with disabilities: Incorporating stress management counseling into your clinical work. Workshop presented at the Georgia College Counseling Association annual conference, St. Simons Island, Georgia.

Blasko, S., Brasfield, C., & Brack, C. J. (July, 2004). Stress management after trauma: Helping hypervigilant clients relax. Poster presented at the 112th American Psychological Association Annual Conference, Honolulu, Hawaii.

Blasko, L. S. & Brasfield, C. D. (November, 2003). Stress management with the dissociative client. Paper presentation at the International Society for the Study of Dissociation (ISSD) 20th Annual International Conference. Chicago, Illinois.

Ashby, J. S., Dickinson, W. L., Bruner, L. P., Martin, J. L., Brasfield, C. D., & Timmons, D. T (August, 2003). Religious coping, coping resources, and depression. Paper presented at the 111th American Psychological Association Annual Convention, Toronto, Canada.

Brasfield, C., Ashby, J., Timmons, D., Martin, J., Bruner, L., Blasko, L. S., & Leavitt, C. (August, 2003). Multidimensional perfectionism and coping among college students. Poster presentation at the American Psychological Association annual conference, Toronto, Canada.

PROFESSIONAL AFFILITATIONS:

2006-2007 American Psychological Association
2006-2007 National Rehabilitation Association

ABSTRACT

AN EXPLORATION OF THE STRESSORS, COPING RESOURCES, AND RESILIENCY OF RURAL MOTHERS OF CHILDREN WITH SPECIAL NEEDS
by
Claudia Durst Brasfield

A child with a severe disability intensifies the demands facing a family (Beck, Hastings, Daley, & Stevenson, 2004; Martin & Baker, 2001; Withers & Bennett, 2003). Mothers specifically face an intense challenge, a concern as a mother's wellbeing directly impacts her child's emotional well-being (Kobe & Hammer, 1994), physical development, and progress within treatment (Lessenberry & Rehfeldt, 2004). These challenges are further heightened for women living in rural communities as little has changed for individuals with disabilities in rural communities over the past twenty years (Letvak, 2002). Although heightened stress among these mothers is significant, it is unclear how best to minimize stress and facilitate adaptive coping and resiliency among these women.

This qualitative dissertation was an exploration into the stressors, coping resources, and resiliency of rural mothers of children with severe disabilities. Ten mothers of children with severe disabilities living in rural, Southeastern communities participated in a semi-structured interview. Supplementary sources of data include member-checking interviews, participant observation, and reflective journaling.

Data derived from these sources include stressors, coping resources, and resiliency factors. Identified stressors include the absence of services, the insufficiency of

available services, the effort required to locate and access services outside the community, social stressors, financial demands, and stressors stemming from personal attributes. All of the coping strategies listed by the participants shared similarities with those utilized by mothers of children with special needs not living in rural areas (Baun, 2002; Ferguson, 2002; Keller, & Honig, 2004). However, social support and spirituality, two identified coping techniques, are highly reflective of traditional, rural culture (Letvak, 2002; Nordal & Hill, 1999; Slama, 2004b; Wagenfeld, 2003). The mothers also identified their primary sources of resiliency to be external to them, their child/family service providers or God. All of the participants had recommendations for additional, beneficial resources for themselves and their children.

These results are informative and significant to research, practice, and advocacy. Ultimately, it is hoped that this study may assist in empowering members of this marginalized group, advancing beneficial governmental policies, and informing interventions to enhance the wellbeing of these mothers and children.

AN EXPLORATION OF THE STRESSORS, COPING RESOURCES, AND RESILIENCY OF RURAL MOTHERS OF CHILDREN WITH SPECIAL NEEDS

by
Claudia Durst Brasfield

A Dissertation

Presented in Partial Fulfillment of Requirements for the Degree of
Doctor of Philosophy
in
Counseling Psychology
in the
Department of Counseling and Psychological Services
in the
College of Education
Georgia State University

Atlanta, Georgia
2007

Copyright by
Claudia Durst Brasfield
2007

ACKNOWLEDGMENTS

Special thanks to:

Dr. JoAnna White, for chairing this committee and your belief in my ability to succeed.

Dr. Greg Brack, Dr. Roger Weed, and Dr. Michele Hill for your guidance and support both on this dissertation and throughout my doctoral program.

the women who participated in this research – your bravery and strength gave me the courage to be a mother and a doctoral student and to conduct this research.

Dora and Elmo who provided me with vital moments of quiet in tough times.

Loving thanks to my family and friends, especially:

Scott, my best friend and husband. Quite simply, I could never have accomplished this feat without your love, support, and humor.

My children, Emerson and Ian, who have been my inspiration throughout this process.

Virginia and Thomas Durst and Lynn and Stanhope Brasfield, my parents. Your unwavering love, considerable spunk, and generosity of spirit have made you my role models. I cannot thank you enough for the countless doors you have opened for me.

Caroline Leavitt, you have kept me going through this program, project, and motherhood strengthening me with your hope even in the bleakest of times. Your friendship has been one of the most important of my life. Shane Blasko, your endless supply of humor and coffee has been equally invaluable. You have always supported me in accomplishing what I would have thought impossible.

This dissertation is dedicated to
J-Roc
1998-2006
May you and your family have peace

TABLE OF CONTENTS

Page

List of Tables iv

Chapter

1 THE IMPACT OF MATERNAL STRESSORS, COPING RESOURCES, AND RESILIENCY ON RURAL CHILDREN WITH SPECIAL NEEDS: A CALL FOR CASE MANAGEMENT 1
Introduction 1
Review of the Literature 2
References 12

2 AN EXPLORATION OF THE STRESSORS, COPING RESOURCES, AND RESILIENCY OF RURAL MOTHERS OF CHILDREN WITH SPECIAL NEEDS 21
Introduction 21
Method 27
Results 42
Discussion 56
Characteristics and Limitations of the Study 61
Implications for Research, Advocacy, and Practice 64
References 69

LIST OF TABLES

Table Page

1 Characteristics of Interview Participants 32

CHAPTER 1

THE IMPACT OF MATERNAL STRESSORS, COPING RESOURCES, AND RESILIENCY ON RURAL CHILDREN WITH SPECIAL NEEDS: A CALL FOR CASE MANAGEMENT

Given the trend towards family-centered, community-based services, the families of individuals with disabilities assume a central role in assuring quality care for their family member with special needs as well as a high quality of life. Although this role is often advantageous for both the individual with a disability and their family (Werrbach, 2002), it also creates multiple, intense demands for the family. Care giving challenges are often greatest for families or communities lacking sufficient resources to assume this role (Werrbach). While urban and rural families of people with disabilities share many of the same difficulties in caring for family members with special needs, rural families face unique challenges that warrant additional attention from case managers (Whipple & Nathans, 2005; Mack & Boehm, 2001). Rural women of children with special needs are a unique and vulnerable population worthy of consideration. With specialized attention directed towards decreasing these mothers' stress, we may enhance the effectiveness of services and improve the child's prognosis (Lessenberry & Rehfeldt, 2004).

As a result of medical advances, the mortality and morbidity rates of children with disabilities are dropping dramatically, resulting in an increased frequency of children with special needs in our communities (Kuster & Merkle, 2004; Martin & Baker, 2001). However, these advances come with challenges. Families of children with special needs

face considerable stress (Ferguson, 2002; Singh, 2000) with mothers particularly vulnerable as they are typically responsible for the majority of the caregiving demands (Smith, Selz, Bingham, Aschenbrenner, Stanbury, & Leiderman, 1985). These challenges are further heightened for mothers living in rural communities as multiple barriers persist for individuals with disabilities in these communities (Coburn & Bolda, 1999; Letvak, 2002) and their caregivers (Hunsucker, Flannery, & Frank, 2000). Unfortunately, as there is a noteworthy absence of literature acknowledging these rural mothers, it is not always clear how best to minimize stress and facilitate adaptive coping and resiliency among these women.

Rural Factors

There are distinct issues facing mothers of children with special needs living in rural settings (Brody & Flor, 1997). Although there have been considerable medical and social advances for children with special needs and their families, little has changed for individuals with disabilities in rural communities over the last 20 years. In addition, some commonalities shared by rural individuals contribute to mental health vulnerabilities (Benson, 2003). Perhaps one of the greatest barriers to emotional wellbeing in rural areas is poverty (Coburn & Bolda, 1999; Nordal & Hill, 1999). In rural settings, 59.6% of families with children live in poverty (Mulder et al., 2001), a number greater than those living in urban areas (American Psychological Association, 1996). This dearth of financial resources is particularly concerning as possessing adequate finances to fund mental health services has been found to greatly reduce stress (Rice, MacKenzie, & Jones, 1989). Rural women also typically have less education and fewer educational and employment opportunities than urban women (Coburn & Bolda, 1999; Nordall & Hill,

1999; Mulder, et al.). As a result of these financial constraints, many of these people rely upon Medicaid and Medicare for assistance (Nordal & Hill; Slama, 2004a). The working women of these communities not only face the "second shift" of work associated with homemaking responsibilities, but also the possibility of a "third shift" of farm work tasks. Adding to this strain, child care alternatives are limited (Nordal & Hill).

Women in rural communities also frequently share common family and social stressors. They often have children at a younger age and are more likely to be caregivers for extended family members (Nordal & Hill, 1999) due to geographic isolation, limited privacy and services within the community, and financial constraints (Mulder, et al., 2001). Social outlets in rural communities are typically somewhat limited (Nordal & Hill; Slama, 2004a). This is particularly harmful for families who have children with special needs as social support is highly predictive of both physical health and emotional well being within the family (Dunst, Lee, & Trivette, 1988; Dunst, Trivette, Hamby, & Pollock, 1990).

Another social stressor is the presence of considerable bias from both internal and external sources. Discrimination may exist within their communities due to the more traditional beliefs about disability (Letvak, 2002). In addition, "urbancentrism," the tendency to attend to problems in urban and suburban areas rather than those within rural communities, results in community stereotyping and perpetuates health care challenges (Benson, 2003).

Women in rural areas also face greater health risks (Mulder, et al., 2001) due to poor self care behaviors such as limited physical exercise, smoking, obesity, infrequent use of preventative healthcare services, and the initiation of health care services later in

illnesses (Mulder, et al.; Nordal & Hill, 1999). As a result, they are more apt to experience chronic illness, incur accidental injury, and experience higher rates of mortality among unborn children, infants, and mothers (Nordal & Hill). Mental health care is critical to maximize the physical and emotional well being of these women and minimize healthcare costs (Rural Health in America, 1995).

In addition to physical health problems, rural women also experience elevated threats of mental health concerns. Forty-one percent of rural women live with depression or anxiety (Mulder et al., 2001). They also have elevated rates of alcoholism (Bushy, 2000; Nordal & Hill, 1999), domestic violence, child abuse, suicide, rape and incest (Bushy). Women living in the Southern United States may be especially vulnerable to emotional disorders due to isolation, poverty, and limited services (Hauenstein & Boyd, 1994; Mulder et al.). Ultimately, rural parents face more personal barriers to caring for their children (Freeman, Slifkin, Skinner, Scwartz, 2005).

In the face of these many vulnerabilities, rural residents are challenged by a pervasive lack of service resources (Mack & Boehm, 2001; Whipple & Nathans, 2005). There is a dearth of skilled case managers in these communities (Fiene & Taylor, 1991) and a lack of specialized medical services (Freeman et al., 2005). In addition, the American Psychological Association reports a shortage of mental health care in 60% of rural areas (Benson, 2003; Mulder et al., 2001). Public behavioral health organizations are often the sole source of assistance and providers well-informed of psychoactive medications are in short supply (Nordal & Hill, 1999). In addition, available services are often inadequately funded resulting in insufficient staff, training deficits, and minimal

opportunities for continuing education or professional consultation (Nordal & Hill; Fiene & Taylor, 1991).

Rural mothers of children with disabilities are in a position of even greater vulnerability as they not only face these common threats, but stress associated with having a child with special needs as well. There are considerable demands facing these families wherever they live.

Family Factors

Numerous and varying factors contribute to a family's stress when caring for a child with special needs (Lessenberry & Rehfeldt, 2004). These stressors may include child related factors such as challenging behaviors; intellectual, physical, and social limitations; extended physical care requirements; limited self-care skills; diagnosis; and prognosis (Abidin, 1990; Dyson, 1993; Hanline, 1991; Lessenberry & Rehfeldt). Families also face parental concerns such as heightened responsibility, unresolved grief, financial difficulties, limited parenting and self-care skills, and stigmatization (Abidin; Lessenberry, & Rehfeldt; Dyson; Hanline). There are also a myriad of variable, socially inflicted consequences of having a child with special needs including stigmatization, disempowerment, lesser social-economic status, and fatigue (Broady & Flor, 1997; Ferguson, 2002; Keller & Honig, 2004; Kuster & Merkle, 2004). As a result of these stressors, these parents may experience excessive self-blame and guilt as well as higher rates of isolation, depression, helplessness, hopelessness and relational conflict (Hanson & Hanline, 1990; Innocenti, Huh, & Boyce, 1992; Kazak, & Marvin, 1984; Keller & Honig, 2004; Meyerson, 1983).

Despite the many challenges facing families with children with special needs, many of these families do successfully adjust. Having a child with special needs does not inexorably manifest in the use of maladaptive coping strategies or in pathology within the family (Bristol, 1987; Harris & McHae, 1989; Kazaj, 1987). A family's response to a child with special needs is highly variable not only because of the individual family members' subjective perceptions, but also because it reflects the larger sociocultural framework of the family (Ferguson, 2002). Due to these variable factors, the coping process differs among and within families.

Within this variability however, common differences exist between paternal and maternal coping. Fathers and mothers tend to identify different stressors (Hastings, 2003) and utilize different means of coping (Riposo, 2000). Fathers' stress tends to be more closely associated with the child's temperament and social acceptability, the quality of his relationship with the child, and the disability's impact on the family (Keller, 1999; Keller & Honig, 2004; Krauss, 1993; Walker, 2002). With coping, fathers tend to rely less on social support than mothers and typically prefer to utilize family support systems when they do seek out help (Riposo).

Although fathers are impacted by a child with special needs, mothers typically bear the brunt of the caregiving and therefore, the resulting demands and stressors. Mothers are also more vulnerable to these stressors given that within the general population, women experience more depression than men (Herrington, 2004). Given these concerns, it is particularly important to investigate the maternal adaptation process to the birth and development of a special needs child (Pimentel & Meneres, 2003).

Although perception of stress is individualized (Matheny, Aycock, Curlette, & Junker, 2003), common stressors include the mother's perception of her child and her parenting aptitudes, lack of social and family support, role restriction, poor health, the care demands, her marital relationship, the family's socioeconomic status, feelings of entrapment, and negative behaviors on the part of the child (Keller, 1999; Keller & Honig, 2004; Sarimski, 1996; Walker, 2002; Wilner & Goldstein, 2001). Among these mothers, women who are younger, of low socio-economic status, or who had experienced past depressive episodes were most likely to experience significant adjustment problems (Walker, 2002; Wilner & Goldstein, 2001).

As with all children, mother child attachment issues are critical to children with special needs. The psychosocial environment within the home influences the psychosocial development of the child (Crnic, Friedrich, & Greenberg, 1983; Floyd & Gallagher, 1997; Karen, 1998; Landesman, Jaccard & Gunderson, 1989; Nihira, Mink, & Meyers, 1985). A mother's wellbeing directly impacts the presence of negative behaviors within the child (Dyson & Fewell, 1986; Hastings, 2003), the child's emotional well-being (Kobe & Hammer, 1994), and physical development (Mahoney et al., 1998). Parental stress is so influential that it may result in a child's poor progress in treatment (Lessenberry & Rehfeldt, 2004). At worst, parental stress levels may be so high that a child may be at risk for abuse or neglect (Lessenberry & Rehfeldt). Ultimately, decreasing a mother's stress enhances the effectiveness of services and the child's prognosis (Lessenberry & Rehfeldt).

Familial resiliency is associated with continuous flexibility and adaptation (Floyd & Gallagher, 1997), the family's structure, the severity of the child's disability, and the

socio-cultural dynamics within the family (Ferguson, 2002). Perhaps most importantly, social support has been repeatedly identified as crucial to a family's adaptation (Judge, 1998; Keller & Honig, 2004; Krueger, 1998).

In addition, these women may also benefit from mental health services to aid in their emotional well-being. However, although research supports that available mental health services have the potential to aid rural families during times of adversity, it should be noted that these communities do have unique needs from mental health support services (Benson, 2003; Slama, 2004a). The traditional values frequently found within rural America may make participation in psychotherapy or psychoeducation more challenging as the clients' more traditional culture may resist the new perspectives that are often promoted within therapy (Slama, 2004a, 2004b). These communities are also challenged by potential threats to confidentiality, anonymity, and objectivity on the part of service providers (Nordal & Hill, 1999). The common rural culture also has the potential to make service provision difficult for practitioners unaware of the cultural differences (Slama, 2004a, 2004b).

With the deficiency of qualified providers, these rural individuals are often compelled to pursue help from primary care physicians, family members, church leaders, or friends. Although this assistance may be an important element within the individual's overall care, it is frequently insufficient on its own (Mulder et al., 2001; Slama, 2004a). In addition, when formal services are available they may not be used due to lack of awareness of their existence, an incapacity to afford the services if they are identified, feelings of stigmatization, concerns over confidentiality, and lack of awareness about emotional disorders and their management (Howland, 1995; Mulder et al.).

Implications for Case Management Practice

Given the multiple challenges facing both rural residents and service providers, case managers are in a unique position to assist with these demands, heighten awareness of these women's needs, and improve services within rural communities. Case managers frequently have intimate knowledge of these rural communities and often are recommended in the life care plans of children with catastrophic injuries or chronic illness (Phillips & Bond, 2004). Case managers working with rural populations would benefit from first assessing and then addressing the culture of their clients (Slama, 2004b). Acknowledging cultural diversity is critical for provision of the individualized services called for by researchers (Hunsucker et al., 2000). A comprehensive knowledge of one's client also fosters resiliency by building upon their existing strengths (Hartshorne, 2002). Rural families also gain from helping professionals adopting more generalist approaches, working collaboratively in teams, and using community resources in nontraditional ways (Whipple & Nathans, 2005). They are also assisted through parent-professional collaboration (Werrbach, 2002) and care coordination (Freeman et al., 2005). Home visits offering parents social support (Whipple & Nathans, 2005) are extremely helpful and minimize the challenges of long distances and extensive travel times for these families (Freeman et al.). Finally, stress management services for the family are also warranted and may include respite care, services outside of the home, or support groups. These stress reducing services are ultimately cost effective as they reduce the number of expensive hospitalizations and the possibility of custodial care (Fiene & Taylor, 1991).

Implications for Advocacy

Case managers may also assist these women through advocacy. The political power of rural America is nominal (Danbom, 1995; Dyer, 1997) and as such, these communities' mental health needs are not sufficiently addressed within mental health care policy development (Ahr & Holcomb; Kimmel, 1992). There is a need for advocacy of any public policy addressing rural mental health issues (Letvak, 2002). Another potential focus of advocacy may be utilizing one's intimate knowledge of a community to facilitating collaboration between behavioral health care providers and community physicians (Benson, 2003; Slama, 2004b) and to ensure that offered services are both beneficial and culturally appropriate (Mulder, et al.; US Department of Health and Human Services Mental Health, 1999).

In Conclusion

A child with a severe disability dramatically amplifies the demands facing a rural woman (Beck, et al., 2004; Martin & Baker, 2001; Singh, 2000; Withers & Bennett, 2003). In response to these challenges and vulnerabilities, case managers may benefit from enhancing their understanding of the stressors, coping resources, and resiliency of rural mothers of children with special needs. It is hoped that these professionals will find significant implications for their work within this study. Ultimately, interventions to reduce maternal stress maximize services for the child and control costs by minimizing care outside of the family. These recommendations are also germane to case managers as they address the field's focus on promoting human well-being and dignity, advancing social justice, and empowering vulnerable populations.

Recommendations for Case Management Practice and Advocacy

- Assess and address the clients' culture to provide appropriate, individualized services
- Evaluate and build upon the individual's and family's existing strengths
- Adopt a more generalist approach when necessary
- Work collaboratively in teams with other community service providers and members
- Use community resources in nontraditional ways
- Engage in extensive parent-professional collaboration and care coordination
- Conduct home visits with the goal of offering parents social support
- Provide or facilitate stress management services for the family
- Arrange services to reduce familial stress (i.e. respite care, outside services, support groups)
- Advocate for any public policy addressing rural mental health issues
- Build collaborative relationships between behavioral health care providers and community physicians

References

Abidin, R. (1990). Introduction to the special issue: The stresses of parenting. *Journal of Clinical Child Psychology, 19*, 298-302.

Ahr, P. R., & Holcomb, W. R. (1985). State mental health directors' priorities for mental health care. *Hospital and Community Psychiatry, 36*, 39-45.

American Psychological Association (1999). *APA rural health initiative 1999 year in review*. Retrieved June 6, 2005, from http://www.apa.org/rural/report99.html

Beck, A., Hastings, R. P., Daley, D., & Stevenson, J. (2004). Pro-social behaviour and behaviour problems independently predict maternal stress. *Journal of Intellectual and Developmental Disability, 29*, 339-349.

Benson, E. (2003). Beyond "urbancentrism." *APA Monitor, 34*, Retrieved June 6, 2005 from http://www.apa.org/monitor/jun03/beyond.html

Bristol, M. M. (1987). Mothers of children with autism or communication disorders: Successful adaptation and the Double ABCX Model. *Journal of Autism and Developmental Disabilities, 17*, 469-486.

Brody, G. H., & Flor, D. F. (1997). Maternal psychological functioning, family processes, and child adjustment in rural, single parent, African American families. *Developmental Psychology, 33*(6), 1000-1011.

Bushy, A. (2000). Health issues of women in rural environments: An overview. *Journal of the American Medical Women's Association, 53,* 53-56.

Coburn, A. F., & Bolda, E. J. (1999). The rural elderly and long term care. In T. C. Ricketts (Ed.), *Rural health in the United States* (pp. 273-285). Thousand Oaks, CA: Sage Publications, Inc.

Crnic, K. A., Friedrich, W. N., & Greenberg, M. T. (1983). Adaptation of families with mentally retarded children: A model of stress, coping, and family ecology. *American Journal of Mental Deficiency, 88*, 125-138.

Danbom, D. (1995). *Born in the country: A history of rural America*. Baltimore, MD: Johns Hopkins University Press.

Dunst, C. J., Lee, H., & Trivette, C. M. (1988). Family resources, personal well being, and early intervention. *Journal of Special Education, 22,* 108-116.

Dunst, C. J., Trivette, C. M., Hamby, D., & Pollock, B. (1990). Family systems correlates of the behavior of young children with handicaps. *Journal of Early Childhood Intervention, 14,* 204-218.

Dyer, J. (1997). *Harvest of rage: Why Oklahoma City is only the beginning*. Boulder, CO: Westview Press.

Dyson, L. L. (1993). Response to the presence of a child with disabilities: Parental stress and family functioning over time. *American Journal on Mental Retardation, 98*, 207-218.

Dyson, L. L., & Fewell, R. F. (1986). Stress and adaptation in parents of young handicapped and non-disabled children: A comparative study. *Journal of the Division of Early Childhood, 10,* 25-35.

Ferguson, P. M. (2002). A place in the family: An historical interpretation of research on parental reactions to having a child with a disability. *Journal of Special Education, 36,* (3), 124-131.

Fiene, J. I., & Taylor, P. A. (1991). Serving rural families of developmentally disabled children: A case management model. *Social Work*, 36, 323-327.

Floyd, F. J., & Gallagher, E. M. (1997). Parental stress, care demands, and use of support services for school-age children with disabilities and behavior problems. *Family Relations, 46*, 359-352.

Freeman, V., Slifkin, R., Skinner, A., & Scwartz, R. (2005). Rural and urban parents report on access to health care for their children with Medicaid managed care. Retrieved on April 22, 2007 from http://www.shepscenter.unc.edu/research_programs/rural_program/WP%2084.pdf

Hanline, M. F. (1991). Transitions and critical events in the family life cycle: Implications for providing support to families of children with disabilities. *Psychology in the Schools, 28*, 53-59.

Hanson, M. J., & Hanline, M. F. (1990). Parenting a child with a disability: A longitudinal study of parental stress and adaptation. *Journal of Early Intervention, 14*, 234-248.

Harris, V. S., & McHale, S. M. (1989). Family life problems, daily care taking activities and the psychological well being of mentally retarded children. *American Journal on Mental Retardation, 44*, 231-239.

Hartshorne, T. S. (2002). Mistaking courage for denial: Family resilience after the birth of a child with severe disabilities. *The Journal of Individual Psychology, 58*(3), 263-278.

Hastings, R. P. (2003). Child behaviour problems and partner mental health as correlates of stress in mothers and fathers of children with autism. *Journal of Intellectual Disability Research, 47*, 231-237.

Hauenstein, E. J., & Boyd, M. R. (1994). Depressive symptoms in young women of the Piedmont: Prevalence on rural women. *Women and Health, 21*, 105-123.

Herrington, A. N. (2004). *The contribution of coping resources, lifestyles, and negative life events to the emotional distress of women*. Unpublished doctoral dissertation, Georgia State University, Atlanta.

Howland, R. H. (1995). The treatment of persons with dual diagnoses in a rural community. *Psychiatric Quarterly, 66,* 33-49.

Hunsucker, S., Flannery, J., & Frank, D. (2000). Coping strategies of rural families of critically ill patients. *Journal of the American Academy of Nurse Practitioners, 12*(4), 123-127.

Innocenti, M. S., Huh, K., & Boyce, G. C. (1992). Families of children with disabilities: Normative data and other considerations on parenting stress. *Topics in Early Childhood Special Education, 12*, 403-427.

Judge, S. L. (1998). Parental coping strategies and strengths in families of young children with disabilities. *Family Relations, 47*(3), 262-268.

Karen, R. (1998). *Becoming attached: First relationships and how they shape our capacity to love.* New York: Oxford University Press.

Katz, L. (1987). *The experience of personal change.* Unpublished doctoral dissertation, Union Graduate School, Cincinnati, OH.

Kazaj, A. E. (1987). Families with disabled children: Stress and social networks in three samples. *Journal of Abnormal Child Psychology, 15*, 137-146.

Kazak, A. E., & Marvin, R. (1984). Differences, difficulties, and adaptation: Stress and social networks in families with a handicapped child. *Family Relations, 33*, 67-77.

Keller, D. W. (1999). Dimensions of parenting stress of mothers and fathers of a school age child with a disability. *Dissertation Abstracts International Section A: Humanities and Social Sciences, 60*(4), 1347.

Keller, D., & Honig, A. S. (2004). Maternal and paternal stress in families with school-aged children with disabilities. *American Journal of Orthopsychiatry, 74,* 337-348.

Kimmel, W. A. (1992). *Rural mental health policy issues for research: A pilot exploration.* Rockville, MD: National Institute of Mental Health, Office of Rural Mental Health Research.

Kobe, F. H., & Hammer, D. (1994). Parenting stress and depression in children with mental retardation and developmental disabilities. *Research in Developmental Disabilities, 15,* 209-221.

Krauss, M. W. (1993). Child-related and parenting stress: Similarities and differences between mothers and fathers of children with disabilities. *American Journal on Mental Retardation, 97*, 393-404.

Krueger, D. B. (1998). Social support intervention for mothers of typical and special needs infants and toddlers: An outcome evaluation. *Dissertation Abstracts International: Section A: Humanities and Social Sciences, 59*, 1897.

Kuster, P. A., & Merkle, C. J. (2004). Caregiving stress, immune function, and health: Implications for research with medically fragile children. *Issues in Comprehensive Pediatric Nursing, 27*(4), 257-276.

Landesman, S., Jaccard, J., & Gunderson, V. (1989). The family environment: The combined influence of family behavior, goals, strategies, resources, and individual experiences. In M. Lewis & S. Feinman (Eds.), *Social influences on development* (pp. 63-96). New York: Plenum.

Lessenberry, B. M., & Rehfeldt, R. A. (2004). Evaluating stress levels of parents of children with disabilities. *Council for Exceptional Children, 70* (2), 231-244.

Letvak, S. (2002). The importance of social support for rural mental health. *Issues in Mental Health Nursing, 23*, 249-261.

Mack, K., & Boehm, S. (2001). Rural child welfare 101. *Children's Voice, 1*, 8-18.

Mahoney, G., Boyce, G., Fewell, R. R., Spiker, D., & Wheeden, C. A. (1998). The relationship of parent-child interaction to the effectiveness of early intervention services for at-risk children and children with disabilities. *Topics in Early Childhood Special Education, 18,* 5-16.

Martin, S. S., & Baker, D. C. (2001). *Families and children with severe disabilities: Daily lives, systems, and concerns.* Paper presented at the meeting of the American Association of Behavioral and Social Sciences, Las Vegas, NV.

Matheny, K. B., Aycock, D. W., Curlette, W. L., & Junker, G. N. (2003). The Coping Resources Inventory for Stress: A measure of perceived resourcefulness. *Journal of Clinical Psychology, 59*(12), 1261-1277.

Meyerson, R. C. (1983). Family and parent group therapy. In M. Seligman (Ed.), *The family with the handicapped child: Understanding and treatment* (pp. 285-308). San Francisco, CA: Harcourt Brace Jovanovich.

Mulder, P. L., Kenken, M. B., Shellenberger, S., Constantine, M. G., Striegel, R., Sears, S. F., Jumper-Thurman, P., Kalodner, M., Danda, C. E., & Hager, A. (2001). *The behavioral health care needs of rural women.* Retrieved April 25, 2005 from http://www.apa.org/rural/ruralwomen.pdf

Nihira, K., Mink, I. T., & Meyers, C. E. (1985). Home environment and development of slow-learning adolescents: Reciprocal relations. *Developmental Psychology, 21*, 784-794.

Nordal, K. C., & Hill, J. G. (1999). *Practice directorate office of Rural Health APA Rural Health Initiative 1999 year in review*. Washington, DC: American Psychological Association.

Phillips, P. P., & Bond, N. J. (2004). The role of the pediatric care manager in life care planning. In S. Riddick-Grisham (Ed.), *Pediatric life care planning and case management* (pp. 31-47). Boca Raton, Florida: CRC Press, LLC.

Pimentel, J. S., & Meneres, S. (2003). The development of children with Down syndrome: The influence of maternal adaptation, mother-child interaction and early forms of support. *European Journal of Special Needs Education, 18,* 209-225.

Rice, D. P., MacKenzie, E. J., & Jones, A. S. (1989). *Cost of injury in the United States: A report to Congress*. Retrieved June 6, 2005 from http://www.cdc.gov/ncipc/pub-res/cost_of_injury/intro-ch1.pdf

Riposo, M. E. (2000). Father involvement with preschoolers in the home in families with children with disabilities. *Dissertation Abstracts International Section A: Humanities and Social Sciences, 61*, 1183.

Sarimski, K. (1996). Parenting stress in early intervention. In M. Brambring, H. Rauh, & A. Beeman (Eds.), *Early childhood intervention* (pp. 208-218). Berlin: Walter de Gruyter.

Singh, D. K. (2000). *Families of children with mental retardation: Effective collaboration.* Paper presented at the biennial meeting of the Division on Mental Retardation and Developmental Disabilities, Baltimore, MD.

Slama, K. M. (2004a). Rural culture as a diversity issue. *Minnesota Psychologist, 1*, 9-13.

Slama, K. M. (2004b). Toward rural cultural competence. *Minnesota Psychologist, 2*, 6-13.

Smith, C. R., Selz, L. J., Bingham, E., Aschenbrenner, B., Stanbury, K., & Leiderman, P. (1985). Mothers perceptions of handicapped and normal children. In J. E. Stevenson (Ed.), *Recent research in developmental psychotherapy* (pp. 111-124). Oxford: Pergamoon.

Walker, A. P. (2002). Parenting stress: A comparison of mothers and fathers of disabled and non-disabled children. *Dissertation Abstracts International: Section B: The Sciences and Engineering, 62*, 3393.

Werrbach, G. B. (2002). Providing intensive child case management services: How do case managers spend their time? Child and Adolescent Social Work Journal, 19, 473-482.

Whipple, E. E., & Nathans, L. L. (2005). Evaluation of a rural Healthy Families America (HFA) program: The importance of context. *Families in Society, 86*, 71-83.

Wilner, P., & Goldstein, R. C. (2001). Mediation of depression by perceptions of defeat and entrapment in high-stress mothers. *British Journal of Medical Psychology, 74*, 473-485.

Withers, P., & Bennett, L. (2003). Myths and marital discord in a family with a child with profound psychological and intellectual disabilities. *British Journal of Learning Disabilities, 31*, 91-95.

CHAPTER 2

AN EXPLORATION OF THE STRESSORS, COPING RESOURCES, AND RESILIENCY OF RURAL MOTHERS OF CHILDREN WITH SPECIAL NEEDS

As a result of medical advances, the mortality and morbidity rates of children with disabilities are dropping dramatically, resulting in an increased frequency of children with special needs in our communities (Kuster & Merkle, 2004; Martin & Baker, 2001). However, these advances come with challenges. Families of children with special needs face considerable stress (Ferguson, 2002; Singh, 2000) with mothers particularly vulnerable as they are typically responsible for the majority of the caregiving demands (Smith, Selz, Bingham, Aschenbrenner, Stanbury, & Leiderman, 1985). These challenges are further heightened for mothers living in rural communities as multiple barriers persist for individuals with disabilities in these communities (Coburn & Bolda, 1999; Letvak, 2002) and their caregivers (Hunsucker, Flannery, & Frank, 2000). Unfortunately, as there is a noteworthy absence of literature acknowledging these rural mothers, it is unclear how best to minimize stress and facilitate adaptive coping and resiliency among these women.

Rural Factors

There are distinct issues facing mothers of children with special needs living in rural settings (Brody & Flor, 1997). Although there have been considerable medical and social advances for children with special needs and their families, little has changed for individuals with disabilities in rural communities over the last 20 years. In addition, some commonalities shared by rural individuals contribute to mental health vulnerabilities

(Benson, 2003). Perhaps one of the greatest barriers to emotional wellbeing in rural areas is poverty (Coburn & Bolda, 1999; Nordal & Hill, 1999). In rural settings, 59.6% of families with children live in poverty (Mulder et al., 2001), a number greater than those living in urban areas (American Psychological Association, 1996). This dearth of financial resources is particularly concerning as possessing adequate finances to fund mental health services has been found to greatly reduce stress (Rice, MacKenzie, & Jones, 1989). Rural women also typically have less education and fewer educational and employment opportunities than urban women (Coburn & Bolda, 1999; Nordall & Hill, 1999; Mulder et al.). As a result of these financial constraints, many of these people rely upon Medicaid and Medicare for assistance (Slama, 2004a; Nordal & Hill). The working women of these communities not only face the "second shift" of work associated with homemaking responsibilities, but also the possibility of a "third shift" of farm work tasks. Adding to this strain, child care alternatives are limited (Nordal & Hill).

Women in rural communities also frequently share common family and social stressors. They often have children at a younger age and are more likely to be caregivers for extended family members (Nordal & Hill, 1999) due to geographic isolation, limited privacy and services within the community, and financial constraints (Mulder et al., 2001). Social outlets in rural communities are typically somewhat limited (Nordal & Hill; Slama, 2004a). This is particularly harmful for families who have children with special needs as social support is highly predictive of both physical health and emotional well being within the family (Dunst, Lee, & Trivette, 1988; Dunst, Trivette, Hamby, & Pollock, 1990).

Another social stressor is the presence of considerable bias from both internal and external sources. Discrimination may exist within their communities due to the more traditional beliefs about disability (Letvak, 2002). In addition, "urbancentrism," the tendency to attend to problems in urban and suburban areas rather than those within rural communities, results in community stereotyping and perpetuates health care challenges (Benson, 2003).

Women in rural areas also face greater health risks (Mulder et al., 2001) due to poor self care behaviors such as limited physical exercise, smoking, obesity, infrequent use of preventative healthcare services, and the initiation of health care services later in illnesses (Mulder et al.; Nordal & Hill, 1999). As a result, they are more apt to experience chronic illness, incur accidental injury, and experience higher rates of mortality among unborn children, infants, and mothers (Nordal & Hill). Mental health care is critical to maximize the physical and emotional well being of these women and minimize healthcare costs (Rural Health in America, 1995).

In addition to physical health problems, rural women also experience elevated threats of mental health concerns. Forty-one percent of rural women live with depression or anxiety (Mulder et al.). They also have elevated rates of alcoholism (Bushy, 2000; Nordal & Hill, 1999), domestic violence, child abuse, suicide, rape and incest (Bushy). Women living in the Southern United States may be especially vulnerable to emotional disorders due to isolation, poverty, and limited services (Hauenstein & Boyd, 1994; Mulder et al.).

In the face of these many vulnerabilities, rural residents are challenged by a pervasive lack of services. The American Psychological Association reports a shortage of

mental health care in 60% of rural areas (Benson, 2003; Mulder et al., 2001). Public behavioral health organizations are often the sole source of assistance and providers well-informed of psychoactive medications are in short supply (Nordal & Hill, 1999). In addition, available services are often inadequately funded resulting in insufficient staff, training deficits, and minimal opportunities for continuing education or professional consultation (Nordal & Hill).

Rural mothers of children with disabilities are in a position of even greater vulnerability as they not only face these common threats, but stress associated with having a child with special needs as well. There are considerable demands facing these families wherever they live.

Family Factors

Numerous and varying factors contribute to a family's stress when caring for a child with special needs (Lessenberry & Rehfeldt, 2004). These stressors may include child related factors such as challenging behaviors; intellectual, physical, and social limitations; extended physical care requirements; limited self-care skills; diagnosis; and prognosis (Abidin, 1990; Dyson, 1993; Hanline, 1991; Lessenberry & Rehfeldt). Families also face parental concerns such as heightened responsibility, unresolved grief, financial difficulties, limited parenting and self-care skills, and stigmatization (Abidin; Lessenberry & Rehfeldt; Dyson; Hanline). There are also a myriad of variable, socially inflicted consequences of having a child with special needs including stigmatization, disempowerment, lesser social-economic status, and fatigue (Broady & Flor, 1997; Ferguson; Keller & Honig, 2004; Kuster & Merkle, 2004). As a result of these stressors, these parents may experience excessive self-blame and guilt as well as higher rates of

isolation, depression, helplessness, hopelessness and relational conflict (Hanson & Hanline, 1990; Innocenti, Huh, & Boyce, 1992; Kazak & Marvin, 1984; Keller & Honig, 2004; Meyerson, 1983).

Conflict within relationships is a particularly viable means of assessing stress within these families. Divorce among families with disabilities is more prevalent than among families of typically developing children (Hodapp & Krasner, 1995); although it is acknowledged that divorce within these families varies as a result of several factors (Joesch & Smith, 1997; Vanderwal, 2002). A mother's propensity towards divorce is impacted by her child's health. Specifically, mothers of children with special needs who have more severe impairments appear to have higher risks of marital disruption than mothers of healthy children (Joesch & Smith). Satisfaction within the marriage is also likely to be impacted by the way in which the parents relate to the child and to each other, the meaning they ascribe to the child's disability, their communication skills, as well as the frequency of affective sharing and the presence of congruent beliefs within the relationship (Vanderwal).

Despite the many challenges facing families with children with special needs, many of these families do successfully adjust. Having a child with special needs does not inexorably manifest in the use of maladaptive coping strategies or in pathology within the family (Bristol, 1987; Harris & McHae, 1989; Kazaj, 1987). A family's response to a child with special needs is highly variable not only because of the individual family members' subjective perceptions, but also because it reflects the larger sociocultural framework of the family (Ferguson, 2002). Due to these variable factors, the coping process differs among and within families.

Within this variability however, common differences exist between paternal and maternal coping. Fathers and mothers tend to identify different stressors (Hastings, 2003) and utilize different means of coping (Riposo, 2005). Fathers' stress tends to be more closely associated with the child's temperament and social acceptability, the quality of his relationship with the child, and the disability's impact on the family (Keller; Keller & Honig, 2004; Krauss, 1993; Walker, 2002). With coping, fathers tend to rely less on social support than mothers and typically prefer to utilize family support systems when they do seek out help (Riposo).

Although fathers are impacted by a child with special needs, mothers typically bear the brunt of the caregiving and therefore, the resulting demands and stressors. Mothers are also more vulnerable to these stressors given that within the general population, women experience more depression than men (Herrington, 2004). Given these concerns, it is particularly important to investigate the maternal adaptation process to the birth and development of a special needs child (Pimentel & Meneres, 2003).

Although perception of stress is individualized (Matheny, Aycock, Curlette, & Junker, 2003), common stressors include the mother's perception of her child and her parenting aptitudes, lack of social and family support, role restriction, poor health, the care demands, her marital relationship, the family's socioeconomic status, feelings of entrapment, and negative behaviors on the part of the child (Keller, 1999; Keller, & Honig, 2004; Sarimski, 1996; Walker, 2002; Wilner & Goldstein, 2001). Among these mothers, women who are younger, of low socio-economic status, or who had experienced past depressive episodes were most likely to experience significant adjustment problems (Walker, 2002; Wilner & Goldstein, 2001).

As with all children, mother child attachment issues are critical to children with special needs. The psychosocial environment within the home influences the psychosocial development of the child (Crnic, Friedrich, & Greenberg, 1983; Floyd & Gallagher, 1997; Karen, 1998; Landesman, Jaccard & Gunderson, 1989; Nihira, Mink, & Meyers, 1985). A mother's wellbeing directly impacts the presence of negative behaviors within the child (Dyson & Fewell, 1986; Hastings, 2003), the child's emotional well-being (Kobe & Hammer, 1994), and physical development (Mahoney et al., 1998). Parental stress is so influential that it may result in a child's poor progress in treatment (Lessenberry & Rehfeldt, 2004). At worst, parental stress levels may be so high that a child may be at risk for abuse or neglect (Lessenberry & Rehfeldt). Ultimately, decreasing a mother's stress enhances the effectiveness of services and the child's prognosis (Lessenberry & Rehfeldt).

Familial resiliency is associated with continuous flexibility and adaptation (Floyd & Gallagher, 1997), the family's structure, the severity of the child's disability, and the socio-cultural dynamics within the family (Ferguson, 2002). Perhaps most importantly, social support has been repeatedly identified as crucial to a family's adaptation (Judge, 1998; Keller, & Honig, 2004; Krueger, 1998; Krueger, 1998).

A child with a severe disability dramatically amplifies the demands facing a rural woman (Beck et al., 2004; Martin & Baker, 2001; Singh, 2000; Withers & Bennett, 2003). Although empirical evidence supports that the heightened stress among these mothers is significant, influential factors in coping and resiliency remain unclear. Given these issues as well as the significant lack of literature on this topic, research into the

stressors, coping resources, and resilience of rural mothers of children with special needs is warranted.

In response to this lack of information, this study sought to enhance understanding of the stressors, coping resources, and resiliency of rural mothers of children with special needs. Specifically, a goal for this research was to learn how these women's emotional well-being was impacted by their rural communities. Due to the exploratory nature of this study, a qualitative research method was selected for its strength in elucidating little known phenomenon and allowing for these women's voices to be heard by researchers, clinicians, and advocates. It is hoped that these professionals will find significant implications for their work within this study.

Method

The purpose of this study was to investigate the stressors, coping resources, and resilience of rural mothers of children with special needs. To undertake this qualitative investigation, a feminist phenomenological approach incorporating grounded theory was utilized (Bogdan & Biklen, 2003; Giorgi, 1997; Olesen, 1994; Phillips & Daniluk, 2004). This research approach is well suited for exploratory investigation of phenomena that are not yet clearly defined within the literature (Denzin & Lincoln, 1994). Due to the unique experiences of these rural mothers as well as their absence in the literature, it is essential that their voices be both heard and understood (Mulder et al., 2001) through the use of personal interviewing. Epistemologically, this investigation accentuated the subjective experience of women with intent to include them as knowers within the community (Olesen).

A feminist phenomenological approach is a method which honors subjective experience and seeks to understand and disseminate the essence of this experience (Mertens, 2005). A phenomenological approach has been considered a suitable method for investigating topics where little is known, as in the case of rural mothers of children with disabilities (Phillips & Daniluk, 2004). In response to the absence of some groups within the literature, such as rural mothers of children with special needs, feminist researchers have made issues surrounding invisibility central to their investigations (Madriz, 2000). As such, there is a history of feminist consideration of women's mental and physical health issues. One example of this is Lempert's (1994) investigation of abused women's experiences and attributions of meaning to their physical abuse. Another example is Broom's (1991) exploration of feminist beliefs within state supported women's health care services. Therefore, empirical and theoretical literature supports the use of feminist theory for studies similar to the one being undertaken.

A grounded theory method was also used to enhance knowledge of the issues facing rural mothers of children with special needs (Strauss & Corbin, 1990). Grounded theory is used within phenomenological studies to aid in the creation and development of a theory where one is lacking (Mertens, 2005). A grounded theory method contributes to a rigorous study through its use of clear guidelines to detail the relationships between the study's concepts (Charmaz, 2000). The methods of grounded theory entail inductive strategies for gathering and analyzing data in order to build theoretical support for the data (Charmaz). This data gathering and analysis process is cyclical. Throughout the data analysis process, the investigator sought to use the ongoing analysis to inform additional data collection to build and modify developing theories (Charmaz).

Ultimately, a feminist phenomenological approach was selected for this study to address the inequity in the literature and to advance the concerns of these rural women. It was hoped that through the usage of these methods that the social injustice stemming from these women's gender inequity might be lessened. It should also be acknowledged that the researcher entered this investigation with a political agenda based on her personal perspective and experiences. Feminist phenomenological inquiry was exclusively appropriate for this study as it honors research as a political activity that questions the objectivity of any researcher (Sielbeck-Bowen, Brisolara, Seigart, Tischler, & Whitmore, 2002).

The inclusion of these philosophies, theories, and methods served as a strong foundation with which to develop this investigation. These concepts have been used conjointly in other studies (Leipert & Reutter, 2005; Suchman, 1995) and meet the recommendations and calls for research from other studies (Brody & Flor, 1997; Hunsucker, Flannery, & Frank, 2000; Lichter, 2003; Merriam, 1998; Mulder et al., 2001; Sherman & Webb, 1988). This methodology also takes into account a factor recommended by Mulder et al. (2001) in their report on rural women's mental health needs, that empirical investigations into the wellbeing of rural women's issues should take into consideration the multiple roles frequently assumed by these women.

Participants

Interview participants. The ten women interviewed were all from a rural Southeastern county. When asked to label their ethnicity, five of the women self-identified as African-American, two identified as Caucasian, one identified as Asian American, one identified as Black, and one identified as White. The average age of the

interview participants was 36 years, with a range of 23 to 48 years. Their annual family income ranged from $9,600 to $80,000. Their children ranged in age from 1 to 10, with an average of 6.4 years. Nine of these women had other children, one of whom had other children with special needs. Eight of the participants were married, one was divorced, and one was never married and no longer in a relationship with her child's father. None of these women were currently involved in any liability claims related to their child's disability.

One of the mothers who participated in this study experienced the death of her child during the course of this investigation. She participated fully in the interview prior to her daughter's death, which was unexpected. However, she did not respond to this researcher's attempts to contact her for member checking after her death.

Member check participants. Following the collection of the interview data and initial data analysis, the participants were contacted to participate in a member checking of the data and analysis. Six of the mothers agreed to participate in this process. Member checking affords qualitative researchers an opportunity to cross-check their work by allowing participants to review the study's material (Janesick, 2000). This process allowed the researcher to verify analysis as accurate and valid.

Research Team

The primary investigator of this study was a female doctoral student at a large, southeastern, state university with clinical and research experiences in disability and women's issues. In reflection of the feminist research paradigm used in this study, the researcher disclosed her status as a mother of typically developing children to the research participants (Olesen, 2000). The researcher arranged and conducted all of the

interviews and member checks, coded all the interviews, and served as the primary contact for participants throughout the study. The principle research assistant was also a doctoral student and a mother. The two additional research assistants were students in a Masters of Professional Counseling program. All of the research team members were European-Americans living in urban or suburban areas.

Recruitment

Participants were recruited in two ways. First, participants were enlisted through the help of the community service providers who typically serve as resources for these women. These included physicians' offices, churches, schools, and governmental agencies. It should be noted that one physician who was of primary assistance was the town's sole pediatrician and the father-in-law of the researcher. Participants were also recruited through a snowball recruitment method by the investigator in an attempt to obtain other possible participants from the women's personal contacts in the community (Merriam, 1998).

Involvement in the study was limited to mothers living in a Southern rural community who have a child with a severe disability under the age of 11 years. There were no restrictions on mother's age, marital status, or ethnicity.

Data Sources

Multiple data sources were used within this study. Information was gained from investigator observation, professional and peer debriefing, research team meetings, researcher reflections, memo writing, demographic and narrative responses, and responses to the follow up member check questions (Charmaz, 2000; Miller & Crabtree, 2000; Merriam, 1998; Ryan & Bernard, 2000; Weitzman, 2000).

Table 1

Characteristics of Interview Participants

Partici-pant	Age	Ethnicity	Marital Status	Family Income	Child's Diagnosis	Child's Age
1	43	African American	Single	$20,000	Hearing impairment	9
2*	41	Asian American	Married	$26,000	[Pierre Robin Sequence]	9
3*	48	White	Married	$35,000	Autism	7
4	23	African American	Single	$9,600	Hypoplastic Left Heart Syndrome	1
5	35	African American	Married	$50,000	Cerebral Palsy	8
6*	23	Black	Married	$24,000	Cerebral Palsy	4
7*	34	African American	Married	$25,000	Wolf-Hirschhorn Syndrome	8
8*	34	Caucasian	Married	$75,000	Mitochondrial Encephalomyopathy	2
9	44	Caucasian	Married	$80,000	HIV; Tourette's Syndrome; Bipolar Disorder; Post-Traumatic Stress Disorder; Schizo-affective Disorder	4

Note. * served as participants in member checking phase.

Demographic questions. Demographic questions were designed to address maternal and child characteristics that past research has indicated influences mother and child stress, coping, and well-being. These questions addressed child variables such as age and disability (Guralnick, 1997, 1998) and maternal variables such as social support (Letvak, 2002), resources (Wilkinson, 1984), education (Krueger, 1998), employment status (Nordal & Hill, 1999), socioeconomic status (Krueger; Walker, 2002), marital status (Keller & Honig, 2004), as well as the number of children within the family and their ages (Bat-Chava & Martin, 2002; Walker). The demographic questions that elicited data for this study are as follows: What is your age? What is your ethnicity? What is your family's annual income? What is your marital status? How many children do you have and what are their ages? How many people live in your home? What is your highest level of education? What is your employment status? What is your child's age? What is your child's disability? When was your child diagnosed with this disability? What resources do you frequently use? What degree of social support is available to you? How many people help you with your child on a regular basis and their relationship to the child?

Interview questions. Initial questions were constructed by the researcher before the interviews began. These questions were based on empirical research in the areas of rurality and caregiving for individuals with disabilities (Bat-Chava & Martin, 2002; Guralnick, 1997, 1998; Krueger, 1998; Letvak, 2002; Merriam, 1998; Nordal & Hill, 1999; Walker, 2002; Wilkinson, 1984). The interview questions were used to initially direct the interview by soliciting information about the participants' experience of caring for a child with a severe disability. The questions that provided a frame for the interviews are as follows: What stressors do you feel are associated with having a child with a

disability? What stressors exist specifically for you as a mother of a child with a disability? What has changed in your life as a result of having a child with a disability? In the lives of your other family members? What coping techniques have been most helpful to you? What factors help you, or other mothers, to be resilient to these stressors? How does living in a rural community affect your parenting as a mother of a child with special needs? What benefits are there to living in a small community? What disadvantages are there to living in a small community? What resources are you currently using to help with your child? What additional resources would you use if they were available? Ideally, what help would you like to see from your community and the government?

The follow up questions utilized during the member-check reflected the content of all the interviews in an effort to elucidate information provided by the participants in their interviews as well as to ask participants their opinions about information provided in following interviews.

Procedure

This study's procedures were informed by the available qualitative and quantitative literature on caregiving (Bat-Chava, Y. & Martin, 2002; Baum, 2002; Becker, Engelhardt, Steinmann, & Kane, 1997; Bristol, 1987; Carlson, Sampson, & Sroufe, 2003; Connors & Stalker, 2003; Do Amaral, 2003; Dyson, 1991, 1993; Ferguson, 2002; Hanline, 1991; Hartshorne, 2002; Judge, 1998; Keller & Honig, 2004; Pimentel & Meneres, 2003; Vanderwal, 2002; Walker, 2002; Withers & Bennett, 2003). Those participants who were interested in participating in the study contacted the researcher by either e-mail or telephone. A meeting time and place was established, with all participants requesting the interview be conducted in their home, with the exception of

one mother who requested that the interview take place at a local restaurant. Prior to the interview beginning, participants signed consent forms and were notified by the researcher about the limits of confidentiality. The individual interviews began with a series of demographic questions identified by previous research as important to investigations on rural mothers with children with disabilities.

The researcher conducted open-ended, semi-structured interviews, lasting approximately 60 to 90 minutes in length (Dick, 1998; Trute, Hiebert-Murphy, & Postl, n.d.). A less structured design within the interview gave the investigator an opportunity to respond to the interview as it unfolded, to explore the emerging perceptions of the participant, and to follow up on new thoughts (Merriam, 1998). This less structured format also facilitated the more culturally sensitive approach to health information collection called for within the literature and by practitioners within the field (N. Hobkins, personal communication, July 22, 2005; Mueller, 2004; L. Nesbit, personal communication, July 22, 2005; Warnecke, 2004). These interviews were exploratory in nature, with the goal of expanding the researcher's knowledge in this area where little is known (Schensul, Schensul & LeCompte, 1999). Interviews occurred until theoretical saturation occurred (Glasser & Strauss, 1967) and it appeared no new concepts, categories, or relationships were emerging from the data.

In line with this exploratory approach, the interviewer introduced the general topics and then followed up in response to the informants' responses. The established protocol was used as a framework but modified and extended to attend to the rising themes within the study as well as to the particular concerns and direction of the informant as appropriate (Merriam, 1998). At the conclusion of the interview, the

primary investigator performed an early member check by reviewing the main points of the dialogue and requesting participant feedback (Merriam). These interviews were audio taped and transcribed.

A follow-up member check was conducted with six participants either in person or over the telephone. The goal of this member-check was to both develop and elucidate the information given within the individual interviews. Follow-up questioning was used to increase the richness of the data obtained (Patton, 1990).

Data Analyses

Although grounded theory does not specify specific means for data collection, it does contribute to the process of data analysis through the progression, enhancement, and relationships of the concepts (Charmaz, 2000). Approaches within grounded theory include concurrently collecting and interpreting data, coding the data in a two-step process, using comparative methods, engaging in memo writing to aid in the analysis of study concepts, using sampling processes to advance developing theories, and incorporating the theoretical framework (Charmaz). During the data collection process of this study, data were found through multiple sources including investigator observation, informal discussions, formal interviews, and researcher reflections (Charmaz).

Throughout the data collection process, a protocol for coding was devised. An emergent approach was taken to coding whereby codes were developed while reviewing the data instead of a priori codes being applied to the data (Crabtree & Miller, 1992). As outlined in grounded theory, the data were coded as they were collected in an effort to begin defining and classifying the data (Charmaz, 2000).

The underlying approach in this constant comparison method entails multiple comparisons including differing perceptions and behaviors between multiple persons; information on one individual at varying times; one episode to another episode; the data to the larger category; and one category with another category (Charmaz, 2000). During analysis, the investigator develops or modifies concepts in reflection of the data rather than applying pre-established tenets (Dey, 1993). The coding process takes place on two distinct levels; the investigator classifies information within the data and also gives consideration to the interpretative constructs associated with the analysis (Merriam, 1998).

The transcripts in this study were coded by both the principle investigator and a research assistant to establish inter-rater reliability. The primary investigator and assistants evaluated the data collected through line-by-line coding to aid the researcher in staying familiar with the subjective reality of the participants, instead of presuming to have common views of the world and to enhance the use of sensitizing concepts, those underlying concepts that enlighten and direct the focus of the study (Charmaz, 2000).

The primary investigator and principle assistant met to process preliminary investigator responses and to evaluate the identified themes and relationships. Through a process of dialogue, inquiring, and testing the researchers developed a more advanced inventory of impressions and groupings and came to consensus on how to code the data. This collaboration aided in modifying the methods of the study as well as developing the underlying concepts (Merriam, 1998; Miller & Crabtree, 2000).

Once this collaboration was completed, an additional two research assistants coded the interview transcripts. These codes, along with the initial assistant's final codes,

were analyzed to determine a consensus estimate. This estimate was used to determine inter-rater reliability. A percent-agreement was determined by totaling the number of cases that were rated the same by the two coders and then dividing that number by the number of total cases (Stemler, 2004).

The next step in analysis reflected more intense memo writing. These memos aided in igniting the investigator's consideration, establishing relationships among the data, as well as in promoting novel consideration of data and the means of coding (Charmaz, 2000; Merriam, 1998; Ryan & Bernard, 2000). This process built the methods and suppositions that are included within the codes. It assisted in linking the interpretations of analysis with empirical certainty. Memo writing places the raw data into memos so that the association between data and conclusions may be preserved and examined openly (Charmaz). Ultimately, memo writing aids in developing a richer analysis (Weitzman, 2000).

Finally, triangulation within this study was established through multiple means. First, a complete literature review aided in elucidating previous research topics as well as in determining where this study fits within the literature (Merriam, 1998). Second, triangulation was sought through the research procedures of the participant dialogue, the demographic forms completed by the participants, the member-checking, the development of themes, and the coding (Fontana & Frey, 2000; Merriam; Miller & Crabtree, 2000; Richardson, 2000). Third, the principal investigator kept a journal throughout the study detailing thoughts, feelings, and experiences. This journal was then compared to see if themes emerge which are similar or dissimilar to the other data within

the study (Merriam). Finally, the memo writing process aided in this process (Fontana & Frey).

Reliability

The data provided within the participant interviews were coded by a total of four researchers: the principle investigator, a primary research assistant, and two secondary research assistants. The consensus estimates for these researchers follow: principle investigator and the primary research assistant (100%), the principle investigator and the first of two secondary research assistants (82%), and the principle investigator and the second of two secondary research assistants (81%). The total consensus average among the researchers is 88%. This index represents appropriate inter-rater reliability, as methodological guidelines for consensus estimates state that inter-rater reliability estimates should be 70% or greater (Stemler, 2004). The data, thus deemed to have sufficient inter-rater reliability, was then categorized to reflect the participants' reports about their stressors, coping, and resiliency as a mother of a child with a severe disability living in a rural community.

Credibility

The researcher utilized the triangulation process to assist in establishing credibility within this study. In addition, the researcher has a history of extensive engagement in the community having spent two years talking with community service providers, people with disabilities, families of people with disabilities, and mothers of children with special needs. The researcher also has 18 years experience in working with people with disabilities in medical, academic, and community based settings. This

extensive experience facilitated her understanding of the phenomenon under investigation and enhanced her ability to establish trusting relationship with the mothers in this study.

Professional and peer debriefing, research team meetings, and data analysis also permitted the researcher to accomplish prolonged engagement and persistent observation. This likely facilitated the participants disclosing more completely and candidly and resulted in a more precise narrative (Lincoln & Guba, 1985). In addition, both informal and formal member checking strengthened the investigative process. All participants were able to provide the researcher feedback throughout the interview process and six participants engaged in extensive consultation after data was collected and initially analyzed.

Transferability, Dependability, and Confirmability

The dependability, confirmability, and trustworthiness of this study was advanced through the use of rigorous methodological strategies and the detailed documentation of both the process and content of data collection, analysis, and interpretation (Lincoln & Guba, 1985). This article includes an account of these methods, processes, and content as well as a description of the participants so that readers may evaluate the validity and implications of this research themselves. It is hoped that this account may aid other researchers, clinicians, and advocates in determining whether this study's findings are both significant and germane to their work.

Results

This exploratory study investigated the phenomenological experiences of mothers of children with special needs living in a rural community. Detailed exploration and analysis of the mothers' experiences caring for a child with special needs led to an

enhanced understanding of these mothers' collective experiences and both confirmatory and emergent findings. In an effort to provide a more complete representation of what these mothers experience, data that were deemed by the principle investigator and empirical research to be more unique to the experience of rural people was the focus of analysis. This rurally relevant data was divided into the following domains: stressors, coping resources, and factors associated with resiliency. Patterns emerged within these domains presenting a picture of the mothers' perspectives about the nature and quality of their stressors, coping, and resiliency. While there was considerable agreement among the participants about frequently experienced stressors and means of coping, participants described considerable differences in the impact of living in a rural area on their parenting of a child with special needs.

In fact, more than any other question the issue of rurality resulted in the most divergence among the mothers. Six of the participants considered living in a rural area to be overwhelmingly advantageous when raising their child. In their opinions, the benefits of these communities far outweighed the limitations. The other four participants expressed the belief that rural living had an overwhelming, negative impact on the wellbeing of their children and themselves. These subjective differences are central to this phenomenological investigation.

Benefits of Rural Living

Despite this considerable difference among the participants, both the mothers who considered living in a rural area to be overwhelmingly advantageous and those who believed it to be overwhelmingly disadvantageous were able to articulate both positive and negative aspects of rural living. For example, the mothers who felt that their

communities were ultimately disadvantageous to their children were able to list benefits of living in a small, rural community on parenting a child with special needs. The most frequently listed benefit was the close presence of family, with seven of the mothers listing this as a considerable advantage to their communities.

> If I didn't live in the country I couldn't rely on my mom, my family, all of us all here together. I have 13 [siblings], all but one is here. I would be totally by myself. I totally rely on them. If I get depressed I can call my sister and she will come over and sit and talk. They come and play with J−Roc for a minute and then they go on. But I can't do that if I'm in the city away from them.

In addition to the benefit of family support, the mothers listed the social benefits of community support, more time to connect with others due to the slower pace, the presence of fewer people, and everyone in the community knowing the child so that the child was not an unsettling novelty when seen in public. This phenomenon of child as an oddity is especially feminist in nature. One mother spoke about the benefits of a small town on her son:

> Havin' a really visible birth defect, and he was, um, very shy, and it bothered him that people would stare at him and stuff and so, I think, you know, livin' way out here was a good thing, and even in town, you know, before long, you've seen everybody, and they've seen you, and so you're not new anymore or interesting.

Mothers also noted that they favored the quiet and larger spaces for the child to play. Six of the mothers also reported that they preferred the increased safety of living in a rural community. They noted less concern over someone hurting or taking advantage of the child and less traffic, making it safer for the child to be out of the house.

> If we were living in the city, I don't feel like he could really get outside and do a lot of different things, you know 'cause I would be worried about cars and things… I mean with him in his wheelchair, he has his freedom to ride. To go down to my sister house when he gets ready 'cause we rarely have traffic backwards and forth. And everybody on this road know that Brandon is in, you know, a chair… so everybody looks out for him. And

> um when we were living in the city, umm I was worried because you know, he didn't have that freedom like he does down here.

Limitations of Rural Living

Despite these advantages, four of the mothers considered their rural communities to be a considerable hardship on parenting their child. One mother interviewed in this study was actively engaged in the process of saving money so that she could move her family back to an urban area where she had lived prior to her child's birth.

> CB: Is there anything about living out in the country that you think is helpful with a child with special needs?
> Felicia: (mouths "Nothing")
> CB: That's fine, you can say that. If it's nothing you can say nothing.
> Felicia: Well, no really, just being close to family, my family is here, but other than that nothing. There's nothing good. Not really.

All of the mothers were able to address multiple limitations of small, rural community on parenting a child with special needs, many of which support feminist theory's focus on women's vulnerability. These identified limitations included the lack of services in the community, the poor quality of the services that were available, social stressors, financial stress, and stressors associated with their personal characteristics.

All of the participants interviewed listed the lack of services available in their communities as a stressor. They noted an insufficiency of assistance with routine medical, emergency medical, and family support needs and shared the stress caused by the extensive effort necessary to locate services outside their communities and the lengthy travel required to access services outside of the community.

The medical stressors that are inherent in parenting a child with special needs are heightened for these rural mothers. Medical management issues of hospitalizations, frequent doctor's visits, and interventions are reported to be more stressful due to the lack of services near their homes and support systems. Two of the mothers had left their

communities multiple times during their child's life to receive treatment in cities throughout the country. Both of these mothers made use of Ronald McDonald houses and although they praised these facilities, they spoke of the difficulty of leaving their other children at home for long periods of time.

> Um, we basically had to … travel, basically to have any kinds of surgeries or therapies we, we basically had to just travel to have anything done for him, you know, there was no support or anything for him in this area.

Four of the mothers also spoke about difficulties they had during medical crises or concerns they had over the possibility of future medical crises because of living in their rural communities. One mother shared how she had to travel to Boston for her daughter to have cardiac surgery five days after her birth.

> So when she left at UAB, I seen her and she was looking well, even though I knew that you know, her heart was slowly failing. And they needed to get her to Boston as fast as they could… I maybe got out of the hospital six to eight days later and then I flew up there the next day. So when I got there she had the surgery already. Her chest and everything was wide open and she was on life support. It was awful, it, that was an awful experience for me. And my boyfriend was trying you know, trying to guide me to what I was going to be looking at, before I got there, but nothing he said was like the actual picture. So they had her wrapped her chest was wide open her ribs and everything were broken down the middle, and they had her wrapped with clear plastic it looked kinda' like saran wrap… and you could actually see her heart, her heart just pumping through the plastic. So that was awful. That was awful, and I had staples and I was crying and, and they were trying to sit me down and my stomach was, you know, how it is when you have a C-section. It was awful. My first experience was awful, because I had never seen anything like that.

This same mother spoke of her fears concerning the lack of specialized cardiac care that her daughter would need in case of a medical emergency:

> Her heart specialist is way in Birmingham and if I were take her, the nearest hospital I would have to get to, would be Birmingham. Even though there in Demopolis, there's a hospital there, they don't have doctors that specialize in cardiac babies, so you still have to go on further, they send their patients to Birmingham. So that's where you have to go if

> something was to happen to her down here. So you can imagine what could happen in the three hours to get her there. You see what I'm saying… we took CPR classes and stuff like that… So that was helpful especially with us being so far away from the doctor. But um, but that's pretty much it, my biggest worry, is what would happen in those three hours.

Another mother shared similar concerns and detailed the lack of emergency services in the area:

> In the rural area ... the ambulance driver have to come from home, you know, to come to the station to *get* the ambulance, and *then* he got to get the information of who's calling, where they live, and then they gotta...I guess pretty much gotta warm the ambulance up and then come out to get the child or patient an adult or whatever but, it takes....a great lot of time, and...that's been hard on the area … It takes a while… some areas have a 9-1-1 addresses and so...that's helpin' *some*, but it still don't speed it up. Sometime it helps to get 'em there, but it don't speed up the time. That's the hard thing too if you got a child that have um...seizures...um...diabetic child, um...child that's allergic to somethin' really bad.

All of the mothers also commented on the absence of sufficient family support services in the area. Three of the mothers wished there were support groups available for them or their children. One mother detailed services that were available in urban areas that were not available to her. She also expressed frustration with her governmental case worker.

> That program they said that they would help not only the child but the family that first year, so they asked me what I needed help with and I said I needed help with my car, they had four different sources that would give you 500 dollars to help you, a piece, to help with your family on anything that you felt that was needed. That wasn't true… 'Cause the regular social worker … um, she's been saying that she would help me get my car fixed since last year… So then, whenever she comes and I ask her about that and she finally said, we might not be able to do the car, but if there is anything else you need let us know. So one time our refrigerator had tore up in the house and I told her about that. She said oh OK, we'll get that, that would be much more easier to do that than to fix the car. They didn't do that either. I waited for like two or three weeks and then I had to get my own… Different programs, they tell you a lot… And their going to help,

> but they don't do it. In the city it's different... I think you get more assistance and help in the city than you do in the country.

One mother spoke of the frustration of trying to participate in marital counseling to assist her and her husband manage the strain their child's special needs had on their marriage.

> Some assistance um, was offered. But after, just like I said going to Tuscaloosa back and forward every day, who had the strength to go to Eutaw. Make one more trip. No. That was all I needed… That was all I could handle. So I think they could have come to me. So they were the only one who really offered support. And like I said we didn't really accept it because I didn't have the strength to go anywhere else to do anything else. You know, so. It was a real struggle but we survived.

Within all of these areas, mothers reported considerable stress as a result of the time and effort spent attempting to locate services for their child, the time and effort spent fighting for services once they were identified, and the waiting period for services once they had been approved. Again, many of these issues reflect the feminist concerns of disempowerment, oppression, and invisibility.

> We've just had to use, um...doctors, and whatever therapists we could find and whatever that we could pay for... I've just not been able to find any services. There was no program like, even where you could go and pay for the child to be in a program. There just *isn't* one. There's nothing locally at all. There's some things in Tuscaloosa that, if you qualify for it, you can get into it and you pay for it, but, um...after my struggle with this speech therapist and stuff, I figured he would probably not qualify… He does see a psychiatrist. And that's in Daphne, Alabama. It took...an unbelievable amount of work to find that man, but, I was going to have to fly the child to Houston (laughs)… to see somebody that, you know, specializes in these post-institutionalized children and their problems that kinda thing, but they, the, uh, clinic in Houston found this man for me that he had worked with them before, so they knew him. But it's like really hard to find a child psychiatrist that is like, the, unbelievable, incredible hard thing that...the neurologist was hell…first we found...Dr. Brasfield sent us to a neurologist that was in Tuscaloosa and he was a very strange person, so we had to find another one, and, uh, we, through uh, like, family, friends and stuff, we found a, a neurologist and, and were able to wrangle an appointment in, uh, Birmingham at St. Vincent's.

All ten of the mothers in the study listed the travel necessary to obtain services and schooling as stressful. One mother noted the distress caused by being separated from her child for specialized schooling at a school for the deaf and blind five hours from her home. Another mother noted her lack of reliable, cheap transportation that made traveling even more difficult. All of the mothers spoke of the effort and cost of transporting the children long distances. This mother expresses the concerns of several of the mother when managing the concerns of children who do not travel well:

> To be at Tuscaloosa at 8:00, we have to get up at 5 am, and then she gets mad on the road I have to stop, feed her, change her pampers, and then get back on the road. And she gets fussy about having her shoes on and we have to stop and pull her shoes off. Sometime she gets too hot, we have to stop and change her clothes. But it's just something you have to get used to.

In addition to the lack of services, all of the mothers also expressed some degree of dissatisfaction with the medical, educational, and family support services that were available to them in their communities. They also noted that they frequently had to use services they knew to be substandard as they were the only ones available to them or the ones that were supported by their financial assistance providers. This mother spoke about her frustrations with the school system:

> 'Cuz I'll tell ya. I have bent over backwards. I've went different places to do different things to get Martell what he needs. I've...had to go...to the state department on the school because they wasn't doin' what they were supposed to do for him, or...didn't wanna get what he needed to work with in the school system so...I've had to do that. I've just been rippin' and runnin' ...I mean, ever since...birth, to get him what he needed and to get him where he needed to be. It's just that...where you really needin' it, then that's where it gets slow about gettin' it, you know, just like I said, through the school system, it is hard to get help from them because the first thing they holla, "We don't have the money." And then...just like, for instance, uh...he needed a FM System. We had one, I was gonna let them use mine. So they were like, "Well, I'm not going to be responsible for it if somethin' happened to it." And I'm like, "Well, OK... you need to get him one." And

> it took me...over a year and half to get an FM System, and I had to go to the state department… in order to make them make the school system get it! And when they coulda' just...gone on and did it, but they gave me the runaround...for a year and a half. It was… rough. Because, um, my child's goin' to school every day. Simply because he wasn't hearin' the teacher clear, he was gettin' farther and farther behind, and it was hard on him, you know, and they said, "Well, he don't understand this," or "He can't get this..."and he wasn't understandin' because he wasn't hearin'. And if the teacher hadda used the FM System, then...wouldn't had that problem. And she didn't just take out the time to work with him. You know, she had...I guess...25 other kids in the classroom, and she said she just didn't have time to do one-on-one...I asked for an aide to be put in the classroom with him...they didn't want to hire an aide, said they didn't have the money to do that, so it was a struggle. For a year and a half, up to two years, it was really a struggle with the school system.

This struggle for power within systems is at the heart of feminist theory and is a confirmatory finding of this research.

All of the mothers also noted social stressors that exist for them within their rural communities. These concerns varied among the mothers. One woman expressed concern over seeing other people with disabilities not being cared for properly or treated well by others. Four of the mothers spoke of the stress caused by ill informed people sharing inappropriate opinions.

> you know, just, people, I call people like that ignorant cause we come into contact with a lot of people… I even had a co-worker to tell me that she felt as though it was my fault that my son was like that cause I didn't drink enough water while I was pregnant with him. Which was very stupid.

Despite variation among the mothers in how they perceived the community to react to their child, all of the mothers touched upon the lack of understanding that existed within their social networks and the community concerning the child's disability and the demands associated with the disability. One mother shared the strain of this lack of understanding had on her marriage.

> …my husband being stressed too. He wouldn't open up. You know, so that cause a lot more stress between me and him. We would basically,

> wouldn't get along on a day to day basis. You know we didn't have anyone we could go to. There was no one we could go to that would understand. They weren't going through it, so how could they understand?

In fact, seven of the mothers expressed some degree of conflict within their marriages or intimate relationship during times of high stress relating to their child. However, neither the mother who was divorced nor the mother who was never married and no longer in a relationship with her child's father, disclosed the cause of the ends of these relationships so it is uncertain if the child's special needs were central to these conflicts. However, given the research conducted on marital stress by Joesch and Smith (1997) and Vanderwal (2002), it is not unexpected that the strain of caring for these children with severe disabilities would negatively impact marital satisfaction.

All of the mothers also addressed the time and energy it took to educate other family members, friends, the community, service providers, or the school system on their child's disability and special needs. One mother spoke about educating her school system on autism…

> They weren't educated… in '98 when I had her, we only had six cases of autism in the whole county. And they were brand new to the school system. They were scratching their heads saying, "What do we do?" The state had their therapist and their therapist knew but they weren't in the school system. Now, I have just learned that one of therapists has come out of the state and has now been put in the school system. So hopefully it can educate the school system on what to do with these children. Because you don't want to waste them. You know, time is precious for them, you have to take the moment and seize it. Because, if you let it go by, they just miss out.

Seven of the mothers also spoke about the isolation they experienced due to this lack of understanding, by the vast distances between themselves and others, or due to their lack of transportation. In many of these cases, the participants were not only figuratively, but also literarily invisible within their communities.

> There's not much social out here, period. So, you know, I pretty well gave up on that years ago… there's not like, you know, a group of mothers or somethin' that you could find out here. There's no group of anything...there's a group of cows. But, other than that, you know, there just really isn't anything.

Three mothers also spoke about stress resulting from discrimination and bias in the community. These findings confirm feminist theory on powerlessness and oppression. However, it is unclear from these shared experiences if the source of the discrimination was rural culture's more traditional beliefs towards people with disabilities as stated by Letvak (2002). One mother shared experiencing feelings of pity from the community. One mother spoke about employment discrimination which occurred when a potential employer did not hire her after asking her to share her child's medical history. One mother spoke about the lack of value people in her community had towards people with disabilities as reflected by comments she received about adopting children with disabilities.

> I get … "Why on earth did you adopt those children?" You know, "Who would adopt a kid like that? Why?" And it's weird. But, yeah… I uh, pretty well gave up on the community years ago.

A lack of support from their family, spouse, or the community was also noted by eight of the mothers. This lack of support is specifically concerning for rural mothers as the literature supports that social support is particularly important for rural people (Letvak, 2002). One mother shared her fear of delivering her second child and caring for her son with Cerebral Palsy while her husband, her sole source of support, is stationed in Iraq.

> But, like I said, no family support, no friends, and, I talked to one of the people at CRS, which, they're aware I will have major surgery to deliver my daughter, and they asked me, "Do you have anybody who can help you out, 'cuz after that surgery, you're not gonna be able to pick Kenny up… you can't pick up anything up to 10 pounds. …for the first two or three

> weeks after the C-section." And I told her, "No, you know, I'll, I'll come up with somethin' or somebody." But the reality is, I don't, have anybody right now, and it scares me to death!

All ten mothers also noted the financial stressors associated with their child with special needs. This stressor is of particular concern as people within rural area typically earn less than people living elsewhere and poverty is an issue for many rural residents (Coburn & Bolda, 1999; Nordal & Hill, 1999; Mulder, et al.). It is also central to this investigation as it reflects lack of privilege and resource as delineated in feminist theory. The mothers shared the high cost of meeting the needs of the child with special needs. One single mother reported that she took a second job to meet the financial needs of her family. In addition, five mothers reported that they had stopped working or lost lots of time at work to care for their children. One mother spoke about trying to care her infant daughter with Autism while both she and her husband tried to work.

> You know it was killing my husband. Because he was trying to work 12 hour shifts. So I said no, we can make it. You work. I'll come home. And we did. Not to say it wasn't expensive. The first four years of her life with all the specialists and the hospital. She was born with … two holes in her heart, a heart murmur. We got $22,000 worth in debt. We had to mortgage the house to pay off the debt. But we got the diagnosis. Everything was going good. You know, you do what you have to do… Thank God we had the house to put up. Because otherwise how do you pay $22,000 worth of debt? The hospital isn't cheap, the diagnosis wasn't cheap. And I don't know how the state's run. I know the government can't give you everything, you know, I know because there are so many children like her out there. But still. But, if they could just help somehow.

Three mothers noted the limited educational and occupational opportunities available to them. This single mother noted her current financial instability and poor long-term, financial outlook.

> If I was in Birmingham, I believe I could finish school and then I could get a better job… Everyone down here is on minimum wage. You either have to get you a good job in the mills or you have to get two jobs to add up to

> the one that you would get in the city. Everyone says the cost of living is cheaper, but in my case the cost of living, it's just as high.

Four mothers addressed stress they believed stemmed from their own personal attributes. These issues of self are central to phenomenological investigations. One mother addressed the difficulty in accomplishing the physical care her child needed due to her advanced age. Two mothers expressed additional stress as a result of their own health concerns. One mother also shared that she considered speaking English as a second language as a deficit in helping her son with his language skills and advocating for him in the medical and school systems. In addition, two mothers spoke of the concerns they had in meeting their child's needs due to their own limited education. One of these mothers had attained a 7th grade and the other a high school education. They both noted a desire to provide their children with assistance in response to inadequate services the child was receiving, but an inability to help their child as they would like due to their own deficits.

> It's really hard... I don't have education and...it's hard. Really... I wish I went to school then I can, you know, read better, or I can speak really good, and so I can teach Martell a lot for myself, because in the country, nobody, you know, come in here and help you, you got to do it yourself.

Coping and Resiliency

All of the coping strategies listed by these rural mothers shared similarities those utilized by mothers of children with special needs who do not live in rural areas (Baun, 2002; Floyd & Gallagher, 1997; Ferguson, 2002; Judge, 1998; Keller, & Honig, 2004; Krueger, 1998). Two means of coping however, warrant consideration as they are highly reflective of the traditional rural culture (Letvak, 2002; Nordal & Hill, 1999; Slama, 2004b; Wagenfeld, 2003).

The first coping strategy that is especially important to rural women is social support. These women listed support that they received from their spouses, family, friends, church, and the child themselves to be particularly important. Seven of the mothers either noted their extensive use of social support while three of the mothers spoke extensively about the stress caused by their inability to use social support as a resource due to their isolation. This mother spoke of the strength she receives from support from her friends, family, and community:

> We've got so many friends…and uh, that are very supportive, and our families… we're so, so fortunate 'cuz Kraig's parents are here… so are my parents… they're wonderful help for us, too. And...all of our family's right here, so that's a plus…for us, too. And then, um, you know, ...I feel like people in this community...there are people all over that pray for Walt on a regular basis, and, I think that if Kraig and I needed somethin', all we would have to do is just say, "We need some help," and I know, without a doubt, that people would come runnin'.

A second coping skill highly reflective of traditional rural culture is spirituality and dedication to religious practice (Nordal & Hill, 1999; Slama, 2004b; Wagenfeld, 2003). All of the mothers also named their spirituality and religious practices as instrumental to their coping. Many of the mothers reported that they believed their child to be a gift or responsibility given to them by God.

> She’s changed me for the better. She’s brought me closer to God. Of course, devastation… anything like this brings you closer to God, puts you where you need to be, on your knees… God gave her to us for a reason, we’re not going to screw it up.

They reported that they had faith in God and felt blessed. They also noted support from their church and through prayer to be of great assistance. This mother shared how she made it through a medical crisis when her daughter was first born:

> Praying, just trusting in God, believing, even though there were times… maybe God meant her to come here and be here for a month and then He was going you know, take her. My mother and grandmother kept calling

> and praying over the phone with me. That's how I got through. That's how I got through. Praying.

While spirituality has been repeatedly identified in the literature as a valuable coping resource, especially for rural populations, praying over the telephone is an emergent finding that demonstrates how this spirituality may be demonstrated.

The mothers interviewed had some difficulty in identifying sources of personal resiliency. They were more apt to place the source of their strengths elsewhere. They often listed family, service providers, or their child as the reason behind their successful coping. In fact, nine of the mothers were complimentary of their children and spoke of them as a source of strength. Traits of the children which mothers felt aided in their coping include that the child is a happy and sweet child, that the child is strong and a fighter that the child is well-liked, and the child has potential for improvement.

> My little boy's so happy, he doesn't have a clue what he's been through. And I think that was what toughened me up. From day one, he has always been a fighter, always, always with a smile on his face. If not, you knew something was wrong with him. So he's given me the strength to go on. There were plenty of times when we had to go to therapy and I was like OK, I don't think I'm going today and he would crawl in there and he would say, "Mama, you know we have to go to the therapy," and I would have to get up.

Maternal qualities that were identified by the mothers as helpful were wisdom, patience, optimism, and determination. They also spoke about beneficial belief systems including their belief that their child is worth the sacrifices, that their child is worth fighting for, and their internal locus of control.

Finally, nine of the mothers spoke about their love and commitment to their children which sustained them when things got tough. One mother labeled this being a "Real Mom."

> Moms always...(laughs) most moms, REAL moms … real moms are more stressful than any family member. So, um...yes, it's very stressful on a real mom. We got play moms and, you know...some moms that don't really bother because, you know, they just...go on about their way. But I'm not that way. Everything goes to the heart.

Another mother talked about how this commitment to a child could sustain a mother:

> There are a couple of other moms in my area they call me and ask me how I deal with it, because they can't deal with it. If you love your child you deal with it. So some of the others, some of them went to drinking or smoking, but if you're strong, you can deal with it.

The detailed exploration and analysis of mothers' experiences caring for a child with special needs within this study has enhanced our knowledge of how these mothers' view their stressors, cope with their multiple demands, and conceptualize resiliency. They also consistently reflect the feminist and phenomenological methodologies which underpin this study. Although they do share much in their thinking and experiences with mothers of children with special needs who do not live in rural areas, these mothers do have unique experiences, strengths, and needs. It should also be noted that in addition to these commonalities, there was considerable variation among these women. The significant variation within this small community is especially noteworthy given the heterogeneity of the rural cultures and communities that exist throughout America. These findings highlight that there are many intra-group and inter-group differences to consider when investigating rural people.

Discussion

The results of this exploratory, feminist, phenomenological study provide important insight into the experiences of rural mothers of children with special needs that is informative and significant to research, practice, and advocacy in the field of psychology. The mothers in this study are remarkable in their dedication to their children

and their persistence in finding and fighting for scarce resources. They demonstrate love, perseverance, and abundant patience. However, they are also in need of considerable support to facilitate adaptive coping to their many stressors.

The results of this study offer both confirmation of past studies as well as emergent findings. These results support that mothers of children with special needs work intensely and constantly to meet the needs of their children. They experience considerable stress as a result of these sometimes overwhelming demands. Common stressors facing these mothers include the child's challenging behaviors, extended physical care requirements, diagnosis and prognosis, decreased intellectual or physical functioning, and deficits in self-care and social skills. In addition, stress emanates from the mother according to her assessment of the child and familial circumstances, the intensity of her attachment to the child, her parenting and self-care capabilities, any feelings of unresolved grief over her expectations and dreams for the child, heightened levels of responsibility, and her risk factors for depression (Dyson, 1993; Hanline, 1991; Abidin, 1990; Lessenberry & Rehfeldt, 2004). These findings support the existing literature identifying mothers of children with special needs as assuming the majority of caregiving duties and as a result experiencing the greatest amount of stress within these families (Smith, Selz, Bingham, Aschenbrenner, Stanbury, & Leiderman, 1985).

This study also supports the presence of a myriad of socially inflicted effects of having a child with special needs that reflect the feminist methodology used in this study. These women regularly experience stigmatization, disempowerment, lesser social-economic statuses, and fatigue (Broady & Flor, 1997; Ferguson; Keller & Honig, 2004; Kuster & Merkle, 2004). Inequity is embedded into the institutions which shape these

women's social norms and lives. Within their communities, these women do not have power or privilege. The social repercussions of having a child with special needs support the need for a feminist approach to address these women's concerns and advance their wellbeing. By giving voice to these women's feelings and concerns, we might promote understanding of their experience and begin a process of social advocacy to advance their power within society.

This research also supports the existing literature on rural women's multiple stressors and vulnerabilities. The participants report supports that rural women frequently live in poverty due to their limited education and the limited educational and occupational opportunities in their communities (Coburn & Bolda, 1999; Nordal & Hill, 1999). Their caregiving demands are heightened by insufficient home care services, financial constraints, the considerable distances between them and the available services, and social isolation may occur (Mulder et al., 2001). In addition to these threats, rural mothers of children with special needs also may experience discrimination within their communities.

With regard to coping with these stressors, the current study shows that a mother's ability to be continuously flexible and adaptive is invaluable (Floyd & Gallagher, 1997). The participants within this study who were thriving expressed the ability to problem solve difficult situations and to adapt personally to their demands. The participants also confirmed that social support is crucial to maternal adaptation (Judge, 1998; Keller, & Honig, 2004; Krueger, 1998) especially for rural individuals (Letvak, 2002). The essentiality of social support was repeatedly addressed by all the mothers in this study. Social connectedness is vitally important, especially considering the frequent

lack of sufficient mental health services (Letvak). Unfortunately, these mothers confirmed that making these connections can be challenging due to constraints in their time and their communities (Nordal & Hill, 1999; Slama, 2004a).

This also study supports that the mothers who are most vulnerable to significant adjustment problems were those who are younger, of low socio-economic status, or who had experienced past depressive episodes (Walker, 2002; Wilner & Goldstein, 2001). In reflection of feminist theory, these are the women who demonstrate the least amount of power and privilege. Within this study, the two mothers who exhibited the most acute stress and least amount of adaptive coping were both 23 years old, had an annual family income of $23,000 and $9,600, and one of whom acknowledged ongoing difficulties with depression. It is these disempowered and underprivileged women in particular who are in need of advocacy effort and additional support from their communities and service providers.

Finally, this study confirms some aspects of the distinct rural culture described within the literature. The participants' report support the rural cultural focus on religiosity, a predilection towards self-depreciation, an orientation towards family, a traditional patriarchal social structure, and a tendency towards self-reliance (Nordal & Hill, 1999; Slama, 2004a, 2004b; Wagenfeld, 2003). Perhaps most importantly, the issue of self-reliance is worthy of consideration from a standpoint of advocacy. Although many mothers reported that they felt that they alone must meet the needs of their children, it should be noted that none of the mothers used self-reliance out of preference. They simply believed they had no other available resources beyond themselves. It is important

to note this critical difference and not assume that these mothers would not use supportive resources if they were available to them.

Even though the results of this study confirm some common descriptors of rural culture, other results contradicted some commonly held beliefs. The participants of this study did not endorse the rural norms of a greater acquiesce to authority, a tendency towards concrete thinking and practical orientation in life, the inclination to express limited emotion, frequent suspicion of strangers or outsiders, the stigmatization of mental illness and some physical disorders, an acceptance of poorer health, fatalism, and an orientation towards work (Nordal & Hill, 1999; Slama, 2004a, 2004b; Wagenfeld, 2003). In fact, these women often vociferously stated views in direct opposition to these values, especially in their acceptance of people with physical and mental disorders. They also exhibited behaviors contrary to these norms including accepting an outsider into their home and divulging considerable intimate and emotional information. It is not wholly clear why these women did not endorse more traditional, rural cultural norms. It is possible that they were unwilling to share these intimate beliefs and inclinations with an outsider. It is also possible that by having a child with special needs that they have needed to defy authority in advocating for their child or even become outsiders in their communities to some degree. Perhaps, the unexpected event of having a child with special needs triggered a questioning of personal and social convictions. This is a question which warrants further investigation.

Whatever the reason for this discrepancy, it is not surprising that these mothers did not endorse all aspects of traditional rural culture. There is considerable heterogeneity

within rural populations and amongst this study's participants. Ultimately, the results of this study speak to the complexity of these rural women, their children, and their lives.

Emergent Theory

The feminist, phenomenological and grounded theory used in this study also converges in emergent findings in the voices of these ten rural mothers of children with special needs. Rural women with children with special needs share several commonalities with non-rural mothers of children with special needs. However, they also comprise a distinct population who share multiple commonalities among themselves. These commonalities include their vulnerability. These women live under multiple layers of oppression, lacking both privilege and voice. They also share elevated levels of stress and common stressors including lack of community resources, difficulties finding and obtaining resources outside of community, social stressors, and financial stress. They also have similarities in their resiliency. They utilize many of the same coping resources; all of the mothers acknowledged their spiritual faith and use of social support as critical. They also have similar attributions of resiliency. All of the mothers demonstrated some degree of resiliency. They also all attributed their strength to external sources, specifically social relationships with others who were strong. This externalization of strength represents in part the emphasis on self depreciation and collectivistic nature of rural cultures and women's tendency towards orienting their lives through relationships.

In addition to the shared commonalties, there is substantial heterogeneity within this group of women. Differences among these mothers include specific stressors, variable ability to cope, and means of coping. Perhaps most interestingly, they also differ significantly in their perception of their rural community.

These results and emergent theory reflect the conjoint use of feminist, phenomenological theoretical methodology. These methodologies greatly assisted in this exploratory investigation; gave voice to rural women in response to their unique experiences, social oppression, and absence in the literature; honored the subjective experience and seeks to understand and disseminate this experience; advanced the concerns of these women by addressing gender inequity and social justice; honored research as a political activity, and supported by the existing empirical and theoretical literature.

Service Recommendations

In reflection of feminist theory, the participants in this study were asked for their input into potential, beneficial means of change. All of the mothers who participated in this study had clear ideas on what additional resources would be beneficial to them and their children. All of the mothers expressed a desire for more comprehensive services in their communities. These desired services varied based on the child's special needs, but unilaterally reflected a desire for specialized pediatric therapies such as occupational, speech, and physical therapy to aid in their child's development or rehabilitation. All of the mothers also expressed a desire for more governmental assistance with two mothers specifically calling for a change in the political climate and policies that impact these children and families. All of the mothers also expressed a desire for changes within their social systems including more support from their family, community, or society in general which might include more disability friendly fun activities for children or heightened community education on disabilities and special needs. For one mother this call for social change took the form of wanting acknowledgement of the difficulty of

caring for these children in rural areas. Another mother also expressed a wish to see more families advocating for children with special needs both politically and within the local medical and educational systems. Many mothers also expressed a desire for more assistance from family support services to aid families in getting children needed services, assistance, and equipment as well as in navigating "the system." All of the mothers also expressed a desire for enhanced services within the school system and one requested more disability friendly daycare options. Finally, six mothers requested accessible psychological services for themselves or their children.

These requested services and supports closely reflect areas listed by professionals as lacking for both families of children with special needs (Broady & Flor, 1997; Ferguson, 2002; Individuals with Disabilities Education Act, 1997; Keller & Honig, 2004; Kuster & Merkle, 2004; Orosz, 1997) and rural women (Benson, 2003; Brody & Flor; Coburn & Bolda, 1999; Mulder et al., 2001; Nordal & Hill, 1999; Wilkinson, 1984). This congruence between professionals and mothers of children with special needs is noteworthy. It is unfortunate however, that although these needs have been repeatedly identified that no significant gains have been made in meeting the needs of these women and their children. They remain invisible and voiceless. The phenomenological and feminist methodology used in this study challenge this inadequacy and calls for global consideration of these concerns as well as local personal and political action.

Characteristics and Limitations of this Study

While this study's results provide important information on mothers with children with special needs, caution should be taken in relating these findings to others mothers who have a child with special needs. Despite the in-depth nature of the data, relatively

few participants were interviewed for this study. All of the participants of this study lived in a Southern community and thus it is unclear as to whether the findings of this study would have meaning for women of other cultures, living in different geographic areas. Similarly, there were few women of middle or high socio-economic status or advanced levels of educational attainment among the participants, so further investigation is needed to determine if these findings have similar meaning to women who possess higher financial and educational resources.

The methods of participant recruitment used for this study also warrant consideration for future studies. Given that mothers were first recruited through community systems including doctor's offices, churches, government offices, and schools and then through the use of snowball sampling where mothers referred other women, it is possible that this study's sample is more connected to both services and support systems and therefore is not entirely representative of the population of mothers in this area. This is particularly a concern as feminist theories emphasize attending to issues of power, privilege, and visibility. It is unclear if the findings of this study would differ if it involved participants who were less connected to available resources.

It should also be noted that there were flaws in the questions used to solicit information from these mothers. Specifically, many of the mothers had considerable difficulty in answering a question addressing resiliency. It is unclear why this topic elicited less information than the questions concerning stressors or coping resources. However, it is possible that these mothers had given little consideration to the internal sources of their strength. It is also possible that this expression of external sources of strength is a reflection of self-depreciation, a traditional component of rural culture, so

that these mothers might not express internal sources of strength even if they were aware of them. Instead, these mothers placed the source of their strength outside of themselves in their children, support systems, or God. These results may also speak to a more collectivistic culture that emphasizes relationships and spirituality as a source of resiliency as opposed to personal attributes. Future research studies may want to consider this cultural factor when investigating resiliency among rural women.

The results of this study also warrant consideration given the research team member characteristics. All of the research team members were European-American, college educated, and living in urban or suburban areas. In reflection of the feminist and phenomenological methodology used in this study, consideration must be given to the resources and power inherent in these qualities as well as our outsider status within the community. Although the principle investigator and the primary research assistant are mothers, their children are typically developing. Since the principle researcher shared this information with the participants, it is possible that additional information was gained due to the shared maternal identity. However, it is also possible that the participants withheld information since her children do not have special needs. In addition, the principle investigator's role within the community may have resulted in altered data. As the daughter-in-law of the community's sole pediatrician, this relationship provided her entrée into the community that would otherwise have been difficult or impossible and allowed these women's voices to be heard when they otherwise would likely have not. However, it is possible that the mothers were not entirely forthright in their interviews because of this relationship. For example, it should be noted that the mothers spent considerable time expressing frustration over the lack of medical services, but did not

critique the medical services that were available to them. Ultimately, research team member characteristics may have altered the data received from the participants as well as influenced the interpretation of this data. Due to these concerns, as well as the considerable diversity among these participants, researchers and practitioners are cautioned not to generalize these findings to all families. Further investigation into this variability and its impact on coping is warranted.

Finally, there is another participant concern that also warrants attention. Tragically, during the course of this study one of the mothers lost her daughter to complications resulting from the child's disability. The loss of this child was a transformative moment for the researcher and the research. This event highlighted the mothers' vulnerability and oppressed status. In addition, although this researcher had some awareness of issues of privilege at the start of this study, this loss brought into sharp clarity my privilege as an able bodied woman and the mother of able bodied children. Until this event, I had not fully understood the vulnerability under which these women live. This awareness strengthened my resolve to honor this loss and give voice to these women's experience.

The Researcher's Experience of the Research

I came upon this research topic quite naturally. It was the next reasonable step after 13 years of conversations with my father-in-law over rural and urban health and mental health issues. It is a fascinating topic for me, thoroughly embedded in my past clinical and empirical work, and reflecting my passion for disability and women's issues.

When beginning this research, I was aware of the excellent professional fit of this research. I also acknowledged that as a mother of one able-bodied child and, at the time,

pregnant with a child who gave every indication of being able bodied, there would be a personal component to this work. However, I totally underestimated how transformative and emotionally charged this two year process would be for me.

Foremost, I was emotionally touched and inspired by every woman I spoke to. Being courteously invited into their homes and lives was an honor. Their grace and strength in the face of devastation is both extraordinary and unforgettable. I am also repeatedly astounded that my participants never expressed any consideration that they were amazing, resilient women. They only spoke of their love for their child and others' support.

The amazing experience of talking with these women and hearing their stories conversely made data analysis extraordinarily hard. I had received so much information in this process I was now faced with the daunting task of assigning importance to what was said. Deciding what should be included in this text was overwhelming; everything said seemed important and valuable. I was struck by my power as a researcher to deem what was most significant and appropriate. Needless to say, there are numerous thoughts and stories that are not included here that further underline the need for research into these women and children's lives. Although I acknowledge this restriction as necessary, it remains a frustration.

During data analysis, I also experienced two concrete and separate events which drastically impacted me. First, one of my participants lost her daughter. I felt intense sadness and vulnerability when hearing of her death. This news brought forth in me a ubiquitous and universal parental fear. I too could unexpectedly and suddenly lose what is most dear to me in life. My dissertation is now inextricably linked with those feelings

of vulnerability. This event also prompted me to think more extensively about my privilege and power, however tenuously held. As a result of this process and in reflection of feminist and phenomenological theory, this death became a significant finding within this study.

I also had a distressing moment during data analysis where I gained heightened awareness into my status as researcher. Although I had taken strides to imbed myself in this community, I was indeed an outsider to these women. I also had additional status due to my relationship with the town's sole pediatrician. This awareness came to me when analyzing the data related to dissatisfaction with available services. I realized that although my participants had expressed some degree of dissatisfaction with the educational and social services available in town, they never expressed any dissatisfaction with the medical services. It is unreasonable to believe that these ten women never experienced frustration or disappointment with these services. Instead, it is likely that they did not disclose these concerns out of respect or concern. Perhaps they did not wish to offend me or my father-in-law or otherwise feared that there would be repercussions for expressing dissatisfaction. Certainly, my father-in-law has a privileged and powerful role within this community. When I came to this understanding, I felt frustration at myself for not being aware of dynamic during the interviews and not attempting to disarm this issue if possible. To this day, I wonder what else was said or not said in these interviews.

After living closely with this work for the last two years and experiencing the inevitable set-backs and frustrations of the dissertation process, I continue to feel passionate about this topic and proud of the work I have done. It is my dearest hope that

my efforts to disseminate this information and to be a change agent for these women and children are successful.

Implications for Research, Advocacy, and Practice

This study's results have multiple implications for researchers, advocates, and practitioners serving rural mothers of children with special needs. First, these findings support that there is a considerable need for further research into this area; these women have not been sufficiently investigated or clearly defined within the literature. This under-representation led the Office of Rural Mental Health Research (2001) to list prevention of mental health issues in rural environments as a research priority. This study adds further weight to this initiative.

As with all exploratory studies, this investigation created more questions than it answered. Specifically, questions concerning resiliency and rurality warrant further empirical attention. It would also be beneficial to compare coping techniques used by rural and urban or suburban mothers. Additional research is also required to better understand what actions may reduce the stress and distress experienced by these mothers, both during times of crisis and throughout their child's life. It would also be of interest to consider the questions of stress and coping through the perspective of rural service providers and what they perceived as needed to better support these mothers. Ultimately, research that considers the experiences and needs of this vulnerable population may better facilitate our understanding of how to more ably support and serve these mothers from a clinical perspective (Brody & Flor, 1997; Hunsucker, Flannery, & Frank, 2000; Lichter, 2003).

Given the multiple challenges facing both rural residents and service providers, there is a call from the American Psychological Association to heighten awareness and improve services within these communities (American Psychological Association, 1999; Benson, 2003; Mulder et al., 2001; Nordal & Hill, 1999; Stambor, 2006). The American Psychological Association specifically lists the following steps that all psychologists should take to assure that quality mental health services are accessible to rural populations: advocating for prescription rights to guarantee more comprehensive services; enhancing the recruitment and retention of psychologists throughout rural communities; supporting legislation which supports rural behavioral health care services; and seeking and implementing financial support for graduate medical education to aid in psychological training rural communities (American Psychological Association).

In addition to these steps, psychologists serving this population would benefit from first assessing and then addressing the culture of their clients (Slama, 2004b). Acknowledging cultural diversity is critical for psychologists to provide the individualized services called for by researchers (Hunsucker et al., 2000). To this end, it is valuable for psychologists to foster resiliency by building upon existing strengths (Hartshorne, 2002). Finally, Turnbull (1988) has identified eight skills that are beneficial to these families that can be facilitated during therapy. These skills include meeting the child's fundamental needs, loving the child unconditionally, developing relationships, knowing both oneself and one's family, feeling and gaining from emotions, asserting oneself so that the child's issues may be resolved, anticipating the future so as to engage in transitional planning, and establishing a sense of balance within one's life (Turnbull).

Ultimately, even the resiliency developed by well adjusted families may be further fostered by mental health professionals (Hartshorne).

Although research supports that available mental health services have the potential to aid rural families during times of adversity, it should be noted that these communities do have unique needs from mental health support services (Benson, 2003; Slama, 2004a). The traditional values frequently found within rural America may make participation in psychotherapy or psychoeducation more challenging as the clients' more traditional culture may resist the new perspectives that are often promoted within therapy (Slama, 2004a, 2004b). These communities are also challenged by potential threats to confidentiality, anonymity, and objectivity on the part of service providers (Nordal & Hill, 1999). The common rural culture also has the potential to make service provision difficult for practitioners unaware of the cultural differences (Slama, 2004a, 2004b).

With the deficiency of qualified providers, these rural individuals are often compelled to pursue help from primary care physicians, family members, church leaders, or friends. Although this assistance may be an important element within the individual's overall care, it is frequently insufficient on its own (Mulder et al., 2001; Slama, 2004a). In addition, when formal services are available they may not be used due to lack of awareness of their existence, an incapacity to afford the services if they are identified, feelings of stigmatization, concerns over confidentiality, and lack of awareness about emotional disorders and their management (Howland, 1995; Mulder et al.).

The political power of rural America is nominal (Danbom, 1995; Dyer, 1997) and as such, these communities' mental health needs are not sufficiently addressed within mental health care policy development (Ahr & Holcomb; Kimmel, 1992). There is a need

to advocate for any public policy addressing rural mental health issues (Letvak, 2002). Another potential focus of advocacy may be facilitating collaboration between behavioral health care providers and community physicians (Benson, 2003; Slama, 2004b) to ensure that offered services are both beneficial and culturally appropriate (Mulder et al., 2001; US Department of Health and Human Services. Mental Health, 1999).

Conclusions

A child with a severe disability heightens the demands facing a family (Beck, Hastings, Daley, & Stevenson, 2004; Martin & Baker, 2001; Singh, 2000; Withers & Bennett, 2003). These children are in need of extensive and individualized medical, educational, and social resources (Individuals with Disabilities Education Act, 1997) to facilitate the wellbeing of the child and the successful functioning of the family. However, these resources are often not readily available for families living in rural communities. As such, the child's mother, most commonly serving as the primary caregiver, is faced with an intense challenge that threatens not only her well-being but the child's welfare as well. Given these issues, as well as the significant lack of literature on this topic, research into the stressors, coping resources, and resilience factors of rural mothers of children with special needs is warranted. Ultimately, it is hoped that this information may contribute to efforts to empower members of this marginalized group, advance beneficial governmental policies, and inform clinical interventions that may enhance the wellbeing of these mothers and children.

References

Abidin, R. (1990). Introduction to the special issue: The stresses of parenting. *Journal of Clinical Child Psychology, 19*, 298-302.

Ahr, P. R., & Holcomb, W. R. (1985). State mental health directors' priorities for mental health care. *Hospital and Community Psychiatry, 36*, 39-45.

American Psychological Association (1999). *APA rural health initiative 1999 year in review*. Retrieved June 6, 2005, from http://www.apa.org/rural/report99.html

Bat-Chava, Y., & Martin, D. (2002). Sibling relationships of deaf children: The impact of child and family characteristics. *Rehabilitation Psychology, 47,* 73-91.

Baum, L. S. (2002). Factors related to use of Internet parent support groups by primary caregivers of a child with special health care needs. *Dissertation Abstracts International: Section B: The Sciences and Engineering, 63*, 734.

Beck, A., Hastings, R. P., Daley, D., & Stevenson, J. (2004). Pro-social behaviour and behaviour problems independently predict maternal stress. *Journal of Intellectual and Developmental Disability, 29*, 339-349.

Becker, P. T., Engelhardt, K. F., Steinmann, M. F., & Kane, J. (1997). Infant age, context, and family system influences on the interactive behavior of mothers of infants with mental delay. *Research in Nursing and Health, 20,* 39-50.

Benson, E. (2003). Beyond "urbancentrism." *APA Monitor, 34*, Retrieved June 6, 2005 from http://www.apa.org/monitor/jun03/beyond.html

Bogdan, R. C., & Biklen, S. K. (Eds.). (2003). *Qualitative research for education: An*

introduction to theories and methods (4th ed.). Boston: Allyn and Bacon.

Bristol, M. M. (1987). Mothers of children with autism or communication disorders: Successful adaptation and the Double ABCX Model. *Journal of Autism and Developmental Disabilities, 17*, 469-486.

Brody, G. H., & Flor, D. F. (1997). Maternal psychological functioning, family processes, and child adjustment in rural, single parent, African American families. *Developmental Psychology, 33*(6), 1000-1011.

Broom, D. (1991). *Damned if we do: Contradictions in women's health care.* Sydney: Allen & Unwin.

Bushy, A. (2000). Health issues of women in rural environments: An overview. *Journal of the American Medical Women's Association, 53,* 53-56.

Carlson, E. A., Sampson, M. C., & Sroufe, L. A. (2003). Implications of attachment theory and research for developmental-behavioral pediatrics. *Journal of Developmental and Behavioral Pediatrics, 24(*5), 364-379.

Charmaz, K. (2000). Grounded theory: Objectivist and constructivist methods. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (pp. 509-535). Thousand Oaks, CA: Sage Publications, Inc.

Coburn, A. F., & Bolda, E. J. (1999). The rural elderly and long term care. In T. C. Ricketts (Ed.), *Rural health in the United States* (pp. 273-285). Thousand Oaks, CA: Sage Publications, Inc.

Connors, C. & Stalker, K. (2003). *The views and experiences of disabled children and their siblings: A positive outlook*. Independence, KY: Taylor and Francis/Routeledge.

Crabtree, B. F., & Miller, W. L. (1992). A template approach to codebook analysis: Developing and using codebooks. In B. F. Crabtree & W. L. Miller (Eds.), *Doing qualitative research in primary care: Multiple strategies* (pp. 93-109). Newbury Park, CA: Sage.

Crnic, K. A., Friedrich, W. N., & Greenberg, M. T. (1983). Adaptation of families with mentally retarded children: A model of stress, coping, and family ecology. *American Journal of Mental Deficiency, 88*, 125-138.

Danbom, D. (1995). *Born in the country: A history of rural America*. Baltimore, MD: Johns Hopkins University Press.

Denzin, N. K., & Lincoln, Y. S. (1994). *Handbook of qualitative research.* Thousand Oaks, CA: Sage Publications, Inc.

Dey, I. (1993). *Qualitative data analysis.* London: Routledge.

Dick, B. (1998) *Convergent interviewing: A technique for qualitative data collection.* Retrieved July 31, 2005 from http://www.scu.edu.au/schools/gcm/ar/arp/iview.html

Do Amaral, R. (2003). How do children with developmental disabilities impact their parents' parental satisfaction, self-esteem, symptoms of stress, ways of coping, marital satisfaction and family support? *Dissertation Abstracts International Section A: Humanities and Social Sciences, 64,* 1183.

Dunst, C. J., Lee, H., & Trivette, C. M. (1988). Family resources, personal well being, and early intervention. *Journal of Special Education, 22,* 108-116.

Dunst, C. J., Trivette, C. M., Hamby, D., & Pollock, B. (1990). Family systems correlates of the behavior of young children with handicaps. *Journal of Early Childhood Intervention, 14,* 204-218.

Dyer, J. (1997). *Harvest of rage: Why Oklahoma City is only the beginning*. Boulder, CO: Westview Press.

Dyson, L. L. (1991). Families of young children with handicaps: Parental stress and family functioning. *American Journal on Mental Retardation, 95*, 623-629.

Dyson, L. L. (1993). Response to the presence of a child with disabilities: Parental stress and family functioning over time. *American Journal on Mental Retardation, 98*, 207-218.

Dyson, L. L., & Fewell, R. F. (1986). Stress and adaptation in parents of young handicapped and non-disabled children: A comparative study. *Journal of the Division of Early Childhood, 10,* 25-35.

Ferguson, P. M. (2002). A place in the family: An historical interpretation of research on parental reactions to having a child with a disability. *Journal of Special Education, 36,* (3), 124-131.

Floyd, F. J., & Gallagher, E. M. (1997). Parental stress, care demands, and use of support services for school-age children with disabilities and behavior problems. *Family Relations, 46*, 359-352.

Fontana, A., & Frey, J. H. (2000). The interview: From structured questions to negotiated text. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (pp. 645-672). Thousand Oaks, CA: Sage Publications, Inc.

Giorgi, A. (1997). The theory, practice, and evaluation of the phenomenological method as a qualitative research procedure. *Journal of Phenomenological Psychology, 28,* 235-260.

Guralnick, M. J. (1997). *The effectiveness of early intervention.* Baltimore, MD: Paul H. Brooks.

Guralnick, M. (1998). Effectiveness of early intervention for vulnerable children: A developmental perspective. *American Journal of Mental Retardation, 102,* 319-345.

Hanline, M. F. (1991). Transitions and critical events in the family life cycle: Implications for providing support to families of children with disabilities. *Psychology in the Schools, 28*, 53-59.

Hanson, M. J., & Hanline, M. F. (1990). Parenting a child with a disability: A longitudinal study of parental stress and adaptation. *Journal of Early Intervention, 14*, 234-248.

Harris, V. S., & McHale, S. M. (1989). Family life problems, daily care taking activities and the psychological well being of mentally retarded children. *American Journal on Mental Retardation, 44*, 231-239.

Hartshorne, T. S. (2002). Mistaking courage for denial: Family resilience after the birth of a child with severe disabilities. *The Journal of Individual Psychology, 58*(3), 263-278.

Hastings, R. P. (2003). Child behaviour problems and partner mental health as correlates of stress in mothers and fathers of children with autism. *Journal of Intellectual Disability Research, 47*, 231-237.

Hauenstein, E. J., & Boyd, M. R. (1994). Depressive symptoms in young women of the Piedmont: Prevalence on rural women. *Women and Health, 21*, 105-123.

Herrington, A. N. (2004). *The contribution of coping resources, lifestyles, and negative life events to the emotional distress of women*. Unpublished doctoral dissertation, Georgia State University, Atlanta.

Howland, R. H. (1995). The treatment of persons with dual diagnoses in a rural community. *Psychiatric Quarterly, 66,* 33-49.

Hunsucker, S., Flannery, J., & Frank, D. (2000). Coping strategies of rural families of critically ill patients. *Journal of the American Academy of Nurse Practitioners, 12*(4), 123-127.

Individuals with Disabilities Education Act. (1997). *IDEA 1997, Laws and Regulations.* Retrieved July 11, 2005 from http://www.cec.sped.org/law_res/doc/law/index.php

Innocenti, M. S., Huh, K., & Boyce, G. C. (1992). Families of children with disabilities: Normative data and other considerations on parenting stress. *Topics in Early Childhood Special Education, 12*, 403-427.

Janesick, V. J. (2000). The choreography of qualitative research design: Minuets, improvisations, and crystallization. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (pp. 379-399). Thousand Oaks, CA: Sage Publications, Inc.

Judge, S. L. (1998). Parental coping strategies and strengths in families of young children with disabilities. *Family Relations, 47*(3), 262-268.

Karen, R. (1998). *Becoming attached: First relationships and how they shape our capacity to love.* New York: Oxford University Press.

Katz, L. (1987). *The experience of personal change.* Unpublished doctoral dissertation, Union Graduate School, Cincinnati, OH.

Kazaj, A. E. (1987). Families with disabled children: Stress and social networks in three samples. *Journal of Abnormal Child Psychology, 15*, 137-146.

Kazak, A. E., & Marvin, R. (1984). Differences, difficulties, and adaptation: Stress and social networks in families with a handicapped child. *Family Relations, 33*, 67-77.

Keller, D. W. (1999). Dimensions of parenting stress of mothers and fathers of a school age child with a disability. *Dissertation Abstracts International Section A: Humanities and Social Sciences, 60*(4), 1347.

Keller, D., & Honig, A. S. (2004). Maternal and paternal stress in families with school-aged children with disabilities. *American Journal of Orthopsychiatry, 74,* 337-348.

Kimmel, W. A. (1992). *Rural mental health policy issues for research: A pilot exploration.* Rockville, MD: National Institute of Mental Health, Office of Rural Mental Health Research.

Kobe, F. H., & Hammer, D. (1994). Parenting stress and depression in children with mental retardation and developmental disabilities. *Research in Developmental Disabilities, 15,* 209-221.

Kottler, J. A. (1994). *Advanced group leadership.* Pacific Grove, CA: Brooks/Cole Publishing Company.

Krauss, M. W. (1993). Child-related and parenting stress: Similarities and differences between mothers and fathers of children with disabilities. *American Journal on Mental Retardation, 97*, 393-404.

Krueger, D. B. (1998). Social support intervention for mothers of typical and special needs infants and toddlers: An outcome evaluation. *Dissertation Abstracts International: Section A: Humanities and Social Sciences, 59*, 1897.

Kuster, P. A., & Merkle, C. J. (2004). Caregiving stress, immune function, and health: Implications for research with medically fragile children. *Issues in Comprehensive Pediatric Nursing, 27*(4), 257-276.

Landesman, S., Jaccard, J., & Gunderson, V. (1989). The family environment: The combined influence of family behavior, goals, strategies, resources, and individual experiences. In M. Lewis & S. Feinman (Eds.), *Social influences on development* (pp. 63-96). New York: Plenum.

Leipert, B. D., & Reutter, L. (2005). Developing resilience: How women maintain their health in northern geographically isolated settings. *Qualitative Health Research, 15*(1), 49-65.

Lempert, L. B. (1994). Narrative analysis of abuse: Connecting the personal, the rhetorical, and the structural. *Journal of Contemporary Ethnography, 22*, 411-441.

Lessenberry, B. M., & Rehfeldt, R. A. (2004). Evaluating stress levels of parents of children with disabilities. *Council for Exceptional Children, 70* (2), 231-244.

Letvak, S. (2002). The importance of social support for rural mental health. *Issues in Mental Health Nursing, 23*, 249-261.

Levy-Wasser, N., & Katz, S. (2004). The relationship between attachment style, birth order and adjustment in children who grow up with a sibling with mental retardation. *British Journal of Developmental Disabilities, 50*(99), 89-98.

Lichter, J. M. (2003). Mothers of preschool children with developmental disabilities: Their experiences, development, and self-concept. *Dissertation Abstracts International Section A: Humanities and Social Sciences, 63*(9), 3357.

Madriz, E. (2000). Focus groups in feminist research. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (pp. 835-850). Thousand Oaks, CA: Sage Publications, Inc.

Mahoney, G., Boyce, G., Fewell, R. R., Spiker, D., & Wheeden, C. A. (1998). The relationship of parent-child interaction to the effectiveness of early intervention services for at-risk children and children with disabilities. *Topics in Early Childhood Special Education, 18,* 5-16.

Martin, S. S., & Baker, D. C. (2001). *Families and children with severe disabilities: Daily lives, systems, and concerns.* Paper presented at the meeting of the American Association of Behavioral and Social Sciences, Las Vegas, NV.

Matheny, K. B., Aycock, D. W., Curlette, W. L., & Junker, G. N. (2003). The Coping Resources Inventory for Stress: A measure of perceived resourcefulness. *Journal of Clinical Psychology, 59*(12), 1261-1277.

Merriam, S. B. (1998). *Qualitative research and case study applications in education*. San Francisco, CA: John Wiley & Sons, Inc.

Mertens, D. M. (2005). *Research and evaluation in education and psychology* (2nd ed.). Thousand Oaks, CA: Sage Publications.

Meyerson, R. C. (1983). Family and parent group therapy. In M. Seligman (Ed.), *The family with the handicapped child: Understanding and treatment* (pp. 285-308). San Francisco, CA: Harcourt Brace Jovanovich.

Miller, W. L., & Crabtree, B. F. (2000). Clinical research. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (pp. 607-631). Thousand Oaks, CA: Sage Publications, Inc.

Mueller, K. (2004). *Improving health service research related to rural minorities.* Retrieved July 12, 2005 from http://www.cdc.gov/nchs/otheract/grants/projects/progdir/mueller.htm

Mulder, P. L., Kenken, M. B., Shellenberger, S., Constantine, M. G., Striegel, R., Sears, S. F., Jumper-Thurman, P., Kalodner, M., Danda, C. E., & Hager, A. (2001). *The behavioral health care needs of rural women.* Retrieved April 25, 2005 from http://www.apa.org/rural/ruralwomen.pdf

Nihira, K., Mink, I. T., & Meyers, C. E. (1985). Home environment and development of slow-learning adolescents: Reciprocal relations. *Developmental Psychology, 21*, 784-794.

Nordal, K. C., & Hill, J. G. (1999). *Practice directorate office of Rural Health APA Rural Health Initiative 1999 year in review*. Washington, DC: American Psychological Association.

Office of Rural Mental Health Research, National Institute of Mental Health. (2001). *Research agenda*. Retrieved June 6, 2005, from http://www.nrharural.org/dc/issuepapers/ipaper14.html

Olesen, V. (1994). Feminisms and models of qualitative research. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (pp. 158-174). Thousand Oaks, CA: Sage Publications, Inc.

Olesen, V. L. (2000). Femnisisms and qualitative research at and into the millennium. In N. K. Denizin & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (pp. 215-255). Thousand Oaks, CA: Sage Publications, Inc.

Orosz, C. (1997). An analysis of positive adaptation in parents of children with special needs. *Dissertation Abstracts International: Section B: The Sciences and Engineering, 57*, 7233.

Patton, M. Q. (1990). *How to use qualitative methods in evaluation.* Newbury Park, CA: Sage Publications, Inc.

Phillips, A. & Daniluk, J. C. (2004). Beyond "survivor": How childhood sexual abuse informs the identity of adult women at the end of the therapeutic process. *Journal of Counseling and Development, 82,* 177-184.

Pimentel, J. S., & Meneres, S. (2003). The development of children with Down syndrome: The influence of maternal adaptation, mother-child interaction and early forms of support. *European Journal of Special Needs Education, 18,* 209-225.

Rice, D. P., MacKenzie, E. J., & Jones, A. S. (1989). *Cost of injury in the United States: A report to Congress*. Retrieved June 6, 2005 from http://www.cdc.gov/ncipc/pub-res/cost_of_injury/intro-ch1.pdf

Richardson, L. (2000). Writing: A method of inquiry. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (pp. 923-948). Thousand Oaks, CA: Sage Publications, Inc.

Riposo, M. E. (2000). Father involvement with preschoolers in the home in families with children with disabilities. *Dissertation Abstracts International Section A:*

Humanities and Social Sciences, 61, 1183.

Ryan, G. W., & Bernard, H. R. (2000). Data managements and analysis methods. In N.K. Denzin & Y.S. Lincoln (Eds.), *Handbook of qualitative research* (pp. 769-802). Thousand Oaks, CA: Sage Publications, Inc.

Sarimski, K. (1996). Parenting stress in early intervention. In M. Brambring, H. Rauh, & A. Beeman (Eds.), *Early childhood intervention* (pp. 208-218). Berlin: Walter de Gruyter.

Sherman, R. R., & Webb, R. B. (1988). Qualitative research in education: A focus. In R. R. Sherman & R. B. Webb (Eds.), *Qualitative research in education: Focus and methods.* Bristol, PA: Flamer Press.

Sielbeck-Bowen, K. A., Brisolara, A., Seigart, D., Tischler, C., & Whitmore, E. (2002). Exploring feminist evaluation: The ground from which we rise. In D. Seigart & S. Brisolara (Eds.), *Feminist evaluation: Explorations and experiences* (pp. 3-8). San Francisco, CA: Jossey-Bass.

Singh, D. K. (2000). *Families of children with mental retardation: Effective collaboration.* Paper presented at the biennial meeting of the Division on Mental Retardation and Developmental Disabilities, Baltimore, MD.

Slama, K. M. (2004a). Rural culture as a diversity issue. *Minnesota Psychologist, 1*, 9-13.

Slama, K. M. (2004b). Toward rural cultural competence. *Minnesota Psychologist, 2*, 6-13.

Smith, C. R., Selz, L. J., Bingham, E., Aschenbrenner, B., Stanbury, K., & Leiderman, P. (1985). Mothers perceptions of handicapped and normal children. In J. E.

Stevenson (Ed.), *Recent research in developmental psychotherapy* (pp. 111-124). Oxford: Pergamoon.

Stambor, Z. (2006). The forgotten population. *Monitor on Psychology*, 37, 52.

Strauss, A., & Corbin, J. M. (1990). *Basics of qualitative research: Grounded theory procedures and techniques.* Thousand Oaks, CA: Sage Publications, Inc.

Suchman, N. E. (1995). Footprints on what was to come: First-year college students' retrospective views of their parents' divorce. *Dissertation Abstracts International: Section B: The Sciences and Engineering, 55*(11), 5089.

Turnbull, A. P. (1988). The challenge of providing comprehensive support to families. *Education and Training in Mental Retardation, 23*, 261-272.

Trute, B., Hiebert-Murphy, D., & Postl, B. (n.d.). *Family strengths in childhood disability.* Retrieved July 31, 2005 from http://www.familystrengths.ca/methodology.html

Vanderwal, J. A. (2002). Parental beliefs and their influence on marital satisfaction and maternal-infant interaction when a developmentally disabled infant is born: An exploratory study. *Dissertation Abstracts International: Section B: The Sciences and Engineering, 62*(7), 3134.

Walker, A. P. (2002). Parenting stress: A comparison of mothers and fathers of disabled and non-disabled children. *Dissertation Abstracts International: Section B: The Sciences and Engineering, 62*(7), 3393.

Warnecke, R. B. (2004). Cross-cultural challenges in health survey research. In S. B. Cohen & J. M. Lepkowski (Eds.), *Eighth conference on health survey research methods* (pp. 121-124). Hyattsville, MD: National Center for Health Statistics.

Weitzman, E. A. (2000). Software and qualitative research. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (pp. 803-820). Thousand Oaks, CA: Sage Publications, Inc.

Wilkinson, K. P. (1984). Rurality and patterns of social disruption. *Rural Sociology, 49*, 23-36.

Wilner, P., & Goldstein, R. C. (2001). Mediation of depression by perceptions of defeat and entrapment in high-stress mothers. *British Journal of Medical Psychology, 74*, 473-485.

Withers, P., & Bennett, L. (2003). Myths and marital discord in a family with a child with profound psychological and intellectual disabilities. *British Journal of Learning Disabilities, 31*, 91-95.