A SECONDARY ANALYSIS OF AGENCY RECORDS EXPLORING SELF-DETERMINATION AS IT RELATES TO GENDER AND DISABILITY

by

LESA NITCY HOPE

(Under the Direction of Edwin Risler)

ABSTRACT

This qualitative research project looked at the issue of exploitation and abuse in the lives of women with developmental disabilities. The research considered the issue related to the construct of self-determination, a concept that considers both internal and external factors in determining a person’s agency in acting in a self-determined manner. Eight women with cognitive disabilities participated in 12 focus group sessions, designed to gain information about internal and external factors related to self-determination that mediated the experience and aftermath. To gather information about internal factors, the participants were queried about personal qualities and characteristics that helped them deal with abuse and exploitation, as well as skills they believed would have been helpful. To look at the external factors that impacted their ability to act in self-determined ways, they were asked about what help they received from others as well as what barriers they encountered. The participants identified a number of personal qualities that helped them deal with the abuse and its aftermath. They also targeted skills they felt would have helped them better deal with the issue. They also identified significant attitudinal and systemic barriers that negatively impacted their ability to make decisions or deal with issues related to the abuse and exploitation. The research found that while some attention should be given to individual skills development to enhance capacity for self-determination, there is significant work to be done at community and systemic levels. As long as the external barriers remain in place, it will be hard for women with cognitive disabilities to exercise true decision making across of a range of options that could mediate the exploitation and abuse.

INDEX WORDS: Self-determination, Disability, Abuse, Exploitation, Women, Social Work

A SECONDARY ANALYSIS OF AGENCY RECORDS EXPLORING SELF-DETERMINATION AS IT RELATES TO GENDER AND DISABILITY

by

LESA NITCY HOPE

B.S., Georgia State University, 1999

M.S.W., Georgia State University, 2000

A Dissertation Submitted to the Graduate Faculty of The
University of Georgia in Partial Fulfillment
of the Requirements for the Degree

DOCTOR OF PHILOSOPHY

ATHENS, GEORGIA

2005

© 2005

Lesa Nitcy Hope

All Rights Reserved

A SECONDARY ANALYSIS OF AGENCY RECORDS EXPLORING SELF-DETERMINATION AS IT RELATES TO GENDER AND DISABILITY

by

Lesa Nitcy Hope

Major Professor:	Edwin Risler
Committee:	Nancy Kropf Zolinda Stoneman Jenny Manders

Electronic Version Approved:

Maureen Grasso
Dean of the Graduate School
The University of Georgia
May 2005

DEDICATION

I would like to dedicate this work to my daughters Nadia and Anna Rose Hope, my husband, Martyn Hope, my family in Montana, Karen and Ted Herman, Gary and Shirley Nitcy, Loren Nitcy, and Marjorie Von Arx, and family in England, including Rosie Hope and Christine Watson. Their love, incredible patience, and tremendous support have made this effort, not just possible, but joyful. This is also dedicated to my grandmother, Anna Birkeland, who encouraged me to get an education, because as she said, “They can never take that away from you.” And of course, to the women who participated, who continue to show courage and resilience in the face of tremendous difficulties. Thank you for your honesty and for your stories.

ACKNOWLEDGEMENTS

I would like to acknowledge many people who provided support and guidance to me. Great thanks to Ed Risler, Nancy Kropf, Zo Stoneman, and Jenny Manders for your guidance, questions, and for helping me wrestle with a difficult topic. Thanks to Carol Rossiter for your facilitation skills and keen insights with the group. Thanks to Mary Yoder, Lana Hardy and staff at AADD for their tremendous support of this work, both in the context of the agency and in support of my education. Also thanks to Lana Hardy for her editing efforts on my behalf. Great thanks also go to Elizabeth Beck and James Wolk at Georgia State University for their support and guidance prior to and during my program at University of Georgia – your belief in my abilities and kind encouragement were greatly appreciated.

TABLE OF CONTENTS

APPENDICES

CHAPTER 1

INTRODUCTION

"It would be interesting to hear the language women would speak if no one were there to correct them."
Terry Tempest Williams

Overview

This qualitative research project looked at the issue of exploitation and abuse in the lives of women with developmental disabilities. The research considered the issue related to the construct of self-determination, a concept that considers both internal and external factors in determining a person’s agency in acting in a self-determined manner. Eight women with cognitive disabilities participated in 12 focus group sessions, designed to gain information about internal and external factors related to self-determination that mediated the experience and aftermath. To gather information about internal factors, the participants were queried about personal qualities and characteristics that helped them deal with abuse and exploitation, as well as skills they believed would have been helpful. To look at the external factors that impacted their ability to act in self-determined ways, they were asked about what help they received from others as well as what barriers they encountered. The participants identified a number of personal qualities that helped them deal with the abuse and its aftermath. They targeted skills they felt would have helped them better deal with the issue. They also identified significant attitudinal and systemic barriers that negatively impacted their ability to make decisions or deal with issues related to the abuse and exploitation. The research found that while some attention should be given to individual skills development to enhance capacity for self-determination, there is significant work to be done at community and systemic levels. As long as the external barriers remain in place, it will be hard for women with cognitive disabilities to exercise true decision making across of a range of options that could mediate the exploitation and abuse.

Purpose

In Chapter 1, an overview of the nature and incidence of abuse and exploitation of people with disabilities is presented. The lack of research on the topic is noted, including lack of research in the field of social work. While social workers have written and contributed to the knowledge base on the general topic of abuse of women, little research has been done on a particular subset, women with cognitive disabilities who have experienced exploitation and abuse. Chapter 1 also includes an overview of the research project.

It is estimated that between 65% and 90% of women with disabilities have been sexually abused at some time in their lives (Reynolds, 2000, Keilty and Connelly, 2001, Westcott and Jones, 1997). Research also indicates that domestic violence and other forms of abuse against people with disabilities, particularly women with disabilities happen at rates significantly higher than found in the general population (Strickler, 2001, Verdugo and Bermejo, 1997, Sobsey, 1994). Even though the numbers are high, little attention has been paid to this issue by researchers and social service providers, including social workers (Carlson, 1997, Monahan and Lurie, 2003, Simpson, 2002). In fact, Mohanan and Lurie, social workers, noted, “There is a dearth of literature addressing the issues presented in the treatment of adult disabled women who were victims of childhood sexual abuse (2003, p. 407). According to Harding (1987), "Women with disabilities traditionally have been ignored not only by those concerned about disability but also by those examining women's experiences" (p. 141). Curry (2002) noted that few research efforts or interventions have been targeted towards women with disabilities who have been abused, even though in a survey of women with disabilities, respondents reported that their top research and policy issue priorities were caregiver abuse and domestic violence.

Cramer, Gilson, and DePoy (2003) noted the lack of attention paid to the issue of disability and abuse in social work curricula, practice and knowledge. They advocated strongly for research to be done so that empirically based services and resources can be developed and evaluated. Challenges identified with conducting research include the inability to recognize the uniqueness of some forms of abuse that are disability specific; negative attitudes about women with disabilities which include being asexual or objects of pity; and the inaccessibility of services, such as lack of personal care services or physically inaccessible settings (p. 186-187).

This research project was an exploratory qualitative study that considered the experiences of women with disabilities who have been abused. The purpose of this study was to gather information from the perspective of women with disabilities who had experienced exploitation and abuse. Through the use of focus groups, women with cognitive disabilities were asked questions about their experiences, including what helped and hindered them as they dealt with exploitation and abuse. A qualitative research process, centered on description and analysis of their stories gained through focus group interviews, was used to gather information about skills and abilities that helped them deal with abuse and exploitation, assistance they received from others, barriers they encountered, and how they thought having a disability intersected with the experience.

While various authors have explored the issue for women without disabilities, there remains a tremendous gap in knowledge about the experience of women with disabilities on the topic of exploitation and abuse (Monahan and Lurie, 2003, Carlson, 1997). The intersection of gender and disability around the topic of exploitation and abuse is an important one. Quantitative research has taken place that has sought to project the numbers of girls and women with disabilities who have been abused (Reynolds, 2000, Keilty and Connelly, 2001, Westcott and Jones, 1997). A missing element from the discourse had been a qualitative perspective that offered the opportunity for a deeper understanding of the experience of these women. While it is important to understand the breadth of the problem, this research offered an opportunity to explore the depth of the issue as well. Eight women participated in 12 focus groups that took place across 12 weeks, at the offices of the Atlanta Alliance on Developmental Disabilities. The focus group participants were asked questions that were intended to gain a better understanding of what they had experienced, how they had dealt with it, who had helped, and what got in the way. It gave the women not only a venue to tell their stories but an opportunity to reflect on what worked in terms of support and what barriers they encountered. An important aspect of the research was to consider the framework of self-determination, and ascertain what helped or hindered women during and after the experience. It is important to point out that the connection of the idea of self-determination to exploitation and abuse in no way says that the women chose the experiences. The framework of self-determination was used to reflect on what skills, attributes, interventions, and policies the women identified that either supported or thwarted their abilities to deal with the experiences. From the data that was gathered and analyzed, there were areas of skills development that warrant consideration, as well as important policy, systems, and community level barriers that must be addressed.

There are multiple issues in the literature that inform the topic. There is a lack of interest on issues related to people with disabilities (Simpson, 2002, Fisher, 2004). Fisher said, “Disparities in health care for people with mental retardation are common problems that often attract little attention from health care professionals or public policy makers” (p. 48). Fine (1992) agreed,

> Despite the prevalence of disability in this society, disabled persons tend to be invisible. Reliable estimates indicate that most people's lives will be touched by disability, but the community avoids the topic in much the same way it avoids encounters with individuals who have

> disabling conditions. Indeed, public reluctance to deal with disability as a potential for one's own life or those of loved ones is reflected in the lack of information about it. Despite the penchant for data collection, the community and its major institutions know relatively little about the extent and experience of disability in the population (p. 139).

This lack of knowledge, attributed to the social invisibility of people with disabilities has been problematic when related to issues of violence and abuse. Women with disabilities' stories of abuse have been ignored, dismissed, and minimized. There may be implications to the well-being of these women as their stories are not heard or acknowledged. Fine continued

> Perhaps even more than nondisabled women, disabled women confront serious psychological and social problems in ending abusive or exploitative relationships. Women with cerebral palsy or mental retardation have been ignored by professionals when they report rape. Even more than the nondisabled girl, a disabled girl is an easy victim of abuse by male relatives. Disabled girls and women, in numbers hard to estimate, are raped at home, in institutions, or on the streets (p. 161-162).

In cases where the stories are heard, there is often another socially constructed barrier that must be addressed. One of the constructed myths of disability is that people are forever childlike. In his book, No Pity, Shapiro (1994) told the story of a rape crisis counselor who was meeting with a group of adults with mental retardation. Shapiro said that the session "misfired," because the moderator assumed incorrectly that their "vulnerability and retardation made them into children" (p. 191). The counselor conducted the course as if they were grade school students, failing to "address the tragedies of real-life adults who have had horrible experiences" (p. 191).

It is suggested that there are a number of reasons why abuse, particularly sexual abuse occurs with such high frequency with people with disabilities. Fisher (2004), Carlson (1997), Sobsey and Doe (1994) and Sobsey (2004) have cited a number of factors that place people with disabilities at increased risk. They said that isolation and a fundamental lack of power contribute to the problem. They also argued that people with disabilities are trained to be compliant in schools, agencies, and other settings, making them easier to victimize. Flaskerud, et al (2000), framed the increased vulnerabilities as related to social, political, and economic conditions, as well as poverty, ethnicity, or marginalized social status. Foucault (1984) pointed to a cultural view that people with disabilities are less than human. He contended that society objectifies people with disabilities or confers some diminished status on them. According to Foucault this sanctioned treating people with disabilities in a less than humane manner. Belsky (1980) said that the dual devaluation in this culture of people with disabilities and of women may increase the vulnerability to abuse.

This research focused on women with disabilities who had experienced exploitation and abuse and considered what supports and barriers to self-determination women with cognitive disabilities encountered as they attempted to deal with the experience. It was important to frame this around self-determination, as it is a topic that has received strong consideration in the field of disability services. Self-determination is a core concept in the field of social work (NASW Code of Ethics, 1999.) The National Association of Social Workers (NASW) has specifically developed a policy statement on “People with Disabilities,” in which the importance of self-determination for people with mental retardation and other disabilities is affirmed, "the person with a disability should determine how and from whom care and assistance are provided" (NASW, 2000, p. 247). For people without disabilities, making choices about life, acting in a self-determined manner, is common place, to the point of being a cultural and social norm. People without disabilities expect they will make choices about where and with whom they live, where they work, how they spend their leisure time, etc. For people with disabilities, particularly cognitive disabilities, acting in a self-determined manner, exercising choices about various aspects of their lives is not a given, not a social norm in many arenas. They may or may not be afforded opportunities and resources to make choices that their counterparts without disabilities take for granted. Salisbury (2004) said, “Those living without a label take personal decision-making for granted, yet the right to self-determination has been denied to individuals with disabilities by services that lack accountability and flexibility, and which ultimately reduce people’s citizenship status” (p. 24).

As more attention has been paid to ideas about the self-determination of people with disabilities, there has been interesting theory discussions about the concept of self-determination. There is an array of definitions of self-determination. At one end of the spectrum, theorists suggest that self-determination relates most to internal attributes and skills. Others contend that it is more defined by external concerns such as access to resources or systemic barriers. This research was intended to consider to what extent these internal factors or external factors were relevant. It is hoped that this information can be utilized to design supports and interventions that better address the support needs of women with disabilities. Definitions that divide the construct into either internal or external factors are unnecessarily dichotomous and polarizing. To support choice making and personal agency for women in these situations, this research found that both internal and external factors were relevant. This indicated that in designing interventions and supports, the best course of action would be to address the issues at micro and macro levels. Interventions should address skills enhancement as well as target policy and system issues.

Research Questions

Using the theoretical frame of self-determination, this research considered the skills, internal attributes, external factors, and systemic factors that mediated the experience.

Eight women with developmental disabilities participated in twelve focus group sessions. They were asked a series of questions about their experiences of exploitation and abuse. The broad research questions to be answered were designed to consider the experience under the umbrella of self-determination. There were broad research questions that were intended to look at both internal and external factors that are central to definitions of self-determination. The broad research questions were:

I. What internal factors were identified by focus group members?

II. What external factors were identified by focus group members?

These broad questions were broken down into simpler, more conversational questions that were more accessible to the women with disabilities. Those questions will be discussed in Chapter 3.

Chapter 1 noted the lack of research that has been done on people with disabilities. This chapter provided an overview of the nature and incidence of abuse and exploitation of people with disabilities and made a case for the need for more research to be done specifically on women with disabilities. While social workers and others have written and contributed to the knowledge base on the general topic of abuse of women, they have not focused on research and interventions for a particular subset, women with cognitive disabilities who have experienced exploitation and abuse. This chapter also introduced the construct of self-determination as a framework through which to ascertain what support as well as barriers women with disabilities experienced as they dealt with exploitation and abuse. Chapter 1 also included a brief overview of the research project.

Chapter 2 is a review of the literature. It further explores the incidence and nature of abuse and exploitation of women with disabilities, as well as the construct of self-determination.

CHAPTER 2

A REVIEW OF THE LITERATURE

In Chapter 2, a review of the literature is presented, with a focus on the nature and incidence of abuse and exploitation of people with disabilities, particularly women with disabilities. This section offers an overview of the concept, relevant guiding principles, a synopsis of the history of the self-determination movement, including historical and current barriers. Definitions and various opinions on the construct are discussed. As is true with all complex issues, self-determination has generated an interesting discourse among self-advocates, families, service providers and professionals, academicians, and funding sources. Change efforts and exemplar practices are also considered. The intersection of self-determination with the topic of exploitation and abuse of women with disabilities is presented. Chapter 2 also includes an overview of the research project.

Abuse and Exploitation of Women with Disabilities

Research demonstrates that the incidence of violence against women with disabilities is high, happening with greater frequency than for women without disabilities in the general population. Data points to a high incidence of abuse against people with disabilities. Valenti-Hein and Schwartz (1995) found that 49% of people with disabilities experience ten or more abusive incidents during their lives. Zirpoli, Snell, and Lloyd (2001) and Sobsey and Doe (1991) said that victims with some level of intellectual impairment are at the highest risk of abuse. It has been estimated that between 33.4% and 59.8% of adults with disabilities have been physically assaulted (Firsten, 1990, Stimpson and Best, 1991). Regarding sexual violence against women with disabilities, the Centers for Disease Control and Prevention (2001) reported rates of sexual violence that ranged from 51% to 79%. Reynolds (2000) cited studies that indicated that more than 90% of people with developmental disabilities experience sexual abuse at some point in their lives. Research also indicates that domestic violence and other forms of abuse against women with disabilities happen at rates significantly higher than found in the general population (Strickler, 2001, Verdugo and Bermejo, 1997, Sobsey, 1994). Gilson, Cramer, and DePoy (2001) focused on specific forms of abuse experienced by women with disabilities, particularly those with physical disabilities, such as “(a) moving a woman in a wheelchair somewhere that she does not want to go, (b)removing the battery from an electric wheelchair, (c)removing the portable ramp from a home, (d)taking away or breaking a telecommunication device for the deaf (TDD), (e)threatening a woman with institutionalization, and (f) failing to assist a women with daily living skills (p. 221-222). Their research also noted a form of abuse experienced by women with disabilities, labeled a form of control/restraint, which was “using disability to demean, discredit, or dismiss” (p. 228). They added, “Of particular note was the additive effect of demeaning or dismissive comment to women with disabilities who belong to a population that is devalued and marginalized by the mainstream culture (p. 229). They also note the impact of poverty and isolation on women with disabilities who experience abuse.

The impact of violence against women with disabilities was noted at a focus group that was part of a research project done in fall of 2000 by Dr. Elizabeth Beck of Georgia State University, funded by the Atlanta Women's Foundation. During the focus group, ten of eleven women with disabilities discussed violence and abuse they had experienced (Beck et al., 2002). They also related the lack of support that they had received from social services, law enforcement, family, and other community members concerning their issues and circumstances. At the close of that discussion, the focus group members indicated that they were interested in further discussing the experience as well as other issues they felt were related to their experiences, such as what supports would have helped and the impact the abuse had on their children.

Violence against people with disabilities is compounded by the lack of resources and support for people who have been victimized. People with disabilities who have experienced violence relate stories detailing the lack of support that they received from social services, law enforcement, family, and other community members concerning the violence and its aftermath (Petersilia, 2000, Rogers, 2004). Rogers said, “Although people with disabilities are disproportionately represented as crime victims, their cases are often overlooked by the criminal justice system.” Sorenson (1996) concurred, “The police, prosecutors, and courts are not bringing perpetrators of these crimes to justice at anywhere near the rate that they do perpetrators of violence against people without disabilities” (p. 25).

Most people with disabilities who have experienced violence have never received any professional counseling or social services following the abuse (Monahan and Lurie, 2003, Carlson, 1997). This may be due to a prevailing myth that people with disabilities do not benefit from counseling or support group processes. This assumption has been largely unexplored in the research literature. Baladerian (2002) noted that "Sometimes even developmental disabilities professionals believe that the victim didn't 'really' suffer (from the abuse), due to the retardation," adding that "Treatment is still required! People have feelings. Not to mention the increased vulnerability of a victimized person." Baladarian said in a presentation in 2004 that there was still a lack of treatment and support services available. There is also a lack of appropriate community mental health services/supports for people with cognitive disabilities and for those who live in poverty, so this group remains largely un-served. In the Atlanta area, providers of support services to assist women who experience violence reported that they served very few women with disabilities in their programs (Task Force Meeting on Metro-Atlanta Providers, June 30, 2002). It was unclear whether the lack of women with disabilities receiving services was due to lack or referrals, or because women with disabilities did not self-identify while using services or for other reasons is not known.

It also seems that the issue appears invisible to disability service providers as there has been limited advocacy or resource development to address intervention and treatment options for people with cognitive disabilities who are victims of violence. While there have been some efforts, most of these have been targeted at developing prevention programs. Some of these programs include the Seattle Rape Relief Project on the Developmentally Disabled, the Los Angeles County Office of

Education's Preschool Abuse Prevention Program for Disabled Children (Balderian, 1985), the DisAbled Women's Network of Canada (Nosek, Hughes, Taylor, and Howland, 2002), and the Center for Research on Women with Disabilities (Taylor, Hughes, Mastel-Smith, Howland, and Nosek, 2002).

Intervention programs for women with disabilities who have been victims of violence are less well documented in the literature. This is a research area where much work needs to be done. Sobsey (1994) suggested that people with disabilities need to be active participants in prevention and intervention activities and that they could benefit from programs or approaches designed to help them overcome the negative effects of their experiences.

There seemed to be some consensus in the literature that women with disabilities are at increased risk of experiencing exploitation and abuse. There also seemed to be some agreement that there has been little research into the experiences of people with disabilities, including interventions or supports for women with disabilities who have had these experiences. The gaps in information made it important to look at the issue from the perspective of women who have had the experience as well as hone in on what supports they received, what supports they needed, what helped them deal with the experiences, and what barriers they encountered as they dealt with and responded to the events and aftermath. A framework for consideration of these questions is the construct of self-determination, which looks at skills, supports, and barriers that relate to dealing with one’s circumstances, problem-solving and making choices, and selecting courses of action based on skills, resource availability, policy and system supports or barriers, etc. The following section explores the construct of self-determination in greater detail. There is a range of ideas about what supports a person in acting in a self-determining manner. Some theorists hold that individual skills and abilities enable a person to be self-determining. Others contend that external forces, such as policy issues and access to resources are more central to the experience of being self-determined. This research looked at both ideas of self-determination around the issues of exploitation and abuse of women with cognitive disabilities. The researcher used focus groups and open ended qualitative questions, to learn more about individual skills and abilities, which the researcher labeled internal factors. The researcher also asked questions that elicited information on supports, resource access and availability, policies, system issues, and attitudinal barriers, which the researcher referred to as external factors.

Self-determination as a Theoretical Frame

For people with disabilities, self-determination is a topic that has taken center stage in the last decade. There is an increasing body of literature in which the issue has been explored, with an array of stakeholders and authors offering important clarification on the idea (Bradley, 2004, HSRI 2001, Robert Wood Johnson Self-Determination Office, 2003). Various research efforts and demonstration projects are underway to explore implementation possibilities and to evaluate what impact these efforts will have on the lives of people with disabilities.

There is a crescendo of support evident in the literature for self-determination, which indicates a change from business as usual for people with disabilities. The National Institute on Consumer-Directed Long-Term Services [NICDLTS], (1996a) issued a report that declared,

> The ability to control one's existence is also an essential part of being human. Many people with disabilities are often denied the opportunity to exercise choice and control over the most basic aspects of daily life. Consumer direction is an approach to the development of disability policy and delivery of rehabilitation services whereby informed consumers have control and the opportunity to make choices. In a consumer-directed system, individuals with disabilities assess their own needs, determine how and by whom their needs should be met, and monitor the quality of the services received (p.5).

Pumpian (1996) added

> Supporting self-determination means that, like their peers without disabilities, people with disabilities have the right to participate in decisions about their lives in a meaningful way and to the greatest degree possible should be provided the skills and opportunities to make choices about their lives based on their preferences, beliefs and values (xviii).

Support for the idea of self-determination is reflected in the National Association of Social Workers' (NASW, 2000) policy statement on "People with Disabilities." The importance of self-determination for people with mental retardation and other disabilities is affirmed, "the person with a disability should determine how and from whom care and assistance are provided" (p. 247). Keigher (2000) added that social work has a role in that it supports a continuum of options in which the person with a disability may be involved in decision-making. Keigher (2000) also pointed out that few social workers focus their professional employment on working with people with disabilities; this lack of interest in people with disabilities by social workers and the profession is problematic as myths about disability persist. Gourdine and Sanders (2002) and DePoy and Miller (1996) found that social work schools do very little to include disability content in their programs.

Kosciulek (1999) suggested that self-determination should also be framed in terms of the development of disability policy and the delivery of rehabilitation services. This approach moves the issue from a micro plane where individuals with disabilities make choices germane to their personal circumstances, to the macro plane, whereby people with disabilities manage programs and develop public and private sector policies at all levels.

The central theme informing the construct of self-determination is the belief that people with disabilities are the experts of their lives. The Southern Collaboration of Self-Advocates for Self-Determination (1997) explained their view on self as expert,

> In self-advocacy and self-determination, people with disabilities are the leaders and the experts. We know what is best for ourselves and we know the best ways to help and teach others. We help each other learn about our rights and responsibilities and how to speak out...We teach each other about self-advocacy and self-determination and what we need to do to change the system so that we all have control over our lives (p. 3)

According to self-advocates, another critical guiding principle is that level and nature of disability do not matter with regards to self-determination. This is evidenced by the declaration made by Southern Collaboration of Self-Advocates for Self-Determination,

> We are human beings with the same human and civil rights as all others. This includes people with serious disabilities and people who don't communicate the same

> way others do. We all deserve the respect
> and freedom others have (p. 8).

Sands and Wehmeyer (1996) suggested that there are various elements that comprise the framework of the construct and said these are areas where teaching and support are important, such as "goal setting, choice making, problem solving, self-regulation, personal advocacy skills, knowledge of self and the external environment, and a host of motivational factors (e.g. locus of control, sense of self-efficacy as necessary for personal control" (p. 340).

History

The scope of experiences of people with disabilities in the United States reveals a long history of isolation, segregation, exclusion, and lack of control over their lives. For decades the conventional and professional wisdom was for families to place their family member with a disability in an institution, or more recently, in some other form of specialized setting, such as a group home, day services center, or sheltered workshop. These practices have consigned people with disabilities to live much of their lives in segregated, congregate settings, under the control of staff and assigned program plans not of their choosing.

In reviewing historical trends on the experience of people with disabilities in the United States, Bradley (1994) detailed three distinct stages or eras of service provision for people with developmental disabilities. The first era was defined by institutionalization and dependence that ended in the 1970's. During this first era people with disabilities were routinely sent to large institutions. People received services in large, congregate care facilities, where their care was custodial (Bradley, 1994). The second stage followed, through the 1990's, and was marked by de-institutionalization and community development. People were served in smaller settings, but there still was a lack of individualization in supports and few opportunities to exercise choice. During this time, group homes were developed as were community centers to provide day support services. This segued into the third, emerging stage which is focused on functional supports for inclusion, improved quality of life, and social integration. During this era, people with disabilities receive more individualized support, and enjoy increased opportunities for employment, for living and recreating in places utilized by people without disabilities (Bradley, 1994). It is within this current stage that self-determination has entered the language and discourse of advocacy, services and policy.

The reasons cited for the historical absence of and current resistance to self-determination for people with disabilities are many and run the spectrum from ignorance to paternalism to malfeasance. Devore and Schlesinger (1987) said people with disabilities were the victims of benevolent oppression, under which their only role was to receive care and be grateful for its provision. Abramson (1985) defined an "autonomy-paternalism dilemma" that exists because service providers feel they must control services and end up, as a result, controlling clients. Schein (1996) argued that a foundational belief permeates services (medical, social, rehabilitation, educational, etc) that holds that professionals possess superior, objective knowledge and as such are in the best position to decide what people with disabilities need; "the relationship between professionals and their clients took the form of a monologue, the familiar one-way conversation in which professionals prescribe and clients merely accept their prescriptions on faith." Skrtic and Sailor (1996) concurred, saying problems existed because of the prevailing belief that the professional was the expert, a belief grounded in objectivism, the dominant philosophy at the beginning of the 1900's, reflected in the model of service provision called the "medical model." Weick and Saleeby (1995) referred to this as the knowledge-power connection, wherein the professional is seen as expert whose knowledge is privileged. Trieschman (1988) said professionals would not relinquish power, and that "programs are designed by the very people who will benefit most from them in terms of professional power, prestige, and income" (p 34). A related view was offered by Nerney, Crowley and Kappel (1995), who suggested that professionals wanted to maintain financial power and made decisions to keep their power intact.

> In truth, "they" (people with disabilities) are not consumers....The fact is, service systems for people with disabilities have too often acted as if people are commodities. The system is a money-generator that restricts choice and creativity. The system's "consumers" can unintentionally become exploited, victimized, and stripped of their power. "They" are essentially bought and sold (p. 25).

The Alliance for Self-Determination (1997) identified 12 barriers to the promotion of self-determination and leadership among people with disabilities. These barriers identified a range of concerns including lack of opportunities to lead, obtain or offer peer support, or collaborate with other self-determination programs. They also cited lack of information on emerging issues and self-advocacy as well as a lack of individualized leadership development.

Self-determination could well be considered the next step in a civil rights movement for people with disabilities, building on earlier work that resulted in legislation such as the Americans With Disabilities Act (ADA), Individuals with Disabilities Education Act (IDEA), and system changes toward community based services. Self-determination was even written into Rehabilitation Act Amendments of 1992 (PL 102-569)

> The presence of a disability in no way diminishes the rights of individuals to live independently, enjoy self-determination, make choices, contribute to society, pursue meaningful careers and enjoy full inclusion and integration in the economic, political, social, cultural and educational mainstream of American society (Sec. I[a][3][A-F]).

These shifts in the landscape of services, and more importantly in the lives of people with disabilities have mirrored other civil rights movements, as other marginalized groups advocated for inclusion, access, and full enfranchisement in society. Access to public transportation, reasonable accommodations, and equal employment opportunity protections are important non-discrimination principles that have been written into law. While these have been critical victories for securing citizenship and community membership status on people with disabilities, significant basic concerns remain.

The Self-determination Movement can trace its beginning to the Independent Living Movement and the efforts of a generation of activists and advocates such as Ed Roberts, Justin Dart, and others, who led the charge for full inclusion, full enfranchisement, appropriate support, and civil rights (Mackelprang and Salsgiver, 1996). The independent living ideology asserts that people with disabilities are not patients or clients, but rather are active and responsible consumers. Nosek and Fuhrer (1992) framed is as "controlling one's life, having options, making decisions, performing daily activities, and participating in the life of the community" (p. 7). According to Mackelprang and Salsgiver (1996), "Independent living proponents reject traditional treatment approaches as offensive and disenfranchising and demand control over their own lives" (p. 10). An important tenet of the Independent Living Movement is that the barriers to self-determination are systemic; they are environmental, social, and cultural.

Definitions of Self-Determination

A variety of definitions have been suggested for self-determination. The following definitions are offered to show the spectrum of thought on this construct. Ward (1988) said "Self determination refers both to the attitudes which lead people to define goals for themselves and to their ability to take the initiative to achieve those goals. Acquiring the personal characteristics which lead to self-determination is a developmental process that begins early in childhood and continues throughout adult life" (p. 2). Wehmeyer (1994) defined it as

> the attitudes and abilities necessary to act as the primary causal agent in one's life and to make choices and decisions regarding one's quality of life free from undue external influence or interference. Self-determined individuals act autonomously, and are self-actualizing and self-regulating. Causal agency implies that it is the individual who makes or causes things to happen in his/her life and that a given action was purposeful or

> performed to achieve an end. It is a critical element contributing to an individual's quality of life across settings, environments, and opportunities" (p. 16).

Georgia's Self-Determination Team, a partnership between People First of Georgia, Institute on Human Development and Disability: A University Affiliated Program, the University of Georgia, and the Office of Consumer Relations, Georgia Department of Human Resources (2000), defined it in the following way.

> Self-Determination means achieving our goals and dreams by having power over our lives, money, resources, and the things we own. It means having choices about where we live and work and choosing the people in our lives... Self-determination means having equal rights in our community" (p. 5).

The Southern Collaboration of Self-Advocates for Self-Determination (People First of Alabama, Georgia and Tennessee) also crafted a definition (1999).

> Self-determination means making our dreams happen by having choice and control over our lives" (p. 2). They noted four principles of self-determination: "freedom to plan a real life, authority to control a targeted amount of money and resources, support from friends, family, community members and service providers (people we chose) for building a life in our community, and responsibility to make good decisions and give back to the community" (p. 2).

Field and Hoffman (1994) defined the concept as "one's ability to define and achieve goals based on a foundation of knowing and valuing oneself" (p. 164). Gilson and DePoy (2004) consider multiple aspects in defining self-determination,

> Self-determination not only refers to direct action but to the capacity of individuals to abstain from professional involvement without penalty….Second, self-determination involves not only the right but also the capacity to set one's goals, decide what one need and wants; and control how goals, needs, and wants are to be actualized. We mention capacity at this point, not to suggest or open the door for the denial of capacity as so often happens to marginalized and oppressed groups, but to acknowledge that the practice of self-determination must be anchored on knowledge and skills. Third, self-determination must engender recognition from other groups regarding entitlement of the self-determining group not only to civil rights but also to equal opportunity and support in achieving both (p. 5-6).

Gilson and DePoy (2004) also suggested that self-advocacy and community activism are natural extensions of self-determination.

Why Self-Determination is Important: Implications Across the Lifespan

Self-determination is a construct that has implications across the life span of people with disabilities. Wehmeyer (1994) suggested that it is best conceptualized as a dispositional characteristic - a set of attitudes and abilities learned across the life span. Authors have related it to functioning and quality of life. Wehmeyer and Schwartz (1998) said, "For individuals with disabilities, self-determination has been linked to more positive adult outcomes, including higher rates of employment, higher rates of pay, and a more positive quality of life” (p. 661).

The implications of not allowing or supporting the self-determination of individuals with disabilities are seen across all phases of life. Price (1990) argued that children with severe disabilities are not taught skills important for self-determination and independent living. They experience little control over their lives and are not given the opportunities to develop the range of skills necessary for adult life. The absence of opportunities to act in self-determined ways consigns them to a limited range of adult experiences and settings. Keirnat (1992) considered the other end of the age spectrum, "elderly residents in nursing homes who were no longer allowed to practice the independent behaviors they were accustomed to performing in the community soon lost these abilities" (p. 6). Researchers have argued that there is a relationship between the ability to understand and manage one's environment and self-esteem (Nosek and Fuhrer, 1992). Studies date back to 1967, which show that people with severe disabilities who had been institutionalized for long periods of time were able to successfully manage their lives in the community (Edgerton, 1967). It is suggested that the converse also seems to be true. Functioning deteriorates under oppressive circumstances and in institutional care settings. Booth (1986) reported the results of a three-year survey of 3400 residents of 176 nursing homes, finding that even in the nursing homes with the highest standards of care, the less control the residents had over their own lives, the more they lost control of their faculties.

The importance of consumer direction and self-determination has been largely absent from considerations for people who are elderly who have disabilities. Stone (2000) said,

> While consumer direction has a long history among younger adults with disabilities, it has been much slower in coming to the field of aging services, only gaining prominence within the last several years. The overarching goal of home and community based services has focused on keeping older people out of nursing homes as the means of promoting independence and autonomy, and the bias of the current system has reflected the assumption that all elders are frail, dependent and in need of protection (p. 6).

The intersection of disabilities and aging warrants specific attention. Self-determination for people who are elderly is an arena that has also generated interesting discourse. Including the attribute of disability adds another layer of complexity to the discussion. A trend in disability services has been to connect older people with disabilities to generic aging service programs. There has also been interest in retirement planning. It is critical when considering self-determination for people with disabilities who are older, that they are not forced or encouraged toward another system of services where their right to self-determination is negated.

Jaskulski, Lakin & Zierman (1995) wrote

> Respect for individuals choices and preferences is an essential component of designing programs for older people with mental retardation. Just as people without mental retardation, some people choose retirement, while others prefer to keep working, or to shift to part-time employment. Some individuals may need help in exploring retirement options, and support in moving into new activities. Prospects are improving however, for older people with mental retardation to be included in activities of their choice (p. 69).

Jaskulski, Lakin & Zierman (1995) identified a number of initiatives addressing the needs of people with disabilities who are older. A few of the exemplar initiatives:

- The Person Centered Later Life Planning Project, developed by the Rehabilitation and Research Training Center Consortium on Aging and Developmental Disabilities, at IHDD, University of Chicago
- The Training Approach to Improving Community Services for Older Citizens, by the North Carolina Developmental Disabilities Council
- Team to Promote Inclusive and Appropriate Aging Experiences for Person with Developmental Disabilities, a collaboration between the Federal Administration on Aging, Hawaii Developmental Disabilities Council, the State Executive Office on Aging, and the University of Hawaii, UAP
- The Nebraska Developmental Disabilities Council wrote "The Mainstream: Eldercare for the Older Adult with Developmental Disabilities"

There are arguments within the field about whether self-determination is best supported by teaching skills and enhancing internal attributes or whether it is best addressed by dealing with environmental and systemic factors. Sands and Wehmeyer

(1996) said, "most professionals view the construct from a perspective of internal attributes of the individual" (p. 340). People who are self-determined act autonomously, self-regulate behavior, are psychologically empowered, and self-realizing (Wehmeyer, Agran and Hughes, 1992).

Members of the Independent Living Movement contend that the barriers to self-determination are environmental, social, and cultural. These activists make a case that the structure of society, laws, social convention, and interactions have created a society where people with disabilities are routinely denied the rights and privileges accorded people without disabilities. They have argued convincingly that self-determination merits attention as a civil rights/social justice issue.

Nerney and Shumway (1996) focused recommendations on systems change. They said there are two problems with the present system: no choice over which agencies provide support and regulations that require the use of formal "qualified" service providers. They argued that the central question is "How can we put structures in place that will enable people with disabilities and families to truly control resources" (p. 3). Their view presumes that self-determination is only real when resources and funding are in the hands of people with disabilities. They advocated changing the professionally structured service system to shift control to individuals and families but voiced strong reservations about whether the professional system would relinquish control. They offered suggestions for what will be necessary.

> Self-determination will involve profound changes in how the present system is organized and financed. It will require provider agencies to re-think their roles, substantial re-training of many in the services system and a fundamental commitment to honoring the aspirations of those with disabilities and families and friends (p 10).

The argument over whether self-determination is an issue that is best addressed at the individual level or at the systems level polarizes the issue. It may be that both sides are, in fact, right. It is important that individuals with disabilities learn skills and have opportunities to gain experience in self-determination. It is also important that people are supported in maintaining decision-making abilities across their lifespan. At the same time, it is equally important that systemic barriers, such as control by professionals over resources be addressed. It is important to look at the issue of exploitation and abuse and determine what aspects of self-determination can better be supported to help women avoid or cope with those situations.

Emerging Change Efforts

One of the hallmark efforts indicative of the relevancy of self-determination is the creation and strengthening of People

First chapters, as well as other self-advocacy organizations. People First began in Oregon in 1973 and over the past 30 years has grown to national and international levels. Self-advocates have joined together to form a national umbrella organization, Self-Advocates Becoming Empowered (SABE). SABE put forth a definition of self-advocacy that has components of self-determination woven into it.

> Self-Advocacy is teaching people with a disability how to advocate for themselves and to learn how to speak out for what they believe in. It teaches us how to make decisions and choices that affect our lives so that we can become more independent. It also teaches us about our rights, but along with learning our rights, we learn our responsibilities (Hayden and Shoultz, 1991; http://www.sabeusa.org/).

Sands and Wehmeyer's (1996) added that "advocates of the self-determination movement profess a set of values and beliefs that under gird efforts to promote this outcome. First among these is the acceptance that disability is part of the human experience and that people with disabilities are people first and have the right to be valued and experience dignity and respect independent of any qualifier of label others might place on them" (p. 336).

In 1997, the Robert Wood Johnson Foundation funded self-determination demonstration projects in 18 states. In a preamble to this funded project, Shumway and Nerney (1996) explained these as multi-year projects that reflected a creative range of attempts to implement consumer directed system development projects in these states, using options such as checkbook systems, where individuals with disabilities have signatory authority over personalized budgets. Other places are using fiscal intermediaries to manage resources.

Partners in Policy Making, developed in 1987 by the Minnesota Council on Developmental Disabilities is a program that promotes the involvement of individuals with disabilities and family members in decision making through teaching leadership, advocacy, and policy making skills. The program is currently offered in 46 states (http://www.partnersinpolicacymaking.com/).

Schools have also begun to look at curriculums and methods to teach students skills necessary for living successful, self-determined lives. Wehmeyer and Palmer (1998) looked at the importance of learned hopefulness and the development of psychological empowerment as suggested that these were central factors that supported an individual's self-determination.

For people with and without disabilities, self-determination is an idea that is intertwined with social justice, power, inclusion, and quality of life considerations. Research is underway to create assessment instruments to evaluate the nature and extent of self-determination experienced by individuals with disabilities and their families. A range of demonstration projects and program initiatives have been implemented that bear watching.

It is important to understand the scope of decision-making and personal determination that is at stake. Supporters of self-determination are talking about real choice and power. This translates to people with disabilities making significant decisions about all aspects of their lives. It could mean that people with disabilities will select their personal support staff and decide how money and resources will be used. It goes far beyond choosing what one will have for dinner to decisions related to the most fundamental choices about life, choices that ultimately determine the quality of that life. These choices are important across the life span; young and old alike have the right to exercise choice and control over their lives. Taking away or preventing a person's right to live a self-determined life has negative consequences. Pumpian (1996) wrote that it was important for people with disabilities to have the

> opportunity to participate to the greatest degree possible in the decision about where and with who they live and work and play and experience the same chances to make choices about what to wear for the day, when to go to the grocery store, or who they want as their personal care attendants as do their peers without disabilities (xviii).

Self-determination is an idea that has generated great discussion; what remains to be seen is whether current change efforts will mean that people with disabilities will have more control and choice, whether they will be given the chance to live self-determined lives. This could have critical implications for people across a range of experiences, including those of people with disabilities who experience exploitation and violence.

Relationship of Theory of Self-Determination to Issue of Violence and Disability

The theory of self-determination under girds the premise of making choices, problem solving, accessing resources, and the ability to deal with the challenges that one encounters. The argument about whether self-determination is centered on skills and internal attributes or on access to resources and macro/systemic issues is important as one tries to develop interventions or supports to address violence and exploitation in the lives of people with disabilities.

To better understand the issues for women with cognitive disabilities, it was important to learn about what opportunities and support they had for problem solving, making choices, accessing resources, and utilizing supports, both formal and informal. Again, this is not to say that women chose these experiences, but rather that there were factors that impacted their ability and opportunity to problem solve, utilize resources, make choices, and access supports. This research showed that there were skills, attributes, and personal characteristics that helped women cope with the experiences and their aftermath. This research also identified attitudinal, systemic, and policy barriers that made it difficult for the women to leave or cope with these experiences. At one level, the women indicated that an increased sense of power and control, ideas that are central to self-determination, would benefit them. At another level, they were able to identify external issues and barriers that impacted their ability to deal with the experiences. Qualitative research methods offered an opportunity to learn from the perspective of those who have an experience. This research centered on finding out, from the perspective of the women, what helped or hindered them in being self-determined as they dealt with the experiences. One of the flaws of much of the disability related research is that researchers, professionals, and academicians do not look to people with disabilities to define or solve the problems they encounter. If we are to truly support the self-determination of people with disabilities, then we must support opportunities for them to address issues that impact their lives.

Given the prevalence and seriousness of the problem of exploitation and abuse of people with disabilities, it is troubling that more has not been done to address the issue. To better understand the issue, a reasonable place to start was with an exploratory study with women with disabilities who have experienced exploitation and violence and determine in what ways self-determination was supported or thwarted with regards to the experience and the aftermath. This research is offered to help with the development of preventive and interventive support services.

In Chapter 2, a review of the literature concerning the nature and incidence of abuse and exploitation of people with disabilities, particularly women with disabilities, was presented. This section covered central ideas about the concept of self-determination, including definitions and differing perspectives on whether it is primarily internally or externally situated. The intersection of self-determination with the topic of exploitation and abuse of women with disabilities was explored. Chapter 2 also presented a brief overview of the research project. In Chapter 3, qualitative research methods for this study are discussed.

CHAPTER 3

METHODOLOGY

Qualitative Research Methods

Chapter III covers the selection and use of a qualitative research methodology, as well as describes the process used for this particular research. This research project was an exploratory qualitative study that considered the experiences of women with disabilities who have been abused. The purpose of this study was to gather information from the perspective of women with disabilities who had experienced exploitation and abuse. Through the use of focus groups, women with cognitive disabilities were asked questions about their experiences, including what helped and hindered them as they dealt with exploitation and abuse. A qualitative research process, using in-depth interviews in a focus group format, followed by a description and analysis of their stories, was used to gather information about skills and abilities that helped them deal with abuse and exploitation, assistance they received from others, barriers they encountered, and how they thought having a disability intersected with the experience.

The selection of a qualitative research methodology was an important consideration in approaching this research project.

Yin (1984), Marshall and Rossman (1995), and Padgett (1998) identified the importance of matching the purpose of the research study with a research strategy. They reported that when the intent of the research is to investigate little understood phenomena and to identify/discover important variables such as the “salient themes, patterns, categories in participant’s meaning structures” (Rossman and Marshall, p. 41), an exploratory study using in-depth interviewing to collect data is a sound choice.

Rossman and Marshall (1995) identified two other criteria with regards to the selecting a qualitative research methodology: informational adequacy and efficiency. Informational adequacy concerns deciding whether the research design will elicit the sought after information. The research questions in this study were focused on gathering information about internal and external factors supporting or impeding the self-determination of women with cognitive disabilities who had experienced exploitation and abuse. Using the in-depth interview process, the researcher was able to hone in on the relevant information and gather enough to the point of information saturation. Participants were queried on the topics until there was marked repetition in their responses, indicating that for the time being, in that context, they had offered the information and content that addressed the questions that were raised. The second criteria, efficiency, relates to using a method that allows “adequate data to be collected at the least cost in terms of time, access, and cost to participants” (p. 42). Through the use of focus groups and by providing transportation support to participants, efficiency matters of time, access, and cost considerations were taken into account to make involvement as easy as possible.

Qualitative research methods offered an opportunity to learn from the perspective of those who have had the experience. Marshall and Rossman (1995) said, “An assumption fundamental to qualitative research is that the participant’s perspective on the phenomena of interest should unfold as the participant views it, not as the researcher views it (p. 80). As the intent of this research was to gather information directly from women with cognitive disabilities regarding what helped or hindered them in being self-determined as they dealt with the experiences of exploitation and abuse, qualitative research methods seemed a reasonable choice. Marshall and Rossman continued, noting that qualitative interviews “allow the researcher to understand the meanings people hold for their everyday activities” (p. 81). Padgett (1998) referred to it as gaining an understanding of the “lived experience” of participants. As was stated earlier, one of the flaws of much of the disability related research is that researchers, professionals, and academicians do not look to people with disabilities to define or solve the problems they encounter. Since the theoretical frame used for this research was self-determination, it seemed consistent to support through the research process opportunities for people with disabilities to address issues that impact their lives.

Participants and Methods

This research used a focus group format (Marshall and Rossman, 1995, and Padgett, 1998), in which in-depth interviews were used to gather data. The focus group was comprised of eight women with cognitive disabilities, specifically those with mental retardation, which is defined in the state of Georgia is a Full Scale I. Q. of 69 or below. The participants all lived in Atlanta, Georgia in Fulton or Dekalb Counties.

All of the participants were age 18 or older. All participants lived independently in the community, and none had legal guardians. Six of the eight participants were African American. Two of the participants are multi-racial. All would consider themselves women of color. All participants received services from the Atlanta Alliance on Developmental Disabilities, an agency that has provided community based support services to people with cognitive disabilities since 1969. For this study, abuse was defined as a relationship in which one experiences one or more of the forms of abuse outlined by the Partnership Against Domestic Violence (PADV) in Atlanta, Georgia. They define domestic violence as “Hurtful and abusive behaviors used by one partner to control and have power over another partner. These behaviors can include threats, physical assault, forced sex, financial control, isolation, and emotional abuse, like name calling” (PADV, 2002). The scope of the definition was broad, and took into consideration the women’s personal perspective of what constituted abuse and exploitation.

This approach to selecting participants reflected purposive, convenience sampling. Padgett (1998) noted that, "qualitative researchers pursue some form of purposive or ‘theoretical’ sampling, selecting respondents based on their ability to provide needed information” (p. 51). She continued, "Like their quantitative counterparts, qualitative researchers also use convenience sample, that is selecting respondents based on their availability...exploiting personal or professional networks to recruit respondents based on their availability” (p. 51). Padgett added that participants are selected based on their ability to provide rich deep information about the issue being discussed. The nature and depth of the experiences of these women with cognitive disabilities was a central factor in their selection as participants in the research project. Volunteers were solicited from participants receiving services from AADD.

Callahan discussed the use of in-depth focus group interviews with women, “women’s participation and the flow of ideas and information would be enhanced by being able to listen to each others’ experience and to interact with each other….A group interview format facilitates women building on each other’s ideas and augments the identification of patterns through their shared experience” (Callahan, 1983, p. 38).

For this project there were twelve focus group sessions, that took place in weekly meetings across twelve weeks, at the offices of the Atlanta Alliance on Developmental Disabilities (AADD), 1440 Dutch Valley Place, Suite 200, Atlanta, Georgia, 30324. Each session lasted one to one and a half hours. Outreach staff from AADD provided transportation to and from the sessions. This particular component facilitated ease of participation for the participants - outreach staff have long term relationships with these women and was an important part of supporting their presence at and participation in the groups. This speaks to the importance of efficiency concerns of qualitative research. Outreach staff provided transportation to make participation easier for the women. Childcare and lunch was provided during the sessions.

Research Questions

Using the theoretical frame of self-determination, this research sought to determine to what extent skills, internal attributes, external and systemic factors mediated the experience of women with cognitive disabilities who experienced exploitation and abuse. The research involved a two step process: First: women with developmental disabilities who participated in the focus groups were asked a series of questions designed to consider the experience under the umbrella of self-determination. They were asked accessible questions to garner information. From the answers to these questions, themes were identified. These themes were reviewed with participants as a member check for clarification or changes. Once there was agreement, the second step of analysis took place. In the second step, themes were then assigned to categories of internal or external factors. These categories of internal factors and external factors addressed the broad research questions, which were:

I. What internal factors were identified by focus group members?

II. What external factors were identified by focus group members?

To get at the information that addressed the broad research questions, simpler, accessible questions were developed to present to participants. To gain initial information from which themes would be drawn, and to address the broad research question regarding internal factors, the following two simpler scripted questions were posed:

1. What skills or personal traits helped you deal with the exploitation and abuse?
2. What skills would have been helpful for you to have?

To address the broad research question regarding external factors, the following simpler scripted questions 3 and 4 were posed to participants:

3. What kind of help did you receive from others?
4. Were there actions that others took that did not help you during this experience?

To gather information about how the women perceived that having a disability related to the experience, in order to determine if personal or societal attitudes about disability contributed to the experience, questions 5 and 6, again made simpler and more accessible, were presented to participants.

5. How do you think having a disability impacted the experience?
6. What would you want other women with disabilities to know to help them deal with this kind of experience?

To reiterate, the following represents the relationship of the scripted questions, from which themes were identified, to answer the broad research questions:

I. What internal factors were identified by focus group members?

    1. What skills or personal traits helped you deal with the exploitation and abuse?

2. What skills would have been helpful for you to have?

3. How do you think having a disability impacted the experience?

4. What would you want other women with disabilities to know to help them deal with this kind of experience?

II. What external factors were identified by focus group members?

3. What kind of help did you receive from others?

4. Were there actions that others took that did not help you during this experience?

5. How do you think having a disability impacted the experience?

6. What would you want other women with disabilities to know to help them deal with this kind of experience?

The simpler, accessible questions were presented to focus group members, with follow-up questions posed by the researchers to get clarification or additional information.

From the answers to the questions, the researcher identified themes. These themes were presented to focus group members, during sessions 7-12, for feedback and clarification. Once there was member agreement, the themes were assigned to categories of internal factors or external factors. The assignment of themes to categories was established to answer the broad research questions.

Method of Data Collection

The data collection method for this study was in-depth interviewing, which is, according to Marshall and Rossman (1995) “relied on quite extensively by qualitative researchers” (p. 80). They continue, “the researcher explores a few general topics to help uncover the participant’s meaning perspectives, but otherwise respects how the participant frames and structures the responses.” (p. 80). Padgett (1998) and de Marris and Lapan (2004) identified in-depth interviewing and review of narratives as important data collection and analysis processes in qualitative research.

A general interview guide was used with the participants (See attached interview guide), with flexibility allowed to rephrase questions and seek clarification when needed. It is more accurate to refer to it as a general guide or what is sometimes called a semi-structured interview rather than a script (Merriam, 1998). At each of the first six sessions, the participants were queried on one of the simplified questions. That question focused the discussion for that particular session. Additional questions were posed by the facilitators related to each question based on participant responses to gain more information or for clarification. The session and question schedule was as follows:

Session 1 - Question to be discussed:

1. What skills or personal traits helped you deal with the exploitation and abuse?

Session 2 - Question to be discussed:

2. What skills would have been helpful for you to have?

Session 3 – Question to be discussed:

3. What kind of help did you receive from others?

Session 4 – Question to be discussed:

4. Were there actions that others took that did not help you during this experience?

Session 5 – Question to be discussed:

5. How do you think having a disability impacted the experience?

Session 6 – Question to be discussed:

6. What would you want other women with disabilities to know to help them deal with this kind of experience?

At sessions seven through twelve, the participants responded to initial themes discerned by researchers, commented on content, and suggested additions or changes. Participant checks on themes and information discerned by the researcher was important to make sure that there was agreement on what had been presented, that it reflected what people intended to report, and that the participants were comfortable with the themes that the researcher gleaned from the discussions. Initial themes were identified and reviewed. The themes that were identified will be discussed in the Chapter 4 of the dissertation.

Session 7 – Question to be reviewed/initial themes and analysis discussed:

1. What skills or personal traits helped you deal with the exploitation and abuse?

Session 8 - Question to be reviewed/initial themes and analysis discussed:

2. What skills would have been helpful for you to have?

Session 9 - Question to be reviewed/initial themes and analysis discussed:

3. What kind of help did you receive from others?

Session 10 - Question to be reviewed/initial themes and analysis discussed:

4. Were there actions that others took that did not help you during this experience?

Session 11 - Question to be reviewed/initial themes and analysis discussed:

5. How do you think having a disability impacted the experience?

Session 12 - Question to be reviewed/initial themes and analysis discussed:

6. What would you want other women with disabilities to know to help them deal with this kind of experience?

Sessions were recorded and transcribed. A thematic analysis using the software N*dist 6 qualitative analysis software, student version, was conducted to determine common ideas that surfaced between participants in the study. The software allowed the researcher to establish codes, review the number of times a theme/topic was discussed as well as the nature of the text with regards to particular themes. For the work here, the themes became the codes. These themes were reviewed by participants during sessions seven through twelve during the feedback loop of the process.

After the themes were identified and reviewed with participants and peer reviewed with the co-facilitator, the themes were analyzed and coded as to being related to internal factors, external factors. Some themes had aspects that could be assigned to both internal and external factors. A table was created, Table 1., that shows how the themes were assigned to the categories of internal factors, external factors, or both. The assignment of themes to categories of internal factors, external factors, or both, answered the broad research questions.

To ensure the rigor of the research, there were a number of criteria used in qualitative research that had to be met. The first was credibility, which intends to demonstrate that the research was done in a manner to ensure that the “subject was accurately identified and described” (Marshall and Rossman, p. 143). Credibility was met in that the women described their experience; it was transcribed. Participants had the chance to review the questions, themes, and analysis and comment on findings. This approach privileged their experience and description of the nature of the topic and the context, which is important to sound qualitative research. Another method to strengthen the rigor of the research was through triangulation. The use of multiple informants is one form of triangulation, which brings multiple sources to inform a question. Eight women participated in the focus group sessions so there were multiple informants involved providing answers to the questions. Another criteria of sound qualitative research criteria is confirmability (Marshall and Rossman, p. 144), which was handled with feedback from a co-facilitator trained in qualitative methods as well as peer review of the findings. A systematic analysis of the content was conducted, so that the analysis and data will be verifiable (Berg, 1998), meaning that another researcher could arrive at similar conclusions using the raw data set. One facet of the systematic analysis is represented by Table 1. in Chapter 4 and the Appendix of the dissertation, which presents the themes identified and reviewed by the participants and co-facilitator, and assignment to categories of internal or external factors.

IRB approval was secured from the University of Georgia. The project was explained to each potential participant and consent forms signed. While difficult topics were discussed, and while there may have been some discomfort for the participants, they all reported appreciation at the opportunity to participate and share information about their experiences. This was consistent with information on qualitative research reported by Padgett (1998) who noted that while difficult subjects are often addressed during qualitative research in social work contexts, usually research participants are grateful for the opportunity to tell their story and there were generally no negative outcomes reported. Confidentiality was assured and their right to discontinue involvement with the project was stressed. A list of counselors and resources was made available though no participants reported wanting to pursue outside support.

Chapter 3 covered the selection and use of a qualitative research methodology. In this chapter the rationale of doing an exploratory qualitative study was presented. The study was designed to gather information directly from the perspective of women with disabilities who had experienced exploitation and abuse. Women with cognitive disabilities participated in focus groups and were asked questions about their experiences, including what helped and hindered them as they dealt with exploitation and abuse. A focused qualitative process, centered on description and analysis of their stories, was used to gather information about skills and abilities that helped them deal with abuse and exploitation, assistance they received from others, barriers they encountered, and how they thought having a disability intersected with the experience. In Chapter 4, findings will be presented.

CHAPTER 4

FINDINGS

Chapter 4 provides the findings of the research. Background information is provided as context in which to consider their responses to the questions. Themes are identified, and supporting narrative is presented. These themes were then categorized into internal or external factors.

Participants

The initial information presented here provides background information on the participants as well as information about the kinds of experiences they had. This overview is provided as a context in which to frame their responses to focus questions. Context is important in qualitative research approaches, as Jensen and Jankowski noted, “qualitative is concerned with meaning in phenomenological and contextual terms” (p. 4). They added that it is important to consider the experience through a process “which is contextualized and inextricably integrated into wider social and cultural practices (p. 4).

There were eight women who participated in the focus groups, all of whom have a diagnosis of mental retardation as defined in the state of Georgia, which is a Full Scale IQ of 69 or below. For purposes of this document the participants shall be known by the following pseudonyms: Rose, Peggy, Andrea, Kendra, Lera, Stacy, Letha, and Linda. They range in age from 26 to 49. Seven of the eight women have children. The eighth woman, Stacey, was four months pregnant. This was her second pregnancy; her first baby was stillborn last year. Three of the eight were currently employed. Seven of the eight had been employed at some point in their life. Five of the eight had admitted to having challenges with addiction at some point. Six of the eight had parents with significant addiction issues. While this information is provided as background information, some aspects of the information are important in the discussions with the group participants.

All participants revealed multiple incidents of violence, including rape and assault. All indicated first being raped by a family member or close friend of the family when they were young, from ages 8-11.

Some examples of the kind of early sexual assault that the women experienced are related here. Andrea said, “When I was eight years old I was raped by my mother’s husband, my stepdad. I told my mom, and it was like my mom didn’t believe me until he raped my sister too. It was like it didn’t even matter that it happened to me. But when it happened to my sister, she put him out. But nothing ever happened to him. So I still don’t know why she did me like that.”

Rose said, “I was raped, really raped, by my stepfather when I was 10. See my mom would go to work and he had been messing with me and she came back one morning and caught him up on top of me and she went to get a gun. And there was all this yelling, and he had to go. But it is hard, cause I still see him around after all of these years. I still have to look in his face. I got this anger, this deep anger in me because of it.”

Peggy said that she was raped at age 11 by a 26-year-old man who lived in the area. She said, “I was walking home one day and he rode up beside me on a bicycle, and he jumped off and grabbed me. He dragged me into an abandoned house, and this girl who I thought I was my friend and some others held me down while he raped me. I screamed and yelled, and my brother heard me and came in and pulled the guy off me. And he was going to get a bat and kill him.”

Stacey said, “My uncle and cousin messed with me, that wasn’t right what they did. I was a child. My momma didn’t believe me.”

These early incidents were simply the start of what would end up being a series of violent episodes the women experienced, some of which included gang rapes. Two stories that represented the gravity of these situations follow. Andrea told a story about when she was 19 years old, and met a man she wanted to date at a club. After an evening of dancing and talking, she left with him, thinking they were returning to his apartment. “He took me to an abandoned building, tore my clothes off, poured gas on me, and threatened to set me on fire if I didn’t do what he asked. Then there were other people there. I just did what they said. I was so scared.” Linda told a story about a gang rape that happened in front of her two children. “The five dudes broke into my apartment and raped me, and my kids could see what was happening. But they (the court) let them off.” (From a review of client files, apparently the District Attorney decided not to prosecute even though there was evidence of the break in, physical evidence of the assault, and the eye witness accounts of the children. The reason given was that due to Linda’s disability and her children’s disability, they were not “credible witnesses” so the charges were dropped. Linda’s two sons have mental retardation.)

All of the women also related stories of financial exploitation by family members, friends, and boyfriends. Letha said, “First, my momma wanted my check so she could get her drugs and then my boyfriend wanted me to put my tax refund into his checking account. He took some bitch he was seeing to the place where I get my hair done, and he was telling everyone how he was going to get my check because I was just stupid.” Linda related a similar story, “He showed up long enough to take my tax check and then he was gone until the money ran out Then he came back to get some more.” Andrea and Peggy both said their partners had gotten angry when they would not give them money to buy pot. “He would get really pissed and act up, especially if he had gone to the dope boy and got it on credit. If I said I wasn’t gonna pay it, he would really go off, say I was tripping.”

All of the women also had the experience of having family members be their representative payee for their SSI checks. They had to go to great lengths to get control of their money, usually submitting to a process that required a medical doctor to attest to their ability to manage their own money. Given their labels of “mental retardation,” this was often not an easy process to complete. Andrea said, “My mom would use my check to buy things like gold watches for her boyfriends. She was doing wrong with my money, and I had to fight for the right to do right with it.” Peggy said her brother had been her payee, and she had to fight to get her check. She said he wouldn’t pay her rent or pay for her food. With support from a support services worker, she said she was able to get control of her money. According to Lera, her sister who “does drugs” used her check to “get her stuff.” Stacey said, “Everyone else has had my money. My momma got it to get her crack; my aunt got it because I lived with her, and she made me sleep on the floor.”

Much of the verbal abuse the women encountered came from family members and friends disparaging them due to their disability. The men would tell them that no one else would want them because of their disability. Family members told them that they should just be glad they had someone who wanted them. The participants said the comments were used to try to “keep us down” and to explain away unacceptable behavior. Kendra said “He thinks you haven’t got it all up there, so he can do anything he wants.” She added, “He said, ‘If I don’t want you, ain’t nobody going to want you.” Letha talked about how her boyfriend would make her go in the back room when his friends came over because “he said I embarrassed him.” Andrea said that an aunt told her she should be glad she had a man, even if he was bad “cause no one else was going to want me anyways. I should be thankful he was even there.”

Other abuse came in the form of either threatening to contact or actually contacting DFCS or other entities to create problems for the women if they did not do what was demanded of them. The perpetrators in some cases had contacted the Child Protective Services Division of DFCS which led to the women being investigated by caseworkers. When investigators became aware of the woman’s disability, this sometimes led to the removal of the children from the home. This will be discussed later under the responses to the focus questions that were posed to the group participants.

Focus Questions

The group participants were asked a series of questions. The themes that were identified are presented as well as quotes taken from their responses.

Question 1. "What skills or personal traits helped you deal with the exploitation and abuse?"

Discussion. Far and away the most important factor that the women identified as helping them deal with the exploitation and abuse was religious faith. Every single participant acknowledged the importance of deeply held religious beliefs during and following the abusive incidents. Peggy said, "While it was happening, like the rape you know, I was talking to God. He brought me through it." Rose added, "The only friend you really have is the Man upstairs." Andrea said, "I pray about what happened. It was hard. But I pray and that helps me."

Having knowledge of certain legal protections offered some protection, as four of the women had used restraining and protective orders to keep men away at various times in their lives. These women knew that they had to have the order on their person and that they had to call the police if the person named in the order came near them. Kendra said, "I kept that piece of paper and if he came near the door, boom, I was on the phone and calling. Because he beat me bad and I called the police to keep him away.” Peggy said she had taken out a protective order when her boyfriend was caught with a gun. “He was crazy, and I knew I could go to the neighbors to use the phone if I had to. But anymore you don’t always know them so well, and they is up in your business and that can cause even more problems.”

Another important skill the women identified as helping them deal with abuse and exploitation was learning how to manage their money. All of the women had family members who had acted as representative payee at one time or another, and all had one or more experiences of feeling that they were not fairly dealt with in those circumstances. They felt that they were afforded more choices when they became their own payees. As Peggy said, “People still wanted my money, but they had to ask; they couldn’t just take it. My brother had been my payee, and I thought I could trust him. But he was taking my money, and now that I get my own check it is better. I can do what I want, and what I want is to take care of my kids’. See, even when my old man comes asking for dope money, I can say ‘get your own, this money is for my kids. He can get rough but I can still say no.”

Participants also identified having skills to locate and maintain employment as having helped them deal with the exploitation and abuse. Linda said, “It makes you feel good about yourself, you know, to have a job. It is good to get out of the house, talk to people, you know be with people. The men don’t like that, but I feel good about my job.” Andrea added, “He wants to know where you are all the time, you know, be right up under you, but he can’t do that at a job. Other places, you can look up and there he is, but at a job, it is like he can’t be there.” Kendra discussed how having a job also gave her greater freedom in getting a place to live. “I went in to the office, and honey they did it all, a credit check. And I had to sign papers, and because I had a job, I got in sooner.” Having one’s own place also allowed the women to establish some boundaries in their relationships. As Linda put it, “He can come to visit, but he can’t stay here; he can’t put his clothes in my closet.”

Another important skill that was identified was asking for help from others to help remove the offending party from the situation. One example of requesting help came from Linda, “I had tried to get rid of the dude, and he wouldn’t leave. He was taking my money and messing around, and he threatened my boys. He was hitting on me. So I told my brothers what was happening. My brothers came over and beat the shit out of him. They put his head in the wall. He left and didn’t come back.” She laughed heartily as she spoke. The other women cheered at the end of her story.

Another skill that one participant related was developing a plan for leaving. Letha had been in an abusive relationship with the father of her youngest child. She said that she came up with a plan to “put him out.” She said she talked with her landlord who agreed to change the locks on her door on a day that her partner was at work. Letha was the only one listed on the lease so her partner could not request a new key from the landlord. On the same day that the locks were changed, she collected all of her partner’s clothes and put them on the street. Letha then left the house so that she wasn’t there when he came home. She stayed away from the house and returned home after a few days. After that, when she came home from work by bus, if she saw him waiting outside her house, she stayed on the bus and rode the route around again until she did not see him. She said, “I would just ride on by, and I had my cell phone so that I could call in case he came up on me. The best part was seeing him chasing people up and down the street who had taken his clothes and stuff. Shit, they had on his clothes, and he was so mad.”

Themes identified. Faith, understanding legal protections available (protective orders), knowing how to manage one’s money, employment skills, knowing how to ask for help, developing a plan to leave the abusive situation

Question 2. What skills would have been helpful for you to have?

Discussion. When asked this question every single woman talked about having a problem with “being too nice.” They said they wished they knew how to “not be so nice” so that people would not take advantage of them. Andrea said, “I wish I knew how to say ‘no,’ but I guess I have a soft heart. I can’t stand to see my family out on the streets. And even though I don’t like my old man around, I wouldn’t want him to not have a place to stay. But I know they all know I am too nice, and so they just show up, you know, wanting money or a place to stay. They come up and eat my food, but then when they have money they don’t help out. And then they get pissed if I don’t give in. Even though my momma has done me wrong, I still got to try to take care of her. You know, ‘cause it is right.” Stacey said, “They take my money. My momma sells my stuff. It is not right. But I need them. And they gonna know they need me too someday. But I am afraid to stay alone. And I love my momma, I try to be nice.” Peggy added, “Even through the fighting and yelling, it makes me so upset and sick, it would be worse if I knew they were sleeping under the bridge. Yeah they piss me off, but if I got something, I try to help. You don’t let them just be like a dog in the street.”

Another skill that they identified related to having knowledge about options for keeping an abusive person away if a restraining order was not working. Andrea said, “I got the paper, but it is just a piece of paper. He came and broke out the windows, just ignored it, and if I called the police, he would just be hiding around the corner. When the police left, he was back. They don’t look to hard on this kind of stuff.” Peggy added, “And if you don’t have no phone, how are you gonna call when, excuse me, the nigger shows up to beat you. Say excuse me while I go to the pay phone down the street, like I even got change or that it works. Get real.”

All the women felt that having better job skills would help them escape abuse and exploitation. Kendra said, “If I have a job and if I have my own money and then my own apartment, I can say who can lay up here or not. It is good to have a place to go and talk to people and like get what you want. And nobody can take how you feel about it away from you.” Rose said, “I wish I had a good job that paid real good money. But even when I worked a little the Social Security office messed up my money so bad and now they say I owe them money.”

They also pointed out that having enough money would mean the ability to keep the phone service connected so that if they had to make a call on violation of a protective order they would be able to make the call. As it stands, many of them have experienced extended periods without phone service due to limited resources. They also said that having more money would mean being able to find better or safer housing.

Another skill they identified was literacy. Lera said, “If I could read better, then I would know more about my money and about things I have to sign.” Rose, Stacy, and Andrea added that they could get better jobs if they were able to read. All were distressed that they had not had better experiences with school or with subsequent attempts at various literacy programs.

During the responses to this question, Peggy said, “I wish I was stronger; there must be some kind of weakness within me, to let this happen, you know, with my old man.” Andrea agreed, “I wish I knew how to really go off on them, because maybe they wouldn’t see me as being weak; you know they would respect me.”

Themes identified. Knowing how to not “be too nice,” knowing what to do if a restraining order was not working, good job skills, more money to keep phone on or access safer housing, literacy, sense of feeling stronger.

Question 3. What kind of help did you receive from others?

Discussion. There were limited examples given in response to this question. None of the women had received counseling support in the aftermath of the episodes of violence they had experienced. One had recently entered into counseling due to “bad nerves.” There were examples given of ancillary support given by AADD staff for things such as getting children returned after DFCS had taken the children away and assistance with locating housing and furniture. All of the women except one had received support with becoming their own payees for their SSI checks.

Linda offered one specific example of support given that the group really enjoyed hearing about. She enjoyed telling it and reflected on it a number of times during the sessions. She was involved with a man who had been physically and financially abusive. He threatened her children, and she had asked him to leave but he refused. Linda told her brothers about her situation. “They came over and beat the dude up, put his head in the wall. They threw his shit out in the street and put him out. And he didn’t come back. Because my brothers said they would kill him. And I think they would have. I was glad he was gone.”

<u>Themes identified</u>. Support getting children back, support locating housing, support becoming own payee, support from others to get abuser out of house

<u>Question 4</u>. Were there actions that others took that did not help you through the experience?

Discussion. The women offered many answers to this question about actions that others took that did not help during the experience.

Kendra said, “His momma called up saying that if I was a Christian lady I would get back with her son, the baby’s daddy. He threw me down the stairs. He beat me with a belt in places that no one could see so no one would know. I told her that, and she said she was still gonna pray that we got back together for the children. Cause I am breaking up the family. Shit, he wanted to bust my head open. Did his momma want me dead? I thought she cared about me. But I see how it is.”

For many of the women, being reported to DFCS by their abusive boyfriends and in some cases the subsequent removal of the children by DFCS was devastating. Peggy said, “When I put him out, he called DFCS on me, and they took my daughter. It took me over a year with Ms. Davis’ help to get her back. It don’t make no sense that they listened to him over me. But he told them I was slow. That really hurt me. I am a good mother to my children.” Rose bitterly talked about her daughter being removed by DFCS. Her daughter remains in state custody. She said, “I tried to do right by my daughter. I was being treated wrong, and instead of helping they took her away.” Kendra said, “He beat me, and they came and took my children, but at least they gave them to my momma.”

Stacey said the police had not been helpful. She cried as she related a story about calling the police when her mother took her clothes and sold them. “She does the crack cocaine and she took my clothes to sell. And I called the police. They came up, but my auntie told them I have the Downs Syndrome and I was retarded and she said I didn’t know what happened. The police listened at her and would not listen to me. So they just left. But I know what happened. That was not right for my auntie to do me like that or for them to do me like that, you know just walk away.”

Many of the women talked about pressure from friends and family members to remain in the relationships. Peggy said, “It was bad enough him telling me no one else would want me “cause I am slow. But my family and friends would say like ‘oh like he is so nice’ and ‘you probably can’t get nobody else.’ Everybody thought he was such a nice guy, but they didn’t know.” Andrea said, “Everybody thought he was such a saint, and never believed if I said any different. But I tell you, a bad man is like a flea: you can’t get rid of him. And he ain’t biting nobody else so they don’t know.”

Linda said it didn’t help “when they (researcher’s clarification: the District Attorney’s office) let those boys go after what they done to me. But they didn’t believe me or my boys. That wasn’t right.”

Many of the women identified the policies and responses of Housing Authority and rental office personnel as difficult. Andrea said, “They make me feel like if the police come up here I am afraid I will get put out. They don’t want no trouble, and even if the police are supposed to be coming to protect you, the rent office will see them at your place and then you are out. They don’t play, you know, one strike and you are out.”

Peggy added, “And your old man is not on your lease and he says he will go to the rent office and tell that he is staying there so if you don’t do like he says your kids will be out on the streets. And he did it too, and the rent office put us out. Thank god for Ms. Davis helping us find a place. We lost everything.”

Kendra related a story of being evicted from housing. “I had been working and then he busted me up and I went to the hospital. I lost my job. The rent office put the eviction papers on the door, but he tore them off. And I didn’t know at first what was happening. When I found out, I went down and told them what happened. I told them I was trying to find another job. But they said there wasn’t anything they could do, and they put my stuff out on the streets. I mean all my stuff.”

Andrea offered another example of actions that were not helpful. She said she had recently gone to a counselor because “my nerves were bad and I started to tell her about what had happened and she told me I just needed to go to church.” Andrea said she wasn’t sure if that was helpful or not.

There was pain and frustration expressed as the women said they were often treated as if they didn’t know or understand anything. Kendra said, “People think because you ain’t got it all up here, that you don’t know. But you do know.” Peggy said, “People just treat you any kind of way, like you are stupid.” Linda said, “They tell you are slow, but you know when people do you wrong.”

Another example the women identified as not being helpful was telling about abuse and not being believed. Stacey said, “I told my momma they was messing with me but she didn’t believe me. They should have believed me.”

Andrea said, “When I was eight years old I was raped by my mother’s husband, my step-dad. I told my mom and it was like my mom didn’t believe me until he raped by sister too. It was like it didn’t even matter that it happened to me. But when it happened to my sister, she put him out. But nothing ever happened to him. So I still don’t know why she did me like that.”

There was a strong consensus that people often discredited, minimized, or negated their concerns when they disclosed information about abusive boyfriends. Lera said, “Everyone thinks he is so nice; he puts on a good show. They tell me I am lucky to have such a nice guy; they don’t know.”

Kendra, who had been severely beaten for three years by the father of her children again spoke about her boyfriend’s mother, “His mother didn’t believe me that all the beatings happened. She told me that she prayed we would get back together. I told her he threw me down the stairs; hit me in the head with a frying pan. He beat her grandson, my son until he had marks on him, like a shoe mark where he stomped my son. I said he was crazy, but his momma told me if I was a Christian woman, I wouldn’t break up the family like I did. I would be a good wife, and we would be back together. I ain’t been with him in two years, and I did love him once but he was going to kill me. I couldn’t believe what she said.”

Themes identified. Pressure from family/friends to remain in relationship, being reported to DFCS, removal of children, police not helpful, district attorney’s office not helpful, Housing Authority officials and policies, counselors not being helpful, other’s perceptions of disability, people not believing them with regards to the abuse

Question 5. How do you think having a disability impacted the experience?

Discussion. In response to address this question, the women referred back to the comments abusive partners had made about what they described as “being slow.” Peggy said, “They tell you that you is slow, that nobody could want you, and it wears you down. Now even if I know he is the one who ain’t all there, he’s the one who bumped his head, it was still hard to hear all that.” Linda said, “It makes people think you don’t know how to do nothing.” Kendra agreed and said, “And that’s what they think when DFCS takes your kids, like you can’t do right. You don’t know nothing, and they just think they know it all.”

Stacey referred back to the incident with the police dismissing her complaint about her mother’s theft, “because my auntie said I was retarded. They would’ve listened to somebody else.”

The group indicated that they felt family and friends minimized or dismissed their stories of abuse, much of which came out under question 4. They reiterated stories of being told they were just lucky to have a man; things weren’t really as bad as they seemed. Andrea felt that having a disability played a part in her mother not responding to the abuse she was experiencing, but that because her sister did not have a disability, she approached the allegations differently.

Themes identified. Partners saying no other man will want you, assumption that you don’t know how to do anything, police not listening due to disability, family and friends minimizing or dismissing experience

Questions 6. What would you want other women with disabilities to know to help them deal with this kind of experience?

Discussion. At first there was laughter as the women made initial suggestions that focused on not being involved with men. Linda said, “Ooohhh no, we don’t need no men. We can do bad by ourselves.” Peggy added, “We need to tell women that all men are crazy, they all bumped their heads and can’t make sense.” But as the laughter waned, the women continued in this vein, suggesting there was a genuine sentiment being expressed. Letha said, “I have learned that I really don’t need a man, and right now I don’t want one. I just want to take care of my kids.” Lera said, “I like the quiet now.” Rose said, “I just like to be home and quiet, not having somebody boss me around. I can watch my stories in peace.”

The tone shifted markedly when Peggy said, “I would tell them you can’t trust anybody. I tell you this that I learned, I don’t have friends. I have acquaintances. I don’t let anyone get too close, ‘cause they will just do you wrong.” Rose concurred, “That is true, the only one you can trust is the Man upstairs.” Andrea added, “And you have to watch over your shoulder all the time, because you don’t know what will happen next. You have to watch your own back because nobody else will. Not family. Not friends. Just your children and yourself. And even your children can grow up and not act right.”

After a pause, Linda said, “Women need to understand that they are not stupid; it is the men who are stupid. We women need to band together and tell men what we want. It isn’t right what they do. We didn’t deserve what they did. Like those old women who get raped. That is wrong.”

<u>Themes identified</u>. Not getting involved with men, being alone is okay, you can’t trust anyone, women are not stupid, we didn’t deserve it

Themes were assigned to categories of internal or external factors. Table 1 shows the themes and assignment (also in Appendix). Questions 1 and 2 provided information that led to the themes listed. These were categorized, with most of the themes making sense as consistent with internal factors. Internal belief systems, knowledge and skills were identified that can be assigned as internal factors. There were some external factors also identified from the themes presented. These had to do with access to resources and engagement with the school system.

Questions 3 and 4 revealed important information about policies and outside forces that impacted the experience. Themes included needing resources, the attitudes of others, and policies and practices of agencies they came in contact with.

Information from question 5 showed that the women thought that the way disability most impacted their experience was through the attitudes of others. They did not regard having a disability as creating challenges, but rather encountered difficulties because of the beliefs and myths others held about disability. The themes were assigned to the external factors category.

Information from question 6 showed that they felt it was very important to dispel myths and to let women with disabilities know that they were not at fault for the exploitation and abuse they experienced. They felt and empowered sense of agency and recognition of personal abilities would best serve women in similar situations. The themes they identified were assigned to internal factors category.

TABLE 1

THEMES ASSIGNED TO INTERNAL AND/OR EXTERNAL FACTORS

From Question 1: What skills or personal traits helped you deal with the exploitation and abuse?

Theme	Internal Factor	External Factor
Faith	Internal belief system	

Understanding legal (protective orders)	Knowledge	
Knowing how to manage one’s money	Knowledge/Skills	
Employment skills	Knowledge/Skills	
Knowing how to ask for help	Knowledge/Skills	
Developing a plan to leave the abusive situation	Knowledge/Skills	

<u>From Question 2:</u> What skills would have been helpful for you to have?

Theme	**Internal Factor**	**External Factor**
Knowing how to not “be too nice”	Attribute/Skills	
Knowing what to do if a restraining order was not working	Knowledge	
Good job skills	Knowledge/Skills	
More money to keep phone on or access safer housing		Resources
Literacy	Knowledge/Skills	Schools not supportive
Sense of feeling stronger	Attribute	

<u>From Question 3:</u> What kind of help did you receive from others?

Theme	**Internal Factor**	**External Factor**
Support getting children back		Advocacy

Support locating housing		Resources
Support becoming own payee	Relates to knowledge and skills	Support services
Support from others to get abuser out of house		Support from family

From Question 4: Were there actions that others took that did not help you through the experience?

Theme	**Internal Factor**	**External Factor**
Pressure from family/ friends to remain in relationship		Attitudes/actions of others
Being reported to DFCS/ Removal of children		Attitudes/actions of others
Police not helpful		Policies/practices
District attorney’s office not helpful		Attitudes
Housing Authority Officials and policies		Policies/practices Legal
Counselors not helpful		Attitudes
Other’s perceptions of disability		Attitudes
People not believing them with regards to the abuse		Attitudes

From Question 5: How do you think having a disability impacted the experience?

Theme	**Internal Factor**	**External Factor**
Partners saying no other man will want you		Attitudes

Assumption that you don’t know how to do anything		Attitudes
Police not listening due to disability		Attitudes Policies/practices
Family and friends minimizing or dismissing experience		Attitudes

From Question 6: What would you want other women with disabilities to know to help them deal with this kind of experience?

Theme	**Internal Factor**	**External Factor**
Don’t get involved with men	Attitude	
Being alone is okay	Attitude	
You can’t trust anyone	Attitude	
Women are not stupid	Attitude	Must address social attitudes
We didn’t deserve it	Attitude	

CHAPTER 5

CONCLUSIONS AND RECOMMENDATIONS

The use of a focus group format in this research worked very well, and moved beyond information sharing sessions to creating a context of support for the participants. It was important for each participant to share her story, and that alone would have made the use of a focus group an appropriate venture, since gathering information from the perspective the participants was needed for this qualitative research process. But there was the added aspect that as each woman discussed her experiences, she was affirmed by the other participants who had shared similar experiences. Women connected parts of their stories and their concerns with the stories and concerns of others in the group. This seemed to add to their understanding that their experiences were neither isolated nor unusual. The participants were also able to reflect to one another that the abuse was not their fault, and that they were strong, capable, resilient people who had survived terrible events. Given the interaction of the participants and feedback regarding how helpful this process had been, strong consideration should be given to creating support group contexts for women with disabilities to discuss their issues. This may include supporting women with cognitive disabilities in accessing generic support groups for women who have experienced violence, or developing groups whose membership can also speak to the experience of disability.

Internal and External Factors

The first and second questions were intended to gather some information about internal factors, that is to say skills and attributes the women had or wish they had to help deal with the abuse. The third and fourth questions were designed to consider external factors, those which had to do with people or policies that impacted their ability to deal with the experience. The last two questions were designed to allow the participants an opportunity to reflect on the impact of disability on their situation and identify things that would help other women with disabilities who were in similar situations.

As it relates to supporting the self-determination of the women who had experienced abuse, both internal and external factors warranted exploration. It is apparent that they had a number of skills and characteristics that helped them survive their many difficult experiences. Their strong faith and resolve to gain control of their finances strengthened their capacity to act in self-determined ways. Even when they were belittled about having disabilities, they continued to weigh their options and make choices that they felt made sense given the circumstances. It can be said they are both resilient and resourceful. They endured horrific events, and even with few financial resources, managed to maintain a place to live, for themselves and when DFCS had not intervened, a place for their children.

For those participants who have struggled with addiction issues, they acknowledged that it had been hard to make good decisions while under the influence. They recognized that there were points in their lives that the drinking had been used to help them cope with the abuse.

While there were important personal characteristics and skills identified by the women that informed their ability to act in self-determined ways when dealing with the experience of abuse, the impact of outside forces, including systemic issues and lack of resources had tremendous impact on them.

As was stated in Chapter 2 of this paper one approach to considering self-determination is to look at the various ways resources are either limited or made available in ways that impact a person’s ability to act in self-determined ways (Nerney, Crowley, and Kappel, 1995; Mackelprang and Salsgiver, 1996).   These are the external factors. External factors can also be system issues that impact a person’s opportunity to select and make choices. External factors were very relevant in the ways in which the women were able to deal with or respond to the abusive situations. External factors limited their options and made their lives much more difficult.

Contacts participants had with various agencies and systems, including Department of Family and Children Services (DFCS), law enforcement, the courts, the Housing Authority, Temporary Assistance for Needy Families (TANF), and the school system were of great concern. Even systems that could or should have offered assistance were seen or experienced as not helpful. Some of this concern was born out of actual contact, for others, merely the threat of involvement created stress in their lives.

Peggy’s story about how her abusive boyfriend called DFCS on her when their children were young because she told him he would have to get out points to the external factors that impact a woman’s experience of the abuse and serve to make a situation worse.

> I was sitting at my apartment, and we had been fighting about it for days. And then he and this girl went out from the apartment, and a worker from DFCS came and said someone had made a call that my baby girl had bruises on her. I got really pissed and told her, come see my baby, I take care of my baby. I showed her there was food in the house and it was clean and made her look over my baby. He was just mad cause I wouldn’t give him money. I had been through so much with my baby ‘cause she was sick when she was born, and I went to the hospital everyday. You ask Ms. Davis, I was there every day. So to have them say I wasn’t taking care of her hurt my heart so bad. But I knew who called DFCS. See they tell you that if you don’t do what they want they are like

> ‘DFCS is gonna get the kids and give them to me,’ and I was like yeah right, you done bumped your head. Ain’t nobody gonna give those kids to you. But I cussed the worker and she was crazy, cause some of those workers are crazy, you know. And they took my baby, and it took me fifteen months to get her back. They said I had a nasty attitude. But shit, they just come in, and yeah, you get mad when they threaten you and when you know that nigger called and got all this going. But Ms. Davis helped me to get her back. I am a good mother, but they can make you feel real bad about yourself, even when it ain’t true.

According to the women, the Public Housing Authority has enacted “One Strike and You are Out” provisions for housing tenants. Tenants can be evicted without due process for many reasons. It has been used to evict tenants who are regarded as troublesome or who have had people regarded as undesirable visit their apartment. The women all cited the “One Strike” policy and felt if the police were to come to their apartments on a domestic violence call, they would be reported to the rent office and lose their place. As many of the women still have children at home, keeping a roof over their heads is paramount. As one participant put it, “I don’t want my children to have to live on the streets. We don’t have any place to go. And we don’t want the rent office to see police coming here, so I don’t push it, you know, getting him out. He just threatens me with calling the rent office, and it shuts me up.”

The threat of being identified by the Housing Authority staff or law enforcement personnel was of great concern to many of the women. “You can’t call the police if he is messing with you, even if you have a protective order. Cause for one, that is just a piece of paper, and if the rent office sees the police coming to your place, they can think you are a trouble maker and they can put you out, so it is better if you just keep it all quiet like. I gotta keep a place for me and my children to stay. So I just put up.”

The women did not see protective orders as effective or viable options, even though they had used the orders in the past to try to keep an abusive partner away. “I had an order, but you got to keep it on you. And if you don’t have a phone, how is that gonna help you? And he can just keep coming around and coming around. See I got him arrested once, and he did some time. But when he got out he told me if I ever did that again, he would kill me. He came and broke out all of my windows. I guess I am scared of him. Cause every time you look up, there he is.

It is interesting to note that the reason abusive partners were currently out of the households was that they had violated parole or probation orders, which were usually drug related. The women had not reported their partners, but rather their partners had missed appointments or had been arrested on other matters and this violated their probation or parole. The women indicated for their own safety it was good that they were not tied to the arrests and incarceration. Kendra captured the sentiment for all the women when she said, “He messed up his own self so that was good for me.”

The intermittent or pervasive poverty that the women experienced really limited their ability to make choices, to act in self-determined ways. Because they had little money, public housing was their only option for housing. This put them under the rules of public housing which in turn made them feel they could not report abuse due to concerns about being evicted from the apartment. The lack of financial resources made it difficult to maintain phone service to call for help.

Poor educational opportunities led to poor employment prospects which led to continued poverty. The women all felt they had been failed by the school system, and all wished they had been afforded greater educational opportunities. Rose said, “If you have a disability, they don’t think you can learn, and so they just give up on you learning anything. I could’ve learned more, but they didn’t think so. They really just put me out. I have tried some of the places that try to help but it would have been better when I was younger.” Lera agreed, “I need to have help with reading but I wish I had been able to get it at school. I didn’t really get too much at school.”

Connection to Extant Literature

This research supported some of the findings described in the literature review of the issue, and diverged from the literature in other respects. Ward (1988) and Wehmeyer (1994) focused on internal factors in defining self-determination. Ward said “Self-determination refers both to the attitudes which lead people to define goals for themselves and to their ability to take the initiative to achieve those goals” (p. 2). Wehmeyer defined it as

> the attitudes and abilities necessary to act as the primary causal agent in one's life and to make choices and decisions regarding one's quality of life free from undue external influence or interference. Self-determined individuals act autonomously, and are self-actualizing and self-regulating. Causal agency implies that it is the individual who makes or causes things to happen in his/her life and that a given action was purposeful or performed to achieve an end. It is a critical element contributing to an individual's quality of life across settings, environments, and opportunities" (p. 16).

The notion that one can make choices and decisions “free from undue external influence or interference” misses the weight that external factors had on the choices available to the participants. The question to be asked is what external influences or interference would qualify as “undue?” By focusing on the “ability to take the initiative to achieve goals,” makes it seem that if the participants were just motivated enough, if they simple took the initiative, their problems would be solved.

While the work of Gilson, Cramer and DePoy (2001) focused on women with physical disabilities, a form of abuse identified as unique to women with physical disabilities who had participated in their research resonated with the experience of the women with cognitive disabilities who participated in this research project. A form of control/restraint listed was “using disability to demean, discredit, or dismiss” (p. 228). This type of abuse was experienced by the research participants, with partners, family members, and community members alluding to their cognitive disabilities in relationship to the abuse. Another area that was consistent between the research done by Gilson, Cramer and DePoy (2001) and this research effort was the implications of poverty, “Poverty and isolation factored into the lives of the participants, exacerbating the effect of abuse and influencing the participants’ responses to abuse” (p. 229). A third connection made between research done by Cramer, Gilson, and DePoy (2003) was the identification of one tactic taken by abusers as that of “using the children as leverage to keep a disabled woman in an abusive environment (p. 192). The women with cognitive disabilities who participated in this dissertation study noted how partners would use the threat of calling DFCS regarding the children to maintain control in the abusive situations.

This research concurred with findings by Baladerian (2004) that there was a lack of access to or utilization of services. The research also was consistent with literature (Petersilia, 2000, Rogers, 2004, and Sorenson, 1996) that indicated that law enforcement and judicial personnel responses to issues related to abuse and disability were inadequate and often inappropriate.

A troubling aspect of the issue of abuse and disability is that little research exists, so there is a limited body of empirical research work to tie the findings to. Disability and violence remains an invisible issue in many research arenas. A recent example happened on December 18, 2004. The author attended a day long training on Intimate Partner Violence put on by staff from the Centers for Disease Control and Prevention (CDC) and Emory University. Dr. Nadine Kaslow, Professor and Chief Psychologist at the Emory University School of Medicine, and Jocelyn Wheaton, MPH, from CDC, discussed risk factors for intimate partner or domestic violence. They listed factors such as “female, young, urban, minority, poor, etc.” Disability was not listed as a risk factor. When asked about it, they simply said it was not something that they considered in the studies they were presenting. It is troubling that even with the high incidence of violence against people with disabilities, particularly women, the issue of disability and abuse is not considered in research initiatives or in dissemination of information. It is seen as a separate issue by researchers or simply is not considered.

The identification of poverty as a risk factor by Dr. Kaslow and Ms. Wheaton dovetails with another aspect brought up by the participants and that relates to the pervasive poverty that people with disabilities experience. Dr. Kaslow (2004) referenced limited resources and poverty as risk factors for intimate partner violence. There has been research done on the intersection of poverty and domestic violence (Williams and Mickelson, 2004) and on the intersection of poverty and disability (Condeluci, 1995) but work needs to be done to fully consider the intersection of poverty, disability and abuse. Also it is important to explore the relationship between employment of people with disabilities and the impact of exploitation and abuse. As two-thirds of working-age individuals with disabilities in the United States are unemployed, and of those working, only 20% are working full time (Braddock et al., 1998), there are income and poverty issues that warrant exploration that may impact people's experience of exploitation and abuse. The participants felt that having employment helped for a number of reasons, including having a place to go where they could be away from their partner. They also stated that having a paycheck afforded them choices of better places to live, as well as allowed them to keep the phone on.

The Role of Social Work

Cramer, Gilson and DePoy (2003) said, “Although domestic violence has received a significant amount of attention in both the scholarly literature and the service sector, little targeted attention has been directed to abused women with disabilities in social work knowledge, curricula, and practice. Thus there is a dearth of empirically-based theory and knowledge informing curriculum and practice with this neglected population of women” (p. 184). Collins and Valentine (2004), also social workers, noted the tendency of social workers to follow a “traditional paradigm” with regards to dealing with women with disabilities, by placing the “problem” within the individual woman with a disability rather than exploring social and external factors and contexts (p. 29).

The social work profession is in a key position to collaborate with women with disabilities on this difficult issue, both at the direct services level, as well as at an advocacy level.

A critical role for social workers to play is to reframe the issue as a macro practice concern. A significant challenge for the profession is that since much of the current education, training, and work focuses on the individual as the locus of interventions, important community level and systems level landscapes are ignored. In their book Unfaithful Angels, Specht and Courtney (1994) railed against the reconceptualization of social work as clinical work with individuals, instead of community social work with a focus on social and economic justice. They said there is a lack of interest in communities, systems and policy issues. This has meant a lack of engagement by social workers as activists and advocates for those issues that bespeak a social and economic justice agenda. Popple and Leighninger (2004) noted in their social work policy text book that

> Practice with individuals, families, and small groups with the goal of treating problems in individual role performance continues to be the focus of most of the social work professions efforts. Even though most social workers will admit that problems with social institutions are at The root of most client problems, we have tended to persist in dealing primarily with the individual client (p. 8).

In part this challenge can be traced to the education and training of social work students. While students learn about the “Person in Environment” framework, the truth is that there is often academic and professional tunnel vision towards honing in on the “person” and dismissing the relevance of the “environment.” For the women in this research study, it is obvious that solely focusing on training or skills development would completely miss the complexity and reality of their lived experience. Defining self-determination as most closely related to the possession of particular skills and attributes places too much emphasis on the individual, and does not adequately consider external issues. It is true that there are skills and knowledge that would assist the women in dealing with their situations, such as undertaking safety planning, but for the most part the skills, attributes, and personal beliefs that the women identified revealed their resilience, their ability to cope with terrible and unjust situations. Addressing situations simply through training or skills enhancement makes them inappropriately responsible for the abuse and consequences. To take the thought a step further, making the individual the focus of interventions becomes a political statement, with the chilling action of blaming the individual for their circumstances and consequences, such as happened in Welfare Reform. The environment, policy issues, and social attitudes, which make up external factors, have to be addressed as they more accurately structured the circumstances and consequences for these participants.

For those social workers who want to provide support at the micro level, through counseling and therapeutic support services, they should include people with disabilities as recipients of their services. They also need to conduct universal screening for women on issues of exploitation and abuse, including women with disabilities, so that they are identified as victims/survivors of abuse and exploitation. As long as abuse and exploitation exists, people will need help dealing with related trauma and mental health challenges. To address this, social workers need to provide counseling services to women with disabilities. Questions about the efficacy of psychotherapeutic interventions with people with mental retardation were addressed by Prout and Nowak-Drabik (2003) who conducted a meta-analysis of 30 years worth of psychotherapy studies and concluded that psychotherapeutic interventions should be considered as part of an overall treatment plan for individuals with cognitive disabilities, including mental retardation.

Social Work education needs to not only emphasize the importance of macro practice but to also infuse disability into the curriculum. Gourdine and Sanders (2002) and DePoy and Miller (1996) found that social work schools do very little to include disability content in their programs. If students received information on disability, it was primarily through a field practicum experience, not as part of curriculum content. Gilson (1998) cautioned about how disability should be included in social work courses, since much of the social work literature on disability issues available is “expert focused” which does not address the perspectives or experiences of people with disabilities. Gilson conducted interviews with people with disabilities who had interactions with social workers. They reported social workers treated them as if they had fewer “aspirations, abilities, and perhaps even fundamental rights than did nondisabled people” (p. 188). It no doubt impacts the level and nature of services offered if these are the attitudes held by social workers.

Recommendations

It seems that the best approach to supporting the self-determination of women with disabilities who experience exploitation and abuse is to understand that while both internal and external factors are relevant, much needs to be done to address the external factors that mediate the experience of abuse and exploitation. The women identified areas where they would like support in developing some skills and abilities. They also identified numerous external barriers to be addressed.

Increasing educational opportunities to help strengthen literacy skills is important. The school system needs to do a better job in, at the very least, teaching functional literacy to people with disabilities. Adult literacy programs are mostly computer based or group learning settings that the women have not experienced as helpful. The women in the group felt that being able to read the mail, rental agreements, bank statements, legal papers, etc. would minimize their vulnerability around financial matters and support their decision making. Our educational support and technology has not rendered us able to teach many people with cognitive or learning disabilities to read, support will continue to be necessary. So until there is improvement in effectively teaching literacy, it is important to have a trusted person read papers, bank statements, etc.

It is also important to increase employment skills and help support women in locating good jobs that provide good pay. This in turn will begin to help them deal with the poverty, an external factor that has limited their options for getting into safer settings or into housing where they are not at risk of eviction if they seek help. There are supported employment programs available to people with disabilities, but to establish greater economic security, higher paying jobs will need to be located. The extent to which supported employment programs target services to the subset of women with disabilities who have been abused is unknown.

The challenges created by the “One Strike” rules that have been put in place in most public Housing Authority offices must be brought to lawmakers’ attention. One of the unintended consequences of the legislation is to increase the risk of domestic violence being unreported to law enforcement. While the Supreme Court upheld the present practices as being consistent with current legislation allowing “One Strike” rules to remain in place, new legislation could be passed that changes the rules. This means new challenges could be brought before the bench.

Having knowledge about the cycle of abuse also seemed important to the women. They said that knowing they were not the only ones who had experienced abuse was helpful. This allowed them to reframe the issue as not being their fault, as being one that many women experience. “I didn’t know there were others just like me. See, it wasn’t me,” said Andrea.

While the women had some information about resources that were available to help, they may be well served by knowing about additional resources that are available. From their perspective, it was helpful simply being with other women who shared similar experiences, to talk about concerns, issues, and provide support to one another. Peggy said, and the group nodded in agreement, “These are my sisters now; they got my back. I know they know what I am talking about. I feel like they really know. That is a good feeling.”

An important next step is to gauge the interest the women have in exploring roles as advocates and change agents. They clearly have important information for policy makers, women’s and victim’s right advocates, as well as law enforcement personnel. DFCS workers should be better trained on the nature of disability and policies that allow for the removal of children simply based on the mother’s disability need to be dismissed. Social workers also need additional training to make sure that they are aware of and responsive to the needs of women with disabilities.

Weakness and Limitations of the Study

The weaknesses and limitations of the research are those that are attributed to qualitative research in general, such as small sample size and not being able to generalize the results to a larger population. A sample size of eight women is small, and although there is relevance to hearing the actual stories from those who have had the experiences, the small sample size does not make it possible for generalization. To better understand how widespread the problem is, a larger quantitative study using a much larger sample size would be important.

Qualitative research is laborious and can take a great deal of time and resources. The cost and effort for any qualitative research must be addressed as a potential limitation of the study.

It was also necessary to probe and reframe questions to gain further clarity from the women. This flexibility in process could be regarded as both a strength and a weakness. It allowed for responsiveness to questions and comments as well as clarification about responses, but also makes exact replication difficult.

Conclusion

This exploratory study points to the need for further research to consider issues related to exploitation and abuse of women with disabilities. There are many topics that warrant additional research, such as the impact employment has on women’s sense of personal agency as well as access to resources. Clearly more research needs to be done on the impact of policies, such as public housing policy, on the women who experience abuse and exploitation. The impact of pervasive, significant poverty needs to be reviewed. It is also important to look at the role of Department of Family and Children Services and review the removal of children from women with disabilities.

This research is offered to enhance information on the issue of exploitation and abuse of women with disabilities. More social workers need to focus their professional efforts in alliance with people with disabilities. There are a number of specific issues that warrant attention. Social workers should support increased employment opportunities for women with disabilities. Social workers who work in the Department of Family And Children Services should become versed on disability and domestic violence. There are legitimate questions to be raised about the policies and procedures in place at the Department of Family and Children Services regarding the removal of children from women with disabilities. Social workers also need to understand the implications of housing policies, particularly those related to the One Strike policies. They need to advocate for changes both in the law and policies that keep women in dangerous situations. The social work profession is charged with advocating for social and economic justice; social workers should focus on the impact of poverty and oppression of women with disabilities.

Chapter 5 presented conclusions and made recommendations based on the research. This research is offered to increase awareness of the topic of abuse and exploitation of women with disabilities. It is hoped that the information from this research project can be utilized to develop supports, interventions, and policies that make a change for the better.

REFERENCES

Alliance for Self-Determination. (1997). In Johnson, J. (1999). Leadership and self-determination. *Focus on Autism and Other Developmental Disabilities,* 14, 4-17.

Beck, E., Williams, L., Park, W., and Hope, L. (2002). An intersectional model: Exploring gender with ethnic and cultural diversity. *Journal of Ethnic and Cultural Diversity* in Social Work, 10, 4, 22-38.

Berg, B. (1998). *Qualitative research methods for the social sciences.* Boston: Allyn and Bacon.

Baladerian, N. (2004). What attitudes, skills, and knowledge are the keys to making a difference. Web conference presentation, September 9, 2004.

Baladerian, N. (2002). Intervention approaches for adults with disabilities who are victims of violence. Commissioned paper for National Conference on Preventing and Intervening with Violence Against Children and Adults with Disabilities. May 2002, Arlington VA.

Braddock, D., Hemp, R., Parish, S., and Westrich, J. (1998). *The state of the states in developmental disabilities*. (5th

Ed.) Washington, D.C.: American Association on Mental Retardation.

Bradley, V. (2004). The impact of self-determination on services and supports. *Impact*, 2-3.

Bradley, V., Agosta, J., Smith, G., Taub, S., Ashbaugh, J., Silver, J., and Heaviland, M. (2001*). The Roberts Wood Johnson Foundation self-determination initiative: Final impact assessment report.* Cambridge, MA: Human Services Research Institute.

Bradley, V., Ashbaugh, J., & Blaney, B. (Eds.), (1994). *Creating individual supports for people with developmental disabilities: A mandate for change at many levels*. Baltimore, MD: Paul H. Brookes Publishing Co.

Bradley, V. (2000). Changes in services and supports for people with developmental disabilities: New challenges to established practice. *Health and Social Work*, 25, 191-201.

Bruyere, S. (1993). Participatory action research: Overview and implications for family members of persons with disabilities. *Journal of Vocational Rehabilitation*, 3, 62-68.

Cantrell, R. & Walker, L. (1993). Participatory action research and policy making: Consumers and nonconsumers deliberate the reauthorization of the Rehabilitation Act. *Rehabilitation Counseling Bulletin*, 37, 37-53.

Carlson, B. (1997). Mental retardation and domestic violence: An ecological approach to intervention. *Social Work*, 42, 79-89.

Collins, K. and Valentine, D. (2004). Discovering women with disabilities: responsive and relevant practice. *Journal of Social Work in Disability and Rehabilitation*. 2, 29-44.

Condeluci, A. (1995). *Interdependence: the route to community.* Winter Park, Florida: GR Press, Inc.

Center for Disease Control, National Center for Injury Prevention and Control. (2001). *Sexual violence against people with disabilities.* CDC, Atlanta, Georgia.

Cramer, E., Gilson, S., and DePoy, E. (2003). Women with disabilities and experiences of abuse. *Journal of Human Behavior in the Social Environment*, 7, 183-199.

Gilson, S., Cramer, E., and DePoy, E. (2001). Redefining abuse of women with disabilities: A paradox of limitations and expansion. *Affilia*, 16, 220-235.

Curry, M. (2002). Responding to abuse against women with disabilities: Broadening the definition of domestic violence. *Family Violence Prevention Fund Health Alert*, 8, 1-5.

DePoy, E. and Miller, M. (1996). Preparation of social workers for serving individuals with developmental disabilities: a brief report. *Mental Retardation*, 34, 54-57.

Ferguson, D., Meyer, G., Jeanchild, L., Juniper, L., & Zingo, J. (1992). Figuring out what to do with the grownups: How teachers make inclusion “work” for student with disabilities. *Journal of the Association for Persons with Severe Handicaps*, 17, 218-226.

Field, S. & Hoffman, A. (1994). Development of a model for self-determination. *Career Development for Exceptional Individuals*, 17, 159-169.

Fine, M. (1992). Disruptive voices: The possibilities of *feminist research*. Ann Arbor: The University of Michigan Press.

Fisher, K. (2004). Health disparities and mental retardation. *Journal of Nursing Scholarship*. 1, 48-53.

Flaskerud, J., Lesser, J., Dixon, E., Anderson, N., Conde, F., Kim, S. (2002). Health disparities among vulnerable populations. *Nursing Research*. 51, 4-85.

Georgia’s Self-Determination Team, A partnership among People First of Georgia, Inc., Institute on Human Development and Disability: A University Affiliated Program and the University of Georgia, & Office of

Consumer Relations, Georgia Department of Human Resources. Athens, GA: Institute on Human Development and Disability, University of Georgia.

Gilson, S., Cramer, E., and DePoy, E. (2001). Redefining abuse of women with disabilities: A paradox of limitation and expansion. *Affilia: Journal of Women & Social Work*. 2, 220-236.

Gilson, S., Brocout, J. and Baskind, F. (1998). *Listening to the voices of individuals with disabilities.* Families in Society, 79, 188-196.

Gourdine, R. and Sanders, T. (2002). Missed opportunities and unlimited possibilities: teaching disability content in schools of social work. *Journal of Health and Social Policy.* 16, 207-220.

Haskell, T. (1984). *The authority of experts: Studies in history and theory.* Bloomington: Indiana University Press.

Jaskulski, T., Lakin, K.C., & Zierman, S. (1995). *The journey to inclusion: A resource for state policy makers*. President’s Committee on Mental Retardation. U.S. Department of Health and Human Services, Administration for Children and Families, Washington. DC.

Jensen, K. & Jankowski, N. (Eds.) (1991). A handbook of qualitative research methodologies for mass communication research. New York: Routledge.

Johnson, J. (1999). Leadership and self-determination. *Focus on Autism and Other Developmental Disabilities*, 14, 4-17.

Kaslow, N. (2004). December 18, 2004 Conference presentation: Risk and resilience in survivors of intimate partner violence. Marietta, GA.

Kemp, E. (1990). *From ADA to empowerment: The report on the Task Force on the Rights and Empowerment of Americans with Disabilities*. Washington DC: The Task Force on the Rights and Empowerment of Americans with Disabilities.

Keigher, S. (2000). Emerging issues in mental retardation: self-determination. *Health and Social Work*, 25, 163-169.

Kloos, E. (1993). Later life: One vision. *Impact* 6, 1-3.

Kosciulek, J. (1999). Consumer direction in disability policy formulation and rehabilitation service delivery. *Journal of Rehabilitation*, 65, 4-10.

Kramp, M. K. (forthcoming). Exploring life and experience through narrative inquiry. In deMarrais, K and Lapan, S. (Eds.). *Theory and Methods in Social Research*. Mahwah, NJ: Lawrence Erlbaum Associates.

Ludi, D. & Martin, L. (1995). The road to personal freedom: Self-determination. *Intervention in School and Clinic*, 30, 164-170.

Mackelprang, R. & Salsgiver, R. (1996). People with disabilities and social work: historical and contemporary issues. *Social Work*, 41, 7-15.

Marshall, C., & Rossman, G. (1998). *Designing qualitative research 2nd edition.* Sage Publications: Thousand Oaks, California.

McLaughin, P., & Wehman, P. (Eds.), (1996). *Mental retardation and developmental disabilities 2nd edition*. Pro-ed: Austin, Texas.

Merchant, B., & Willis, A. (Eds.), (2001). *Multiple and intersecting identities in qualitative research*. Mahwah, NJ: Lawrence Erlbaum Associates, Inc.

Monahan, K. & Lurie, A. (2003). Disabled women sexually abused in childhood treatment considerations. *Clinic Social Work Journal*, 31, 407-418.

Padgett, D. (1998). *Qualitative methods in social work research*. Thousand Oaks, CA: Sage.

National Association of Social Workers. (2000). *Social work speaks: National Association of Social Work policy statements, 2000-2003 (5th ed.)*. Washington, DC: NASW Press.

National Institute on Consumer-Directed Long Term Services. 1996a). *Principles of consumer-directed home and community based services*. Washington DC: author.

Nerney, T., Crowley, R., & Kappel, B. (1995). *An affirmation of community: A revolution of vision and goals*. Durham: University of New Hampshire, Institute on Disability.

Nerney, T. & Shumway, D. (1996). *Beyond managed care: Self-determination for people with disabilities*. Concord, New Hampshire: Institute on Disability.

Nosek, M. & Fuhrer, M. (1992). Independence among people with disabilities: A heuristic model. *Rehabilitation Counseling Bulletin*, 36, 6-31.

Olney, M. (2001). Communication strategies of adults with severe disabilities: Supporting self-determination. *Rehabilitation Counseling Bulletin*, 44, 87-95.

Partnership Against Domestic Violence (2002). *A woman's guide to living violence free*. PADV: Atlanta, GA.

Petersilia, J. (2000). Invisible victims – violence against people with developmental disabilities. *Human Rights*, 9, 9.

Popple, P. and Leighninger, L. (2004). *The Policy-Based Profession (3rd ed.).* Boston: Pearson Education, Inc.

Prout, H. and Nowak-Drabik, K. (2003). Psychotherapy with persons who have mental retardation: An evaluation of effectiveness. *American Journal of Mental Retardation*, 108, 2.

Reinharz, S. (1992). *Feminist methods in social research*. New York: Oxford University Press.

Reynolds, L. (2000). *The Arc's Q & A on People with Mental Retardation: People with Mental Retardation and Sexual Abuse*. Silver Spring: Maryland.

Robert Wood Johnson Self-determination Program Office (2001). *Self-determination program summary*. Manchester, NH.

Rogers, L. (2004). Investigation of the sexual assault case when the victim is mentally retarded or developmentally delayed. Presented at the Symposium of Legal Justice for Individuals with Disabilities who have experienced Violence or Abuse, Gwinnett County, GA, April 20, 2004.

Rothman, J. & Smith, W. (1996). Client self-determination and professional intervention: Striking a balance. *Social Work*, 41, 396-406.

Salisbury, B. (2004). The role of community living facilitators in British Columbia's systems change initiative. Impact 24-25.

Sands, D., & Wehmeyer, M. (1996). *Self-determination across the lifespan*. Baltimore, MD: Paul H. Brookes Publishing Co.

Schein, E. (1972). *Professional Education*. New York: McGraw-Hill.

Shapiro, J. (1994). *No pity*. New York: Times Books Random House.

Simpson, J. (2002). How can I help? Responding effectively to the mental health care needs of individuals with intellectual disabilities. *Internet Journal of Mental Health.* 1, 34-45.

Skrtic, T. (1995a). *Disability and democracy: Reconstructing (special) education for postmodernity*. New York: Teachers College Press.

Skrtic, T. & Sailor, W. (1996). Voice, collaboration and inclusion. *Remedial & Special Education*, 17, 142-158.

Sobsey, D. (2004). Multifactorial model of violence against people with disabilities. Web conference presentation, September 16, 2004

Sobsey, D. (1994). Violence and abuse in the lives of people with disabilities: The end of silent acceptance? Baltimore: Paul H. Brookes Publishing Co.

Sobsey, D & Doe, T. (1991). Patterns of sexual abuse and assault. *Sexuality and Disability*, 9, 243- 259.

Sorenson, D. The invisible victims. *Impact*, 10, 25-26.

Sterns, H. & Sutton, E. (1993). Retirement of older people with developmental disabilities. *Impact* 6, 6-8.

Stone, R. (2000). Consumer direction in long-term care. *Generations*, 14, 5-10.

Strickler, H. (2001). Interaction between family violence and mental retardation. *Mental Retardation*, 39, 461-472.

Task Force Meeting on Metro-Atlanta Providers, June 30, 2002 held at AADD Offices, Atlanta, GA.

Tomlinson, S. (1995). The radical structuralist view of special education and disability: Unpopular perspectives on their origin and development. In T.M. Skrtic (Ed.) (1995a). *Disability and democracy: Reconstructing (special) education for postmodernity*. New York: Teachers College Press.

Tower, K. (1994). Consumer-centered social work practice: Restoring client self-determination. *Social Work*, 39, 191-197.

Trieschmmmann, R., (1980). *Spinal cord injuries: psychological, social and vocational adjustment*. New York, Pergamon Press.

Turnbull, A. & Turnbull, R. (2000). Achieving 'rich' lifestyles. *Journal of Positive Behavior Interventions*, 2, 190-193.

University of Minnesota, Institute on Community Integration (1995). *The self-advocacy groups 1995 directory for North America*. Minneapolis, MN: Institute on Community Integration, University of Minnesota.

Valenti-Hein, D. & Schwartz, L. (1995). The sexual abuse interviews for those with developmental disabilities. James Standfield Company. Santa Barbara: California.

Verdego, M. & Bermejo, B. (1997). The mentally retarded person as a victim of maltreatment. *Aggression and Violent Behavior,* 2 143-165.

Ward, M. & Meyer, R. (1999). Self-determination for people with developmental disabilities and autism: Two self-advocates' perspectives. *Focus on Autism and Other Developmental Disabilities*, 14, 133-140.

Wehmeyer, M. (1993). Factor structure and construct validity of a locus of control scale with individuals with mental retardation. *Education and Psychological Measurement*, 53, 1055-1067.

Wehmeyer, M., & Palmer, S. (1998). Factor structure and construct validity of scores on the Hopelessness Scale for Children with students with cognitive disabilities. *Education and Psychological Measurement*, 58. 661-668.

Wehmeyer, M., & Schwartz, M. (1998). The relationship between self-determination and quality of life for adults with mental retardation. *Education and Training in Mental Retardation and Developmental Disabilities*, 33, 3-12.

Weick, A., & Saleeby, D. (1995). A postmodern approach to social work practice. The 1995 Richard Lodge Memorial Lecture, Adelphi University School of Social Work, Garden City, NY., In Witkin, S. (1999). Constructing our future. *Social Work*, 44, 5-9.

West, M., Kregel, J., & Rebell, W. (1994). A new era of self-determination. *Impact* 6, 4-7.

West, M., and Parent, W. (1992). Consumer choice and empowerment in supported employment services: Issues and strategies. *Journal of the Association for Persons with Severe Handicaps*, 17, 47-52.

Westcott, H. & Jones, D. (1999). Annotation: The abuse of disabled children. *Journal of Child Psychology and Psychiatry*, 40, 497-506.

Wheaton, J. (2004) December 18, 2004, Conference presentation: *A public health approach to prevention*. Marietta, GA.

Williams, S. and Mickelson, K. (2004). The nexus of domestic violence and poverty. *Violence Against Women*, 10, 283-294.

Witkin, S. (1999). Constructing our future. *Social Work*, 44, 5-9.

Yin, R. (1984). *Case study research: Design and methods.* Beverly Hills, CA: Sage.

Yuskausas, A., Conroy, J., & Elks, M. (1997)*. Live free or die: A qualitative analysis of systems change in the Monadnock self-determination project*. Ardmore, PA: Center of Outcome Analysis.

Zirpoli, T., Snell, M. & Loyd, B. (2001). Characteristics of persons with mental retardation who have been abused by caregivers. *The Journal of Special Education,* 21, 31-41.

APPENDIX A

INTERVIEW GUIDE USED WITH PARTICIPANTS

Interview Guide used with Participants

Session 1. Thank you all for being willing to help us better understand your views and experiences. We are going to be talking about exploitation and abuse, and we want to find out about experiences you have had. We are going to define exploitation and abuse using the definition used the Partnership Against Domestic Violence. They define it as "Hurtful and abusive behaviors used by one partner to control and have power over another partner. These behaviors can include threats, physical assault, forced sex, financial control, isolation, and emotional abuse, like name calling." Do you have any questions about the definition?

We can now take some time, for you to talk about examples of exploitation and abuse.

Thank you for sharing your examples. Now we are going to focus on questions to help us understand more about your experiences.

Today we are going to focus on the following question: What skills of personal traits helped you deal with the exploitation and abuse? We will be asking additional questions when we would like more information or when we want to get a better understanding of what you have said.

So to start, let's focus on the question "What skills or personal traits helped you deal with the exploitation and abuse?"

(As the women offered answers to the questions, additional questions were posed for clarification. This flexibility in questioning is allowed in many qualitative processes, including in-depth interviewing.)

(At the end of the session)
Thank you for your answers. We will cover a different question next week. Later we will also discuss the themes or common ideas we heard and find out if we were on target. Are there any questions?

Thanks and we will see you at the next session.

Session 2. Thank you all for being here today. As we said before, we are going to focus on a question about your experiences. Today we are going to focus on Question 2: What skills would have been helpful for you to have?

So, let's focus on this question: "What skills would have been helpful for you to have?"

(As the women offered answers to the questions, additional questions were posed for clarification. This flexibility in questioning is allowed in many qualitative processes, including in-depth interviewing.)

(At the end of the session)
Thank you for your answers. We will cover a different question next week. Later we will also discuss the themes or common ideas we heard and find out if we were on target. Are there any questions?

Thanks and we will see you at the next session.

Session 3. Thank you all for being here today. Today we are going to focus on Question 3: What kind of help did you receive from others?

So, let's focus on this question: "What kind of help did you receive from others?

(As the women offered answers to the questions, additional questions were posed for clarification. This flexibility in questioning is allowed in many qualitative processes, including in-depth interviewing.)

(At the end of the session)
Thank you for your answers. We will cover a different question next week. Later we will also discuss the themes or common ideas we heard and find out if we were on target Are there any questions?

Thanks and we will see you at the next session.

Session 4. Thank you all for being here today. Today we are going to focus on question 4: Were there actions that others took that did not help you during this experience?

So, let's focus on this question: "Were there actions that others took that did not help you during this experience?"

(As the women offered answers to the questions, additional questions were posed for clarification. This flexibility in questioning is allowed in many qualitative processes, including in-depth interviewing.)

(At the end of the session)
Thank you for your answers. We will cover a different question next week. Later we will also discuss the themes or common ideas we heard and find out if we were on target Are there any questions?

Thanks and we will see you at the next session.

Session 5. Thank you all for being here today. Today we are going to focus on question *5:* How do you think having a disability impacted the experience?

So >, let's focus on this question: "How do you think having
a disability impacted the experience?"

(As the women offered answers to the questions, additional questions were posed for clarification. This flexibility in questioning is allowed in many qualitative processes, including in-depth interviewing.)

(At the end of the session)
Thank you for your answers. We will cover a different question next week. Later we will also discuss the themes or common ideas we heard and find out if we were on target Are there any questions?

Thanks and we will see you at the next session.

Session 6. Thank you all for being here. Today we are going to focus on question 6: What would you want other women with disabilities to know to help them deal with this kind of experience?

So, let's focus on this question: "What would you want other women with disabilities to know to help them deal with this kind of experience?"

(As the women offered answers to the questions, additional questions were posed for clarification. This flexibility in questioning is allowed in many qualitative processes, including in-depth interviewing.)

(At the end of the session)
Thank you for your answers. Next week we will begin reviewing themes we heard in earlier sessions. We will present these to you and see if you agree with what we came up with, see if we are on target. Are there any questions?

Thanks and we will see you at the next session.

Session 7. Thank you all for coming today. We are going to begin our review of the themes that we identified from the questions that you answered. We are going to repeat the question and list the themes. Let us know if you agree or disagree with the themes. Are there any changes to be made? Does that make sense to everyone, any questions?

The question we are going to revisit today is: "What skills or personal traits helped you deal with the exploitation and abuse?"

The themes we identified were: Faith, understanding legal protections available (protective orders), knowing how to manage one's money, employment skills, knowing how to ask for help, developing a plan to leave the abusive situation

We are going to take these one at a time and get your feedback.

(Themes were taken one at a time and feedback solicited from focus group members.)

Thank you for your feedback. Your ideas will be added to the project.

Session 8. Thank you all for coming today. We are going to continue our review of the themes that we identified from the questions that you answered. We are going to repeat the question and list the themes. Let us know if you agree or disagree with the themes. Are there any changes to be made? Does that make sense to everyone, any questions?

The question we are going to revisit today is: "What skill would have been helpful for you to have?"

The themes we identified were: Knowing how to not "be too nice",'knowing what to do if a restraining order was not working, good job skills, more money to keep phone on or access safer housing, literacy, sense of feeling stronger

We are going to take these one at a time and get your feedback.

(Themes were taken one at a time and feedback solicited from focus group members.)

Thank you for your feedback. Your ideas will be added to the project.

Session 9. Thank you all for coming today. We are going to continue our review of the themes that we identified from the questions that you answered. We are going to repeat the question and list the themes. Let us know if you agree or disagree with the themes. Are there any changes to be made? Does that make sense to everyone, any questions?

The question we are going to revisit today is: "What kind of help did you receive from others?

The themes we identified were: Support getting children back, support locating housing, support becoming own payee support from others to get abuser out of house

We are going to take these one at a time and get your feedback.

(Themes were taken one at a time and feedback solicited from focus group members.)

Thank you for your feedback. Your ideas will be added to the project.

Session 10. Thank you all for coming today. We are going to continue our review of the themes that we identified from the questions that you answered. We are going to repeat the question and list the themes. Let us know if you agree or disagree with the themes. Are there any changes to be made? Does that make sense to everyone, any questions?

The question we are going to revisit today is: "Were there actions that others took that did not help you during this experience?"

The themes we identified were: Pressure from family/friends to remain in relationship, being reported to DFCS, removal of children, police not helpful, district attorney's office not helpful, Housing Authority officials and policies, counselors not being helpful, other's perceptions of disability, people not believing them with regards to the abuse

We are going to take these one at a time and get your feedback.
(Themes were taken one at a time and feedback solicited from focus group members.)

Thank you for your feedback. Your ideas will be added to the project.

Session 11. Thank you all for coming today. We are going to continue our review of the themes that we identified from the questions that you answered. We are going to repeat the question and list the themes. Let us know if you agree or disagree with the themes. Are there any changes to be made? Does that make sense to everyone, any questions?

The question we are going to revisit today is: "How do you think having a disability impacted the experience?"

The themes we identified were: Partners saying no other man will want you, assumption that you don't know how to do anything, police not listening due to disability, family and friends minimizing or dismissing experience

We are going to take these one at a time and get your feedback.

(Themes were taken one at a time and feedback solicited from focus group members.)

Thank you for your feedback. Your ideas will be added to the project.

Session 12. Thank you all for coming today. Today is our last session with the research project and we are going to finish our review of the themes that we identified from the questions that you answered. As we have done before, we are going to repeat the question and list the themes. Let us know if you agree or disagree with the themes. Are there any changes to be made? Does that make sense to everyone, any questions?

The question we are going to revisit today is: "What would you want other women with disabilities to know to help them deal with this kind of experience?"

The themes we identified were: Not getting involved with men, being alone is okay, you can't trust anyone, women are not.stupid, we didn't deserve it

We are going to take these one at a time and get your feedback.

(Themes were taken one at a time and feedback solicited from focus group members.)

Thank you for your feedback. Your ideas have been really important and we are grateful for your insight and involvement. Thank you for participating in this project.

APPENDIX B

IRB APPROVAL FORM

m Institutional Review Board
____.;' Human Subjects Office
*''—11TM>''TM1 . ''''''^''''''''Tr^r'' 606A Graduate Studies Research
Center
'1 lie University **Or** ClCOn^m Athens, Georgia 30602-7411
(706) 542-6514; 542-3199
t of The Vice President for Research Fax No. (706) 542-5638
HS Assurance ID No. : FWA00003901

APPROVAL FORM

Date Proposal Received: 2004-02-27 Project Number: H2004-10643-0

Name	Title	Dept/Phone	Address	Email
Ms Lesa Nitcy Hope	PI	Social Work Tucker Hall+7016	927 Woodland Ave Se Atlanta GA 30316 (404) 881 -9777x210	lesa@aadd.org
Dr. Edwin A. Risler	CO	School of Social Work Tucker Hall +7016 542-5471		erisler@uga.edu

Title of Study: A Secondary Analysis of Agency Records Exploring Self-Determination as it Relates to Gender and Disability

&Wi^Ci£W:MM*SUaa«3Ur*.H«^i.itiC^^ ;,•-,:•.•_;.-„,--.•*•• ••....• ; ...-.;-::.-;-..:.;..-,1r,.".y:;,«H:Seii'i!;^.'!,i-.;;^ri',:>;vVV,:-;i,'-' s«i'.;'Av.',-. _-..<. ;,(••<:.,,,;, M-, sa .. I,-!• ;uv-tx<;-1. •»>,•;&., iff "»~-:j •U&UtC83BanKI)KMUC*KKjIKil EU«!t£S?n9Xaa9ra*gBaMKEMIQmKiK3MQMttaH8i

. . . Modifications Required for Approval and Date Completed: 2004-03-12

45 CFR 46 Category: **Administrative** 4 None

Approved : 2004-03-12 Begin date : 2004-03-12 Expiration date : 2005-03-11

NOTE: Any research conducted before the approval date or after the end data collection date shown above is not covered by IRB approval, and cannot be retroactively approved.

?••;:• ^:~*.K^^^r^'^zxi^w&mtitef*Kii^^*

-ber Assigned by Sponsored Programs: Funding Agency:

Form 310 Provided: No

Your human subjects study has been approved as indicated under IRB action above.

Please be aware that it is your responsibility to inform the IRB ...
. . . of any adverse events or unanticipated risks to the subjects or others within 24 to 72 hours; ..
.. . of any significant changes or additions to your study and obtain approval of them before they are put into effect; ...
.. . that you need to extend the approval period beyond the expiration date shown above; .. .
.. . that you have completed your data collection as approved, within the approval period shown above, so that your file may be closed.

For additional information regarding your responsibilities as an investigtor refer to the IRB Guidelines. For your convenience in obtaining approval of changes, extending the approval period, or closing your tile, we are proviciilig you with a blue Researcher Request form. Detach this blue form, complete it as appropriate, sign and date it, then return it to the IRB office. Keep this original approval form for your records.

Christina A. Joseph, Ph.D., Chairperson,
Institutional Review Board